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INFLUENCE OF A HOME-BASED ASTHMA HEALTH EDUCATION PROGRAM ON QUALITY OF LIFE AND COPING IN PARENTS OF CHILDREN WITH ASTHMA

by

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Thesis submitted to the

School of Graduate Studies and Research

in partial fulfilment of the requirements for the

degree of Master of Science in Nursing

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DEDICATION

Je voudrais dédier ce travail à mes parents, Loretta (née Ferguson) et Paul Doyon pour l'amour continuel qu'ils m'ont donné. Leur détermination et goût du travail me guideront toujours. Que je puisse partager l'amour à l'exemple de ma mère et poursuivre la veine d'or comme mon père.

To Anne and Mike Dolinar, Bogu hvala, for your love and support. To my husband George and children Paul and Anne-Marie whose love, patience and understanding made this work possible.

ABSTRACT

INFLUENCE OF A HOME-BASED ASTHMA HEALTH EDUCATION PROGRAM ON QUALITY OF LIFE AND COPING IN PARENTS OF CHILDREN WITH ASTHMA

Rose-Marie Dolinar, 1997

Asthma is the most common chronic illness of childhood and caring for a child with asthma can affect the parent's well-being and coping resources. The study examined the influence of a home-based asthma health education program on parental quality of life and coping. Hymovich's Contingency Model of Long-Term Care (Hymovich & Hagopian, 1992) guided the study which utilized a pretest-post-test control group design. Forty families were randomly assigned either to receive home-based asthma health education or booklet representing conventional care. Results of the three-month follow-up indicated improvement in the parent's perception of their child's asthma, as measured by the Caregiver Perception of Change (CPC) survey. Reduction in parental need for asthma information, reduction in parental concerns and increased use of coping strategies were observed, as measured by Hymovich's Parent Perception Inventory (PPI). Although no changes were detected by the Paediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ), a significant correlation was seen between parental quality of life and parental coping.

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CHAPTER 1

INTRODUCTION

1.1 PROBLEM STATEMENT

Asthma is the most common chronic disease of childhood (Donnelly, 1994; Christie & French,1995). Researchers estimate that one in ten Canadian children have symptoms of asthma at some point in their childhood (Zimmerman, Gold, Lavi, & Feanny, 1996) while Canny and Levison (1993) estimate that over 150,000 Canadian children are affected. In the United States (U.S.) asthma affects approximately 4 million children (Capen, Dedlow, Robillard, Fuller, & Fuller, 1994). A trend towards increased morbidity and mortality from asthma has been observed in Canada (Mao, Semenciw, Morrison, MacWilliams, Davies, & Wigle, 1987) and world-wide (Hargreaves, Dolovich, & Newhouse, 1990). Although death from asthma is rare, asthma-related mortality rates have increased steadily in the U.S. and other countries since the late 1970s (Buist & Vollmer,1994).

Childhood asthma has a considerable impact on the health care system and families alike. In 1989, there were over 24,000 Ontario hospital admissions of children under 15 years of age for the treatment of asthma; this translates to more than 65 children admitted to hospital each day (Ontario Lung Association, 1992). In contrast with the large number of admissions, however, the rates of hospital day use for children, aged 1 to 9 years with asthma have dropped dramatically in many regions. For example, in Sudbury, a drop from 32.1 days per 1000 children per year in 1986 to 16.9 in 1991 has been observed (Ontario Ministry of Health, 1994). Earlier discharges from hospital have not resulted from a cure for

Ministry of Health, 1994). Earlier discharges from hospital have not resulted from a cure for asthma; rather, these data reflect improved therapeutics and a larger trend within the health care system. Once a child is discharged from hospital, responsibility for asthma management rests with the parents.

Recognition of inflammation as a key aspect of asthma is probably the single most important advance of the last decade (Waller, Teuber, & Gershwin, 1994). Before 1970, health professionals considered asthma as a mild reversible condition due to spasms, or contractions of the tubes of the lungs (Zimmerman et al., 1996). In 1994, Hauptman defined asthma as a chronic disorder in which inflammation of the bronchial airway is characterized by recurrent episodes of cough, wheeze, and shortness of breath. The paradigm shift regarding the etiology of asthma sheds new light on the importance of the parental role and of health education. Instead of waiting until an asthma episode develops and worsens into a full-blown exacerbation, parents can assist their child with preventative measures and thus avoid crisis situations.

Twenty years ago, the most effective asthma therapy consisted of bronchodilator medications, consistent with the understanding that asthma was a disease primarily due to bronchoconstriction. Today, however, this view of asthma persists among health care givers, showing why health education is needed to clear up misinformation and important to providing effective treatment. Parents need to understand asthma as an inflammatory disease, and what medications are available to treat the inflammation; in addition, there is a need to allay the many fears surrounding the use of anti-inflammatory inhaled

corticosteroids. Health education provides an opportunity for the parent to voice concerns and ask questions. Armed with the necessary understanding, parents can therefore, not only treat their child's asthma symptoms (i.e. cough and wheeze), but also address the causative factor (i.e. the inflammation).

The chronicity of asthma may greatly impact on the resources available to the parent in terms of time, energy, finances and health. The care of a child with asthma may encompass ongoing treatment on a daily, monthly and yearly basis. Clinical manifestations of asthma for children can range from relatively few symptoms to severe prolonged attacks requiring hospitalizations, numerous medications, and inhalation therapy (Brook, Mendelberg, & Heim, 1993). Therefore, the child's asthma can easily become the focus of the family's energies and efforts.

Health education represents an important intervention in assisting parents with their child's asthma management. Assessing the impact of this intervention has been a challenge for researchers (Duffy & Halloran, 1987). Historically, the outcome measures of emergency visits, hospitalization rates and pulmonary function tests were used to evaluate medical treatment interventions for asthma patients (Rowe & Oxman, 1993). Studies of asthma health education interventions on the other hand, have generally used asthma-related knowledge levels as outcome measures (Brook et al., 1993; Capen et al., 1994; Duffy & Halloran, 1987; Faroux, Just, Couvreur, Grimfield, & Tournier, 1992). However, asthma-related knowledge tests have not reliably predicted how a person will ultimately manage asthma on a day-to-day basis (Clark & Starr-Schneidkraut, 1994).

According to Rowe and Oxman (1993), more valid and sensitive measures are needed to capture subtle, yet meaningful changes resulting from different approaches in asthma management. Clark & Starr-Schneidkraut (1994) propose the parent's quality of life as a desired endpoint of asthma management since the parent is responsible for day-to-day asthma management. In health research, quality of life generally refers to "health-related" domains or areas. Schipper, Clinch and Powell (1990) propose using the World Health Organization definition of health as a basis for defining quality of life: " A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1947). In reference to this definition, the following aspects may contribute to such a state of well-being for the parent of a child with asthma: (1) the parent has uninterrupted sleep and is physically healthy (physical well-being); (2) the parent identifies needs, seeks out help and utilizes coping strategies to deal with feelings and concerns surrounding their child's asthma (mental well-being); and (3) the parent interacts socially with family members, relatives friends and co-workers (social well-being).

For the parent of a child with asthma, quality of life can be defined as a state which fluctuates unpredictably due to periods of exacerbation that characterize chronic conditions (Strauss & Munton, 1985). To maintain well-being, the parent must actively guard this "health-related" quality of life state. The parent must learn to cope with their child's condition as well as minimize any effects on daily living. Through the provision of health education, nurses can help the parent to identify, interpret and react to the stresses of their child's asthma.

Effective coping strategies can assist individuals in maintaining a desirable level of well-being or quality of life. Coping strategies are a set of behaviours used under stress in an attempt to improve a situation. Hymovich and Hagopian (1992) present five broad categories of parental coping strategies used in managing a child's chronic condition: seeking information, performing skills, seeking and using resources, monitoring and self-monitoring, and adhering to therapy. Access to health professionals, knowledgeable in asthma management, may also influence the parent's ability to cope with the variability and/or unpredictability of their child's asthma. A chronic condition such as asthma, presents a particular coping challenge since it affects every aspect of a person's quality of life (physical, emotional, social, financial, and spiritual). However, a review of the literature revealed that only a few studies have examined quality of life and coping ability of parents of children with asthma.

Currently, asthma information needs of parents are addressed in several ways by many different health professionals. Physicians, pharmacists, respiratory therapists and nurses all contribute to the knowledge and skills required by the parents caring for the child at home. Nurses provide information in the emergency department, on the pediatric unit, and more recently in asthma education clinics resulting in predominantly community-based programs. Another choice of educational setting would be the family's home. Being with the parent in their home provides an opportunity for the parent to ask specific questions related to their child's asthma, for example, potential asthma triggers in the child's environment.

In the past, public health nurses provided information to families in their homes on a variety of health topics, but, today's public health focus is population-based, not disease specific (Ontario Ministry of Health, 1989). Consequently, for many families, access to home-based asthma education is limited. Attending community-based programs pose many problems for parents. For example, lack of transportation, children's nap and school bus schedules and the life situations of single and dual-parent families are examples of situations which may limit participation to community asthma programs. A home-based approach to asthma health education can be offered at the convenience of the parent as well as enable all family members to participate.

There are no formally-evaluated home-based asthma health education programs offered at the present time in Ontario. The Lung Association Air Force Asthma (AFA) Program (Ontario Lung Association, 1995) is a recognized community-based asthma education program which has been offered in various Ontario communities over the past five years. Summary statistics from one office of the Ontario Lung Association indicate 95% (n=32) parent satisfaction with asthma information received and audio-visual presentation (personal communication, J. O'Connor, Renfrew Country, 1997). Besides parent satisfaction, the program has never been formally evaluated to determine its influence on specific parameters such as quality of life and coping ability. Executive directors of three branches of the Ontario Lung Association have reported recruitment difficulties and low attendance for the AFA program (personal communication, D. Bourdeau, Ottawa-Carleton, J. O'Connor, Renfrew County, D. Klein, Sudbury-Nipissing, October 1995). A number of

approaches were utilized in an effort to improve attendance. Sessions have been offered in the evenings and weekends, including baby-sitting services and lunches, with a goal to promote the number of participating families. In spite of these efforts, the numbers of participating families have remained low in relation to the number of affected families. A home-based approach may provide a solution to families who are not able to attend a community program, by bringing the health education to the parents rather than attempting to bring parents to programs. As well, the parent may enhance the identification of specific informational needs within the home setting as opposed to a non-contextualized knowledge-based approach.

The research and evaluation literature have shown the potential of asthma health education to promote the health of children and their families by preventing recurrences of crisis situations, and encouraging effective parental coping. However, despite the potential of home-based interventions to serve families unable to attend community-based education programs, alternative methods of delivering these programs have not been formally evaluated. Furthermore, there is little available data on the influence of needs-based health education programs on the specific outcomes of quality of life and coping in parents of children with asthma.

1.2 STUDY PURPOSE

This study compared the influence of a home-based asthma health education program with conventional care on quality of life and coping in two randomly-allocated groups of parents of children with asthma over a three-month period.

1.3 SPECIFIC STUDY OBJECTIVES

The specific objectives of this study are:

1 To measure the influence of a home-based asthma education program on quality of life and coping in parents of children with asthma over a three-month period.

2. To determine the relationship between quality of life and coping in parents of children with asthma.

3. To explore the relationship between sociodemographic data, parental coping and quality of life.

CHAPTER 2

LITERATURE REVIEW

This chapter reviews the current state of knowledge regarding the major study variables. The content is organized as follows: 1) asthma in childhood: burden of illness; 2)) asthma-related health education and its influence on parents; 3) parental quality of life; and 4) parental coping. At the end of this chapter, the conceptual framework selected and the research hypotheses tested in this study are presented.

2.1 ASTHMA IN CHILDHOOD: BURDEN OF ILLNESS

The high incidence of childhood asthma, estimated as one in ten children (Zimmerman et al., 1996) impacts on health care costs as well as day-to-day living. Krahn, Berka, Langlois and Detsky (1996) measured the direct costs incurred by inpatient care, emergency services, physician and nursing services, ambulance use, medication and devices, as well as indirect costs such as absence from work, inability to perform housekeeping activities, school absences, and time spent travelling and waiting for medical care. Results for all ages indicated that the most significant health care cost of asthma was medications at 41% of total cost estimate, followed by inpatient care at 28%. Physician services accounted for 15% of cost estimate and nursing at 0.1%. Community health education accounted for 0.6% of cost estimate. School absence contributed to 28% of estimated indirect health care cost based on caregiver productivity loss.

Although estimated cost of asthma provides one view of the impact of asthma, Townsend, Feeny, Guyatt, Furlong, Seip and Dolovich (1991) examined quality of life burden of asthma for pediatric patients and their parents. The authors surveyed 100 patients with moderate asthma and one parent of each patient to determine the impact of the disease on day-to-day life. For the children, symptoms of asthma formed the most frequently mentioned component of the disease, although few of the children perceived that their asthma posed a major disruption to their lives. Parents cited worry and concern about the disease and medications used to treat it and their inability to relieve their child's symptoms as the major components of disease burden. The authors concluded that strategies could be aimed at easing parental worries and concerns surrounding the care of a child with asthma.

2.2 ASTHMA-RELATED HEALTH EDUCATION

Historically, asthma health education focused on increasing knowledge of parents and children (Duffy & Halloran, 1987; Carson, Council & Schauer, 1991). Recently, research has linked asthma-related health educational programs for families with improved morbidity indicators related to night symptoms and restricted activities (Deaves, 1993). There are basically two types of approaches to asthma health education: 1) programs geared for the child alone; 2) programs geared for parent/caregiver/family. A number of studies have addressed outcomes for the school-age child (Capen et al., 1994; Deaves, 1993; Ryan-Wenger & Walsh, 1994); however, since over 80% of children are diagnosed with

asthma before the age of 5 the parent is involved early in child's asthma care (Zimmerman et al., 1996).

Brook et al. (1993) randomly assigned 26 families of children with asthma (mean age 9.3 years) to receive conventional care, consisting of regular follow-up with a pediatrician, or to receive a one hour weekly educational program during 4 months, where parents received lectures and explanations about various aspects of asthma. Outcomes measured included parental knowledge levels, evaluated using a previously unvalidated researcher-constructed questionnaire, and children's hospitalization rates over a one-year period. The weekly meetings were given by pediatric respiratory specialists, allergists, psychiatrists, psychologists, social workers, or physiotherapists. Parents who participated in the educational program had significantly higher knowledge questionnaires scores ($p<0.01$), and their children had lower rates of hospitalization ($p< 0.05$). While these results are of interest, sample size was small, and the major instrument used had no reported psychometric properties. Furthermore, Brook et al. (1993) acknowledge that parental knowledge of the condition does not guarantee appropriate management of asthma at home.

Parental confidence has been used as an alternative outcome measure in the literature evaluating asthma education. A previously developed program, "Open Airway" was adapted and provided to 74 children ages 4 to 14 years and their parents (Moe, Eisenberg, Vollmer, Wall, Stevens, & Hollis, 1992), using a stratified randomized design. Using unvalidated measures, the authors found increases in parental confidence in managing their child's

asthma, as well as increased use of appropriate medication. There was no control group in this study.

Research conducted by Alexander, Younger, Cohen, and Crawford (1988) on low-income families looked at the effect of asthma education on emergency room utilization. Twenty-one parents, with children from 15 months to 13 years of age, were randomized to receive the Clinical Nurse Specialist (CNS) asthma education intervention or were assigned to a control group receiving conventional care. The study ran over a twelve-month period. Results demonstrated a significant decrease ($p=0.001$) in emergency room utilization for the group followed by the CNS, and no change for the control group.

In summary, few controlled studies of asthma education for parents have been conducted. Available asthma knowledge questionnaires (used as outcome measures in most of the evaluation) were developed by the authors and require further validation (Clark & Starr-Schneidkraut, 1994). Furthermore, program content and delivery process were not described in most cases and sample sizes were often small. Two other gaps were noted: home-based approaches have not been evaluated, and with the exception of the study by Moe and colleagues (1992), no other studies have examined parental psychological well-being or quality of life outcomes.

2.3 PARENTAL QUALITY OF LIFE

Chronic illness touches many areas of a person's well-being and thus can affect overall quality of life (Strauss & Corbin, 1984). Quality of life is an important area of study

for nursing researchers and clinicians since it has the potential to capture the effect of the chronic illness on the family.

Quality of life has been defined in a number of ways. Schipper et al. (1990) suggest using the World Health Organization definition of health as the basis for understanding the meaning of quality of life: "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1947). Spilker (1990) states that the major domains of quality of life include physical status and functional ability, psychological status and well-being and social interaction, as well as a person's economic status. Since a wide range of social and economic factors can influence well-being in this broader sense, Spilker (1990) proposes a narrower concept, that of "health-related" quality of life or perceived health status which is an appropriate conceptual definition for a study in nursing. Although quality of life related to health problems is usually studied in relation to the person actually experiencing the illness, it is also possible to examine quality of life in patient's family members. For parents caring for a child with asthma, quality of life involves the parent's perceptions of the impact of their child's illness on their own physical, mental, and social well-being.

Pediatric asthma management can affect particular domains of parental quality of life such as the parent's sleep (physical domain), work attendance (functional domain), level of anxiety (psychological domain), ability to spend time with spouse, family and friends (social domain), and available funds (financial domain). The parent attempts to maintain a certain level of well-being or quality of life, yet at the same time must monitor their child's

breathing, administer medications, be alert for potential asthma triggers, seek assistance from health care professionals, ensure an outlet for the release of emotional strain due to concerns, and maintain financial stability to afford the cost of medications and equipment.

The study of parental quality of life in childhood asthma is relatively new and consequently the research literature in this area is sparse. Most recently, Juniper, Guyatt, Feeny, Ferrie, Griffith and Townsend (1996) developed and evaluated a Paediatric Asthma Quality of Life Questionnaire including a Pediatric Asthma Caregiver Quality of Life Questionnaire (PACQLQ). Tested on a sample of 47 parents/caregivers, the PACQLQ demonstrated moderate ability to capture changes in parental quality of life as demonstrated by yielding Pearson correlation coefficients of 0.35 with symptom change in asthma quality of life, 0.34 with activities, and 0.28 with the emotional domain of parents.

Woodman and Robinson (1990) provided an asthma health education session to 19 mothers of children with severe asthma with a stated purpose of improving the quality of life of families dealing with childhood asthma. The session was coordinated by two nurses with guest speakers including a physiotherapist, an Asthma Society representative and a physician. Content was organized by the nurses and included information on the history of asthma, triggers of asthma, inhaler technique, breathing exercises, drug usage as well as guidelines on when to call for medical attention. The program was evaluated with an unvalidated researcher-developed questionnaire four weeks following the program. Although the usefulness of the session was evaluated, quality of life as an outcome was not

measured. Further investigation is required to determine the impact of asthma health education on quality of life of parents.

Little is known about how quality of life in parents of children with asthma relates to either sociodemographic variables or other factors such as the severity of the child's asthma. It is important to examine these relationship to better understand what factors influence parental quality of life in order that parents at high-risk for problems may be identified and assisted adequately.

2.4 PARENTAL COPING

Coping with chronic illness is a multifaceted phenomenon. According to Brook, Weitzman and Wigal (1991), parental anxiety and stress is associated with childhood asthma. As for individuals experiencing stressful events, and for parents of children with asthma, coping involves problem-solving as well as regulating the emotional response (Lazarus & Folkman, 1984). How a parent deals with their child's breathing difficulties depends on available coping resources, access to help, ability to problem-solve, and capacity to deal with emotional response.

One way parents cope is by seeking information about their child's condition. A number of studies have examined informational needs of parents caring for a child with asthma. Mesters, Pieterse, and Meeters (1991) used two focus group interviews of parents (N=38) to determine informational needs. Topics identified included asthma attack preventive measures, side effects of medication, the proper use of inhalers, and access to an

"asthma expert". The cross-sectional study by Faroux et al. (1992) evaluated the understanding of asthma medications and compliance with treatment in 50 parents (one parent per family) of children aged 18 months to 15 years. These parents of asthmatic children answered a questionnaire developed by the authors. Results indicated that 50% of parents could explain the effects of bronchodilators, 30% admitted having forgotten to give their child prescribed medications, and 50% could describe appropriate measures for treating a moderate or severe asthma attack. Faroux and colleagues concluded that insufficient knowledge of parents regarding asthma management may be a factor in poor adherence to treatment, and therefore by extension, could explain some of the observed morbidity and mortality related to childhood asthma. Furthermore, Faroux et al. (1992) concluded that there was a strong need for family education programs with regular refresher sessions.

Duffy and Halloran (1987) assessed the informational needs of 35 parents of children with asthma and evaluated the effect of an asthma educational program and found that parents lacked information about respiratory anatomy, asthma triggers and asthma medications. Parents may seek information from various sources including physicians, nurses, family, friends, community agencies, television, newspapers or other sources. However, the accuracy of information regarding asthma varies widely depending on the source. Nurses and other health professionals who specialize in asthma health education can provide dependable information to families coping with this chronic illness (Clark, Gotsch, & Rosenstock, 1993). Although information alone cannot alleviate all parental stress and

anxiety associated with childhood asthma, by addressing parent needs for information, nurses may strengthen parental coping.

A major role of nurses working with families dealing with childhood chronic illness is to help them cope more effectively with stressors arising from the child's care (Hymovich & Hagopian, 1992). The process of coping with and adapting to a child with a chronic condition is ongoing and developmental. As a parent adapts and increases coping ability, a question arises as to whether or not coping will impact upon the quality of life of the parent. By studying these and other factors related to coping such as sociodemographic variables, a better understanding of parental coping will result.

2.5 CONCEPTUAL FRAMEWORK

Hymovich's model was selected as the conceptual framework for this study on quality of life and coping of parents (Hymovich & Hagopian, 1992). Previous studies have used this model in research involving families with children experiencing cancer (Aitkien & Hathaway, 1993) and cystic fibrosis (Hymovich & Baker, 1985).

The purpose of the Hymovich model was to describe the impact of a child's chronic condition on the family in terms of family stressors, and family coping strategies. The Hymovich model emphasizes the use of the nursing process to identify system characteristics and contingency variables, assessing needs, planning necessary interventions, implementing these interventions and reassessment to determine if needs have been met. Hymovich's model (figure 1) has been adapted for this study (figure 2).

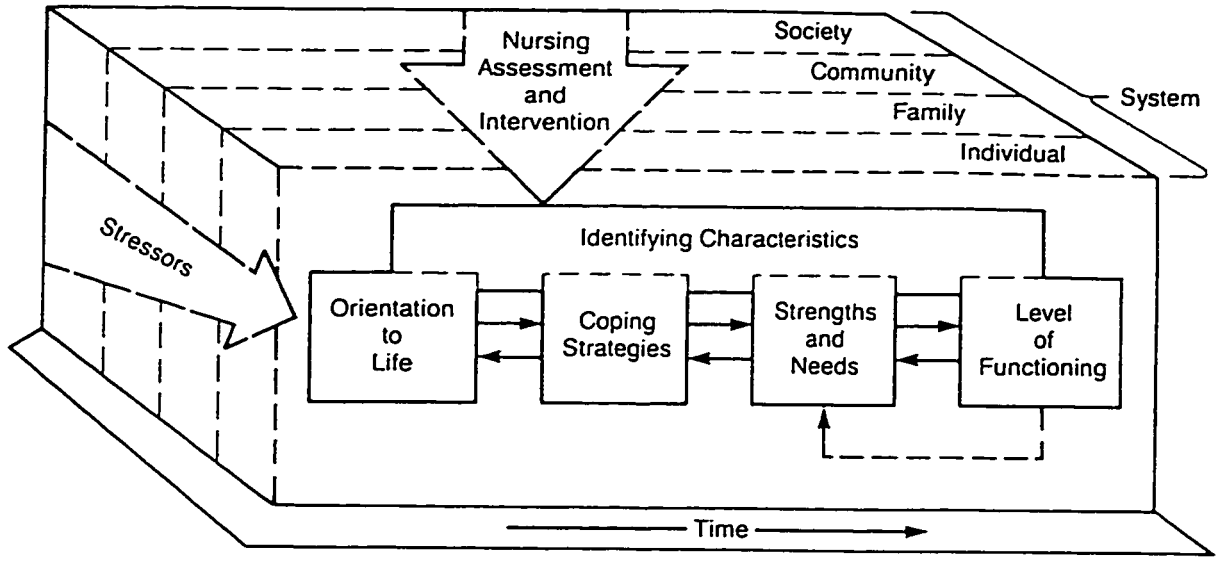

Figure 1: Hymovich's Contingency Model of Long-Term Care (Hymovich & Hagopian, 1992) (reprinted with permission).

	NURSING INTERVENTION (Asthma Health Education) ↓				
STRESSORS (involved in the care of child with asthma) →	PARENTAL COPING (affected by stressors and possibly strengthened by the intervention)				
	Knowledge and experience (informational needs)	Problem solving ability (concerns)	Beliefs (beliefs)	Positive affect (feelings)	Coping strategies (coping strategies)
	Time →				

Figure 2: Parental coping resources in response to stressors and nursing intervention, (adapted from Hymovich & Hagopian, 1992).

In adapting the Hymovich framework for the present study, particular application is the following: the main parental stressors are related to the care of their child with asthma; the system level chosen was the family; assessment of needs was done with the Hymovich Parent Perception Inventory (1988). The order of assessment categories is reflected in the adaptation of the model, as seen in the comparison of figure 1 and 2.

In the process of parental coping, global description, Hymovich (1983; Hymovich & Hagopian, 1992) includes the subconcepts of informational needs, concerns, beliefs, feelings and coping strategies of the parent which are contained within the contingency model framework (Figure 1). In addition, the subconcepts can be described in terms of available parental coping resources. The Hymovich model subconcepts suggest parameters for assessing the parental coping resources and possible changes in coping status following nursing intervention.

Hymovich (1983) states that the subconcepts of informational needs, concerns, beliefs, feelings and coping strategies can be assessed in order to evaluate interventions designed to address the needs identified in the initial assessment. A complete nursing assessment will identify potential stressors and the nursing intervention aims to assist the family to cope with stressors encountered (Hymovich & Hagopian, 1992). Each parent has an individualized set of needs and concerns and available coping resources including previous knowledge and experience, problem solving ability, beliefs, feelings and coping strategies. Nursing interventions designed to address the needs and concerns of the parent have the potential to enhance the parent's overall coping ability.

In addition to informational needs and concerns, parents will have their own set of beliefs and feelings surrounding their child's chronic illness. The beliefs of the parent may both assist in the overall coping process or potentially hinder coping. Parental feelings can range from feelings of loss of control and depression, to feelings of happiness and hopefulness. Feelings of adequacy in performing treatments, preventing complications and meeting daily needs are important components of one's ability to cope with the care of a chronically ill family member (Hymovich & Hagopian, 1992). Each parent utilizes a set of individual coping strategies ranging from health promoting strategies such as asking for help, crying, praying, exercising, reading, getting away for awhile, and trying to relax, to potentially harmful coping strategies such as taking alcohol and smoking.

Level of functioning of the family influences the family's ability to cope with their child's illness. The nurse is in a key position to enhance the coping ability of the family faced with the challenge of caring for a child with asthma. The following nursing skills can be used to intervene with families using the Hymovich model: expert interpersonal communication, adult education knowledge, stress management techniques, expert asthma management information, advocacy and community referral.

The Hymovich model emphasizes the use of the nursing process to identify system characteristics and contingency variables, assessing strengths and needs, planning necessary interventions, implementing these interventions and reassessment. This model helps the nurse perform an appropriate assessment of the stressors and coping strategies in order to provide appropriate and meaningful interventions. By using the Hymovich Contingency

Model of Long-Term Care (Hymovich & Hagopian, 1992), nurses can systematically assess and provide interventions specific to the needs of the family. However, no studies were found relating parental quality of life to coping with the Hymovich conceptual model.

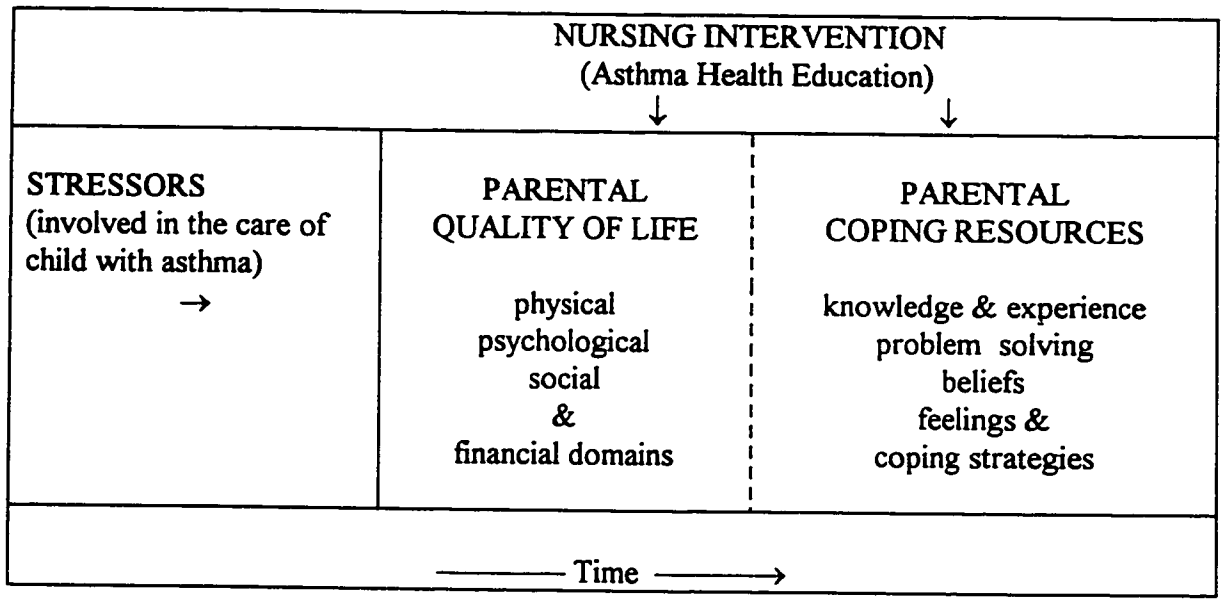

Figure 3: Parental quality of life and parental coping resources in response to stressors and nursing intervention.

Figure 3 demonstrates the relationship of the study variables in the context of the conceptual framework. The theoretical framework selected and literature published to date on asthma health education, quality of life and coping pointed to a need to examine these variables with respect to one another. What is unknown is whether a nursing intervention influences parental quality of life or coping and whether a relationship exists between parental quality of life and parental coping. If the parent mobilizes coping resources, does

this translate into improved quality of life? The relationship between confounding variables (sociodemographic data), quality of life and coping of parents requires further examination.

2.6 RESEARCH HYPOTHESES

The study tested the following hypotheses regarding the influence of a home-based asthma health education program on parental quality of life and coping:

1. A significant change in quality of life and coping in parents of children with asthma occurs as a result of receiving a home-based asthma health education program.

2. A significant relationship exists between quality of life and coping in parents of children with asthma.

3. A significant relationship is shown between sociodemographic data, quality of life and coping in parents of children with asthma.

CHAPTER 3

METHODOLOGY

This chapter describes the methodology selected to attain the specific objectives stated and to test the research hypothesis. The methodology specified is composed of the following: 1) research design; 2) population and setting; 3) sampling procedure; 4) operational definition of variables; 5) description of instruments; 6) data collection procedure; 7) plan of statistical analysis; 8) ethical considerations; and 9) methodological limits of the study.

3.1 RESEARCH DESIGN

The influence of a home-based asthma health education program on the quality of life and coping of parents of children with asthma was evaluated using a pretest-post-test control group design. The chosen design has components of a classic experimental research design: 1) random treatment allocation; 2) researcher-controlled manipulation of the independent variable; and 3) researcher control of the experimental situation, including a control group as described by Burns and Grove (1993).

Random treatment allocation means that each subject has an equal chance of being assigned to either the experimental or the control group, which results in potential balance between groups on known and unknown confounding variables (Gehlbach, 1993). The treatment (nursing intervention) which was the independent variable, was only provided to the experimental group, and not to the control group.

3.2 SETTING AND POPULATION

3.2.1 Setting

This study was conducted in the Sudbury region of northeastern Ontario, an area composed of municipalities within and outside the city proper in a radius of approximately 50 kilometres. Sudbury, with a population of 161,000 (Statistics Canada, 1991), is a major health care referral centre for the region. Of the six pediatric medical practices in the city, one with a high concentration of asthma cases was selected for obtaining the sample. The pediatrician in charge of this practice follows approximately 600 children with asthma per year (V.J. Kumar, personal communication, January 1995).

3.2.2 Population

The target population were natural or adoptive parents of at least one child with asthma 10 years of age or younger. The age of the child was set at 10 years of age or younger in order to reach desired sample size. Only parents of children with chronic stable asthma were included, specifically children with diagnosed asthma for over 6 months who were not visiting the pediatrician in connection with an acute exacerbation of asthma.

3.2.3 Eligibility criteria

For inclusion in the study, the parents were to:

1. have asthma management responsibilities for their child,

2. have no previous participation in a formally-accepted asthma health education program;
3. agree not to take part in any other formally-accepted asthma education program for the duration of the study (3 months);
4. be able to read, write and communicate in English;
5. agree to participate and sign a consent form.

3.3 SAMPLING PROCEDURE

3.3.1 Sample size

Sample size was calculated prior to recruitment. The sample size was based on a quality of life pilot study (Townsend et al., 1991). Calculation was based on a level of power of .80 (1-β), corresponding to a 20 percent chance of a Type II error, a situation in which a study fails to detect effects that truly exist in the larger population (Burns & Grove, 1993). Based on Townsend and colleagues' work with the 13-item Pediatric Asthma Caregiver Quality of Life Questionnaire (PACQLQ), the standard deviation for each group was set at δ=7.5. For the purpose of this study, it was decided that the smallest difference detected between groups on the PACQLQ that would be clinically significant was Δ=6.5, representing a change of 0.5 for each of the 13 items (13 x 0.5). Based on the Northeastern Ontario Family Medicine in-house sample calculation program, with a power of 0.80, (1-β= 0.20), and α of 0.05, the sample size for each group required for a two-tailed test with

unpaired data was 21 subjects per group (Appendix A). Therefore based on this calculation, a total sample size of 42 parents was estimated to provide reasonable assurances of detecting a minimum clinical difference should one exist and avoiding Type I and II errors.

3.3.2 Recruitment

A space equipped with a table, chair and telephone was provided in the pediatrician's office. Subjects were recruited over a 4-week period. A recruitment poster (Appendix B) was placed in each examination rooms of the office suite, and interested parents contacted the secretary for further information. The secretary and researcher supplied copies of the information sheet (Appendix C) to all parents wishing additional information, and a consent form (Appendix D) was signed by those willing to participate in the study. The researcher was available in the office to answer any study-related questions. Copies of the consent form were kept by both the parent and researcher.

3.3.3 Group assignment

As each parent signed and submitted a consent form, he or she was assigned a number from 1 to 45 in the order of entry. Before data collection, the treatment allocations were determined using a table of random numbers with the Moses-Oakford Method of Randomization (Meinert & Curtis, 1986) (Appendix E). The numbers were assigned the letters H (home-visit) for the experimental group and S (standard care) for the control group.

3.4 OPERATIONAL DEFINITION OF THE VARIABLES

The operational definition of the variables are presented in the following sections: the independent or treatment variable, dependent or outcome variables, and confounding variables (Figure 4).

3.4.1 Independent Variable

Home-Based Asthma Health Education Program

The **experimental group** received a home-based health education intervention called the Air Force Asthma (AFA) Program (Appendix F). The AFA program has been given by nurses, physicians, and respiratory technologists to parents and children with asthma in various locations of Ontario over the past five years. The AFA program was developed by the Ontario Lung Association in consultation with the Ontario Thoracic Society, the Ontario Respiratory Care Society as well as nurses, physiotherapists, educational psychologists, parents of asthmatic children, and children with asthma. The content covered by the program includes: parts of the respiratory system, effects of asthma, treatment, triggers, and medications of asthma, crisis management, monitoring and prevention, and using a symptom diary. The program is updated regularly (the latest revision was in 1995) and is based on current scientific understanding of asthma pathophysiology and accepted treatment approaches. The program includes a teaching manual, set of slides, and recommended format. The Lung Association provides regular training sessions for instructors.

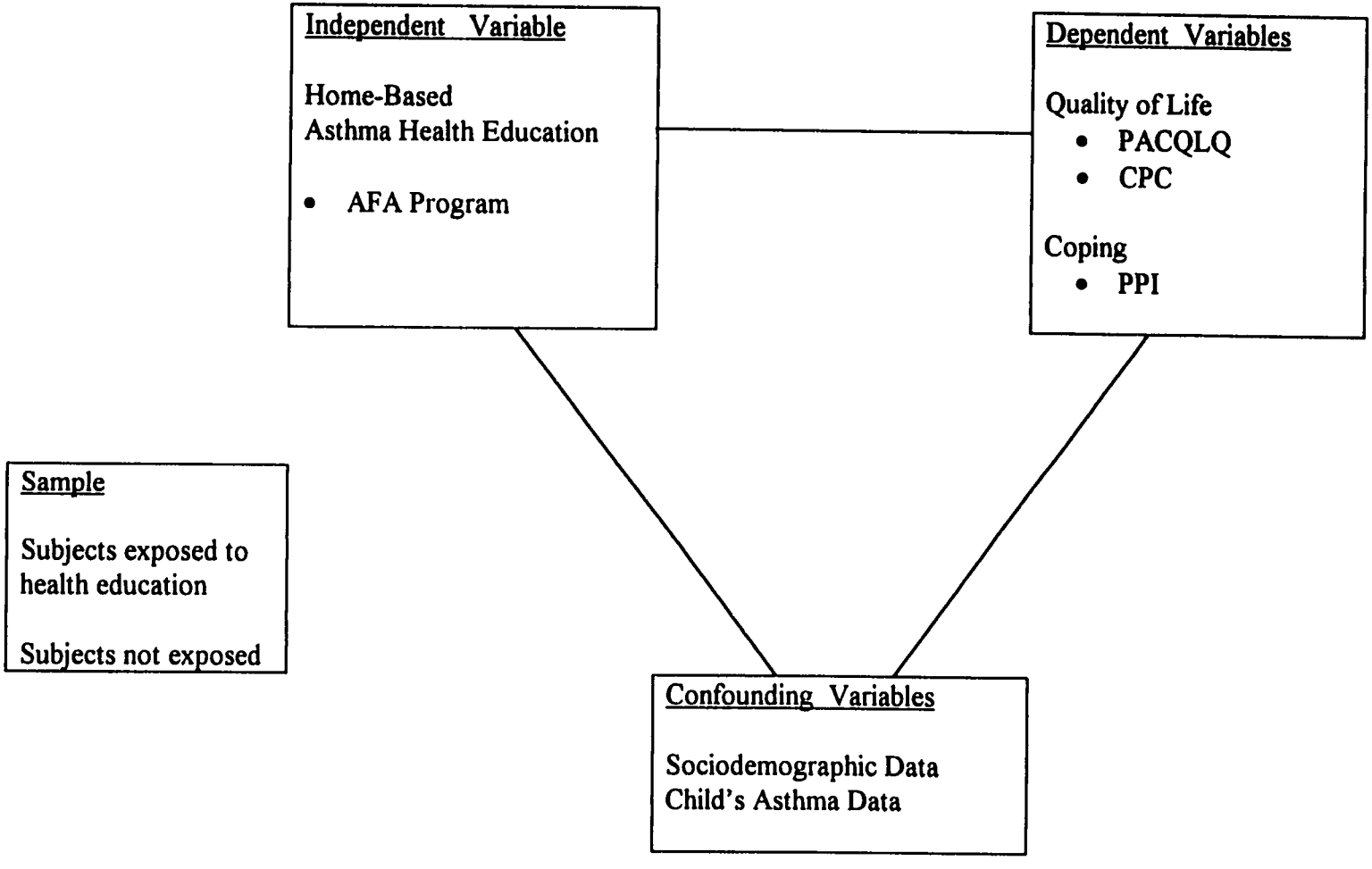

Figure 4: Relationship of variables

The **control group** received a booklet entitled "Childhood Asthma: A Handbook for Parents" (Canny & Levison, 1993) from the researcher. The parents in the control group were given the booklet to represent conventional care. Since conventional care is usually in the form of verbal information given by a health professional, the booklet was more than what is normally provided in terms of asthma information. The pamphlets were provided by the Ontario Lung Association, Sudbury-Nipissing branch. Table 1 summarizes the asthma information received by both groups, as well as major similarities and differences.

Table 1: Comparison of asthma information provided by group.

	EXPERIMENTAL GROUP	**CONTROL GROUP**
Content	Parts of the respiratory system	Parts of the respiratory system
	Effects of asthma	Effects of asthma
	Treatment	Treatment
	Triggers	Triggers
	Medications	Medications
	Asthma crisis management	Asthma crisis management
	Monitoring & prevention	Monitoring & prevention
	Using a symptom diary	Using a symptom diary
Delivery	Home-based format	Booklet format
	Face-to-face	Hand out

3.4.2 Dependent Variables

Quality of Life

Quality of life is operationally defined as components or domains of the parent's life that might be affected by their child's asthma. In the context of this study, quality of life refers to health-oriented perceptions relating to physical, emotional and social domains (Spilker, 1990) rather than happiness, satisfaction or living standard. Parental quality of life was measured with the Pediatric Asthma Caregiver's Quality of Life Questionnaire (Juniper et al., 1996), (Appendix G).

The Caregiver Perception of Change in Child's Asthma Survey (Juniper et al, 1996) (Appendix H) was used as an adjunct to the PACQLQ in examining quality of life. In the context of this study, the Caregiver Perception of Change refers to the parent's rating of change of their child's asthma following receipt of the intervention (i.e. asthma health education information). Quality of life measures include two levels of inquiry: a specific questionnaire such as the PACQLQ, (e.g. "were you awakened during the night by your child's asthma?") along with a rating of change such as the Caregiver Perception of Change in Child's Asthma Survey (e.g. "how much better or worse is the child's asthma after receiving the health education"). In principle this allows one to examine difficulties typically encountered as a parent with a child with asthma while at the same time looking at the global rate of change in the child's condition (Spilker, 1990).

Coping

In this study, coping is operationally defined in terms of 5 coping sub-concepts measured by subscales of Hymovich's Parent Perception Inventory (PPI) (Hymovich, 1988), Appendix I. The following independent scales of the PPI were used to capture overall parental coping: 1) Help; 2) Concerns; 3) Beliefs; 4) Feelings; 5) Coping Strategies. These sub-concepts are operationally defined as follows:

1. Help Scale refers to the amount and type of parent informational needs including, for instance, physical care of child, diet or nutrition, the child's condition, managing the child's behaviour, the child's medication, and knowing when to see the physician, as well as usual sources used for information or help related to child's asthma.

2. Concerns Scale is defined as practical issues faced by the parent such as time with family members, getting out of the house without children, feeling worn out, finding someone to stay with child, the weather affecting the activities of the child, wondering what child's future will be, cost of medication.

3. Belief Scale refers to parenting philosophy such as putting personal needs ahead of child's needs, handling problems alone or asking for help.

4. Feelings Scale relates to particular emotions experienced by the parent during the past three months, such as anger, anxiousness, confidence, contentment, defeat, depression.

5. Coping Strategies Scale identifies the number and type of coping strategies which the parent uses (Number and Type), how often the parent uses these (Frequency), and how helpful the coping strategies are for the parent (Helpfulness). Coping strategies are operationally defined as what a parent will do to make the situation better or try to make oneself feel better. Examples provided within the instrument include: crying, talking with someone, looking at options, blaming someone, exercising, smoking, asking for help, praying, talking alcohol or medication.

3.4.3 Confounding Variables

Sociodemographic Data

The sociodemographic data collected included parent age, gender, education, family size, family income, employment and marital status. These data were obtained with the general information & asthma questionnaire (see Appendix J) developed for this study.

Child's Asthma Data

The data collected on the child's asthma included number of asthma attacks which the parent had to deal with during the three-month study period, medications and health care utilization for asthma. An asthma attack was defined in this study as a time when a

parent had to use extra measures to maintain asthma control, such as giving more than the regular dosage of asthma medication.

3.5 DESCRIPTION OF THE INSTRUMENTS

3.5.1 General Information and Asthma Questionnaire (Appendix J)

The questionnaire, developed for this study contained 24 items regarding sociodemographic data, and child's asthma data. Sociodemographic data were obtained from questions 2 to 19. Child's asthma data were obtained from questions 1 and 20 to 24.

3.5.2 Paediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ)

The PACQLQ is a 13-question self-administered questionnaire measuring two domains of caregiver quality of life: activities and emotions. Guidelines are also provided for administration of the tool by interview (Juniper, 1994). The PACQLQ is constructed on a 7-point Likert scale ranging from 1 (all of the time) to 7 (none of the time). The tool takes less than 5 minutes to complete and asks caregivers to recall impairments experienced during the previous week taking into account, at follow-up visits, their response at the prior visit (Juniper et al., 1996). More than one administration point is recommended, and three points were obtained in the Juniper et al. (1996) study. The present home-based study administered three data collection points within the three-month study period to determine effect of time and group.

Two domains of parental quality of life were measured: activities (questions 2, 3, 4, 6, 8) ("Did your child's asthma interfere with your job or work around the house") and emotions (questions 1, 5, 7, 9, 10, 11, 12, 13) ("Did you feel upset because of your child's cough, wheeze, or breathlessness"). Individual items are weighted equally and the results are expressed as the mean score per item for each of the domains (activity limitation and emotional function) as well as for overall quality of life (Juniper et al., 1996). Therefore, both the domain and overall scores range from 1 to 7. Since there are 13 questions with a range of results from 1 to 7, the total score is the sum of all questions (minimum score is 1x13=13 and maximum score 13x7=91) and the individual weighted score is the total sum divided by the number of questions. Therefore for the overall quality of life score, the total sum is divided by 13; for activities, the total is divided by 5; and the emotions domain total score is divided by 8.

Reproducibility of the instrument was calculated on data from patients who were stable between clinic visits to determine intraclass correlation coefficients which were 0.85 for overall qualily of life, 0.80 for emotional function, and 0.84 for activity limitation (Juniper et al., 1996).

Parental burden of illness in relation to pediatric asthma was examined by Townsend et al.'s (1991) validation study of the PACQLQ. The Impact-on-Family Scale (Stein & Reissman, 1980) evaluates the impact of a child's illness on financial, family/social, personal strain and mastery domains. Correlations between the PACQLQ sub-scales and this tool were between -0.54 and -0.65 providing evidence of criterion validity (Juniper et al., 1996).

3.5.3 Caregiver Perception of Change in Child's Asthma

The Caregiver Perception of Change (CPC) in Child's Asthma is a two-item instrument based on the Juniper et al. (1996) study to rate the parent-perceived change in the child's asthma. The score is determined by two questions: the first question determines the sign of the score, a positive (+) or negative (-) to "is your child's asthma better or worse"; the second question relates to the magnitude of the change on a scale of +7 (a very great deal better), to -7 (a very great deal worse) with a mid-range of 0 (no change). Pearson correlation coefficients obtained by Juniper et al. (1996) between changes in the PACQLQ and the Caregiver Perception of Change in Child's Asthma Survey were 0.52 for emotional function and 0.41 for activity limitation.

3.5.4 Parent Perception Inventory (PPI)

The PPI is the latest revised version of the Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ) (Hymovich, 1981,1983; Hymovich & Baker, 1985). The PPI was developed for use with parents of children with long-term disabilities or chronic illnesses measuring changes in the past three months. It may be used either in its entirety or as separate sub-scales. This three-month time frame for the PPI determined the length of the follow-up period for the present study. The PPI is composed of 172 items subdivided into 5 sub-scales. Table 2 itemizes the sub-scales used in this study, as well as provides the range of possible scores for each based on the Likert scale ranges.

The scoring for the Help scale is the sum of all items, based on a choice of 18 informational needs, with higher scores indicating the magnitude of help needed. The scoring for the Concern scale is the sum of all items, based on a choice of 34 concerns, indicating the magnitude of concern level. The scoring for the Beliefs scale is the sum of all 12 items, with a high score indicating how strongly the belief was for the parent. The Feelings scale scoring is the sum of all 21 items with the negative feeling scores reversed, indicating the magnitude of positive feelings. The Coping scale is the sum of 29 choices of coping strategies used by the parent. The Helpfulness of Coping strategies scale is the sum of the coping strategies indicating the magnitude of helpfulness. The frequency coping scale is the sum of how often each coping strategy is used.

Table 2: Description of PPI sub-scales by number of items, range of results and minimum and maximum scores

PPI sub-scales	**Number of items**	**Likert Scale range**	**Scores Min - Max**
Help scale	18	1-3	18 - 54
Concerns scale	34	0-4	0 - 136
Beliefs scale	12	1-3	12 - 36
Feelings scale	21	0-3	0 - 63
Coping strategies scales a) number b) helpfulness c) frequency	 29 29 29	 0-3 0-3 0-3	 0 - 29 0 - 87 0 - 87

Cronbach's alpha reliability coefficients for each of the sub-scales were calculated with the following results: Help scale 0.92; Concern scale 0.93; Beliefs scale 0.40; Feeling scale 0.91; Coping strategies 0.62; Coping helpfulness scale 0.80. Test-retest reliability was performed on the Help scale 0.86; Concern scale 0.82; Feelings scale 0.74; Coping strategies 0.78; and Coping helpfulness 0.82 (Hymovich, 1988).

3.6 DATA COLLECTION PROCEDURE

Both the experimental and control groups completed the same schedule of data collection (Table 3). The time required for completion of the questionnaire package varied from 20 minutes to 45 minutes at baseline; 5 minutes to 10 minutes at 1 month; and 20 to 35 minutes at 3 months. Baseline measures were collected at the parent's home (experimental group) and pediatrician's office (control group). Data for T_2 and T_3 were collected by telephone for both the experimental and control groups. As mentioned earlier, the PPI tool asks for information on coping in the last three months, and this determined the study time period. Three administrations of the PACQLQ were done in order to obtain similar patterns of collection from previous studies (Juniper et al., 1996).

3.6.1 Baseline (T_1)

The purpose of the first data collection was to establish baseline values on all variables measured in this study for both the experimental group and the control group.

Table 3: Schedule of data collection

Instrument	Baseline T_1	One month T_2	Three months T_3
General Information & Asthma Questionnaire			
Sociodemographic data	X		
Child's asthma data	X		X
Quality of Life			
PACQLQ	X	X	X
Caregiver's Perception of Change		X	X
Coping			
PPI: Help	X		X
Concerns	X		X
Beliefs	X		X
Feelings	X		X
Coping strategies	X		X

Experimental Group: The experimental group received the home-based health education program from March 1996 to April 1996. The home-based asthma education program was provided, in the same manner for all subjects in the group. Before the health education session was given, the parent completed the self-administered questionnaires (General Information & Asthma Questionnaire, PACQLQ, and PPI).

The same teaching manual and slides provided by the Lung Association were used to ensure consistency of content and approach. The asthma health education session followed the format set out by the slide presentation, in numerical order of the slide. The program was provided in the following order: (1) what is asthma; (2) triggers of asthma; (3) treatment of asthma; (4) coping with asthma.

Control Group: The control group completed the self-administered questionnaires (General Information & Asthma Questionnaire, PACQLQ, and PPI) in the pediatrician's office. No specific one-on-one educational intervention was provided apart from distributing the Childhood Asthma, A Handbook for Parents (Hospital for Sick Children, Toronto, 1993).

3.6.2 One month (T_2)

Experimental and Control Groups

Within 1 month of receiving the health education information (home program or booklet), subjects in the experimental group and control group provided answers to PACQOL and Caregiver's Perception of Change questionnaires by telephone. It was necessary to call all experimental and control group parents at home in order to obtain answers to follow-up questionnaires.

Questionnaire administration followed the "Guidelines for Questionnaire Administration" (Juniper, 1994, p.6) which recommends asking questions exactly as worded, never "helping" the parent to choose an answer, be neutral in response to the parent's answer, ask questions in order specified. Time 2 and Time 3 used informed administration, that is the parents were told prior to answering a question what answer was given the last time. In addition to giving the patients a basis for comparison, this method results in a decrease in variance (random error) of the measurement and some data exists suggesting that it does not introduce bias (Guyatt, Berman, Townsend & Taylor, 1985).

3.6.2 Three months (T_3)

Experimental and Control Groups

Three months following the start of the study, all subjects in the experimental and control group provided answers to the PPI, PACQOL and Caregiver Perception of Change in Child's Asthma by follow-up telephone calls. As mentioned earlier, the PPI tool asks questions relating to the past three months, therefore it determined the length of time between Times 1 (baseline) and 3 (3 months).

3.7 STATISTICAL ANALYSIS

SPSS® version 6.1 for windows was used for descriptive and inferential analysis of data.

3.7.1 Descriptive analysis

The descriptive analysis included characteristics of the population: age and gender, education, family size, family income, employment and marital status. Child's asthma data included the number of asthma attacks the parent managed during the 3-month study period, medication used for asthma control, as well as health care utilization during the same period of time. Health care utilization included number of visits to the physician, emergency department, after-hour clinic, as well as number of hospitalizations.

Parental quality of life was determined by calculating overall quality of life, and sub-scales of activity and emotional domains, as well as parent perception of change totals.

Parental coping was determined by information needs, concerns, beliefs, feelings, and coping strategies. Table 4 provides the type of data measurement obtained for each variable. From interval level data, measures of central tendency and dispersion were calculated (median, standard deviation, and range).

3.7.2 Inferential analysis

Since sample sizes were small (n=20 per group), considerations were given to perform the most appropriate statistical methods. Since it is difficult to assess normality of small samples, both parametric (t-test) and non-parametric (Wilcoxon) methods were used.

The Wilcoxon matched-pairs signed-ranks test (non-parametric) and paired t-test (parametric) were used to determine the statistically significant differences within group for the test variables, to determine effect of time from T_1 to T_2, and from T_1 to T_3. The Wilcoxon Rank Sum W Test (non-parametric) and t-test for Independent Samples (parametric) were used to determine the statistically significant differences between group for the test variables to determine the group effect at T_1, T_2, and T_3. Pearson product moment correlations were calculated to determine relationships between the study variables and sociodemographic data on the whole sample (N=40).

Table 4: Classification of data by level of measurement

Data	Level of Measurement
Sociodemographic data	
age, family size and number of children with asthma	interval
education, income, employment status	ordinal
gender, marital status	nominal
Child's asthma data	
number of attacks in past 3 months	interval
medications needed for control	nominal
health care utilization (number of visits to physician, emergency, walk-in clinic, hospital admissions)	interval
Parental Quality of life	
PACQLQ: Overall, Activity & Emotional Domains	interval
Caregiver Perception of Change in Child's Asthma	interval
Parental coping	
PPI	
Help score	interval
Concerns score	interval
Beliefs score	interval
Feelings score	interval
Coping strategies scores:	
a) number score	interval
b) helpfulness score	interval
c) frequency score	interval

In order to test each of the three hypotheses, specific statistical tests were needed. Hypothesis 1 states that a significant change in quality of life and coping of parents occurs as a result of receiving a home-based asthma health education program. The following tests were used to test this hypothesis.

For group effect: Wilcoxon Rank Sum W Tests

t-tests for independent samples

For time effect: Matched-Pairs Signed Rank Tests

paired t-tests

Pearson product-moment correlations were computed to examine the linear relationships between the PACQLQ and PPI measures, to test hypothesis 2, which states that a significant relationship exists between quality of life and coping of parents of children with asthma. Pearson product-moment correlations were calculated to examine linear relationships between sociodemographic data (age, education, family size and number of children with asthma) and quality of life and coping (hypothesis 3).

3.8 ETHICAL CONSIDERATIONS

The study protocol was approved by the ethics committee of the University of Ottawa, University Human Research Ethics Committee (UHREC) confirmed by the receipt of a certificate of clearance dated February 23, 1996 (Appendix K). Participation in this study was, as mentioned earlier, voluntary and subjects were informed of their right to withdraw at any time. Informed consent was obtained from the participants prior to the study. A copy of the information sheet and a copy of the signed consent form was retained by each participant. Confidentiality was respected by using code numbers rather than subject names on the questionnaires. Consent forms were kept in a locked file cabinet separate from the data. Confidentiality was also assured by interviewing subjects in private locations such

as their homes, the pediatrician's office, or over the telephone. Subjects were informed that they would not be identified by name in any publication which could result from the study.

Benefits of participation for both groups in the study included receiving current information regarding asthma management for children. Since the Air Force Asthma program is available in the community and limited resources precluded further involvement, the control group was not offered the home-based asthma health education program at the end of the study.

3.9 METHODOLOGICAL LIMITATIONS

Design features such as unrepresentative samples, single settings, instruments with limited reliability and validity contribute to methodolocigal limitations (Burns & Grove, 1993). In the context of this study, the major limitations to generalizability of results relate to: 1) the tools limited testing for psychometric properties; 2) the use of a single setting and the sample size; 3) the data collection procedure in relation to the recall bias and telephone follow-up; 4) potential for social desirability related to same data collector; 5) a potential for recall bias since the parents did not submit a symptom diary.

CHAPTER IV

RESULTS

This chapter presents results relating to: 1) sampling and data collection; 2) descriptive analysis on sociodemographic data and outcome variables; and 3) inferential statistics testing the working hypotheses. Major results pertain to similarities and differences in the experimental and control groups before and after intervention and relationships between the major study variables (health education program, parental quality of life, and parental coping).

4.1 SAMPLING AND DATA COLLECTION

All 45 parents who accepted to participate in the study met the eligibility criteria and were enrolled between February 28, 1996 and April 4, 1996. Randomization to treatment resulted in 22 parents being allocated to the experimental group and 23 parents to the control group. Despite numerous attempts to contact parents, five parents were lost to follow-up due to the following reasons: unlisted telephone number (1/45), no answer on repeated attempts to contact by telephone (3/45), and the child's condition had changed and needed hospitalization for asthma at the time of the study (1/45) (exclusion criteria pertaining to child's condition, see section 3.2.2). These losses were evenly distributed across the study groups (2 parents in the experimental group and 3 parents in the control group). As shown in Table 5, of the number of parents who entered the study (n=45), 40 (89%) completed the questionnaires at T_1, T_2, and T_3.

Table 5: Distribution of recruited parents by group and by time.

Number of Parents	Experimental	Control	Total
Initial recruitment	22	23	45
Baseline (T_1)	20	20	40
1 month (T_2)	20	20	40
3 months (T_3)	20	20	40

4.1.1 Data Collection

Data were collected at three points in time (T_1, T_2 and T_3) over a four-month period (early March to early July 1996) from each of the 40 participant families. Initial data collection (T_1) questionnaires (early March 1996 to mid-April 1996) were completed on site in the pediatrician's office for the control group or in the family's home for the experimental group. Twenty home visits were conducted during a five-week period, between March 1996 and April 1996. All data collection for T_2 and T_3 for both the experimental and control groups was completed by telephone. T_2 data collection corresponded to 1 month after enrolment (April - late May), and T_3 data collection corresponded to 3 months following enrolment (late May - early July).

4.2 DESCRIPTIVE ANALYSIS

Description of the characteristics of the sample will be provided in the sections dealing with sociodemographic characteristics of the parents, and the child's asthma data

including basic demographic data of the child, the number of asthma attacks, asthma medications and health care utilization. Information was collected to provide sample profiles by studied variables through time.

4.2.1 Sociodemographic characteristics of the parent

Parental characteristics of the experimental and control groups are presented in table 6 by age, gender, education, family size, income, employment and marital status. Overall, the groups appear quite similar except for age groupings. The age of the parents ranged from 29 to 41 years (mean 34.20, s.d. 3.6) for the experimental group and from 21 to 48 years (mean 34.65, s.d. 6.3) for the control group. Ninety percent (90%) of the experimental and eighty percent (80%) of the control group contact parents were mothers. Fifty five percent (55%) of experimental and 70% of the control subject parents had post-secondary education. The majority of subjects in both groups reported family incomes of $40,000 per year or greater. Employment status indicated that 50% of the parents in the experimental group worked full-time, compared to 65% for the control group. Dual-parent families were the norm, with 90% for the experimental group, and 80% for the control group.

Other sociodemographic data gathered for comparison purposes included religion and ethnicity. Religious affiliation for the experimental group was 75% RC, and 10% Protestant, in comparison to 90% RC and 5% Protestant for the control group. Eighty percent (80%) of the experimental group and 85% of the control group stated attending religious services sometimes to never.

Table 6: Distribution of parental characteristic by group, age, gender, education, family size, income, employment and marital status.

Characteristic	Experimental		Control		Total	
	n=20	(%)	n=20	(%)	N=40	(%)
Age						
21-30	1	(5.0)	4	(20.0)	5	(12.5)
31-40	17	(85.0)	12	(60.0)	29	(72.5)
41-50	2	(10.0)	4	(20.0)	6	(15.0)
Gender						
Male	2	(10.0)	4	(20.0)	6	(15.0)
Female	18	(90.0)	16	(80.0)	34	(85.0)
Education						
High School ≥ grade 10	9	(45.0)	6	(30.0)	15	(37.5)
College/University	11	(55.0)	14	(70.0)	25	(62.5)
Family Size						
1 child	3	(15.0)	5	(25.0)	8	(20.0)
2 children	9	(45.0)	10	(50.0)	19	(47.5)
3 children	5	(25.0)	5	(25.0)	10	(25.0)
4 children or more	3	(15.0)			3	(7.5)
Family Income						
$ 5,000 - $ 9,000			1	(5.0)	1	(2.5)
$10,000 - $19,000	3	(15.0)	1	(5.0)	4	(10.0)
$20,000 - $29,999	1	(5.0)	2	(10.0)	3	(7.5)
$30,000 - $39,999	2	(10.0)	3	(15.0)	5	(12.5)
$40,000 +	14	(70.0)	13	(65.0)	27	(67.5)
Employment Status						
Full-time	10	(50.0)	13	(65.0)	23	(57.5)
Part-time	2	(10.0)	3	(15.0)	5	(12.5)
At home	8	(40.0)	4	(20.0)	12	(30.0)
Marital Status						
Married/Common-law	18	(90.0)	16	(80.0)	34	(85.0)
Separated/Single	2	(10.0)	4	(20.0)	6	(15.0)

Seventy five (75%) of both the experimental and control groups stated French as one of the cultures of ethnic origin. The remaining 15% for both groups listed many cultures of ethnic ancestry. Table 6 summarizes the sociodemographic characteristics of the parents. Examination of this table reveals no major differences between experimental and control groups.

4.2.2 Child's asthma data

Although the focus of the study was parents of children with asthma and not the children themselves, basic demographic data of the children with asthma were gathered in order to verify equivalence of the groups. Table 7 summarizes the characteristics by group, age, gender, and number of children with asthma.

Within 20 families of the experimental group, there were 30 children with asthma, compared to 26 children in the 20 control families. The majority of the parents had one child with asthma (55% experimental; 75% control), two or three children with asthma were found in 45% of the experimental group, and 25% of the control group.

The mean age of children in the experimental group was 5.4 years (s.d. 2.6) compared to 4.8 years (s.d. 2.5) for the control group. Age ranged for both groups was 1 to 10 years. The ages and gender of the children with asthma in both the experimental and control groups was similar.

Table 7: Distribution of children with asthma by group, age, gender and number of children with asthma per family.

Children with Asthma	Experimental		Control		Total	
	n =30	(%)	n =26	(%)	N=56	(%)
Age						
Infant/Toddler (≤2)	4	(13.3)	5	(19.2)	9	(16.1)
Pre-school (3, 4, 5)	12	(40.0)	13	(50.0)	25	(44.6)
School-age (≥6)	14	(46.7)	8	(30.8)	22	(39.3)
Gender of child						
Male	14	(46.7)	10	(38.5)	24	(42.9)
Female	16	(53.3)	16	(61.5)	32	(57.1)
Number of children with asthma per family						
1 child	11	(55.0)	15	(75.0)	26	(65.0)
2 children	8	(40.0)	4	(20.0)	12	(30.0)
3 children	1	(5.0)	1	(5.0)	2	(5.0)

The child's asthma data included asking how many asthma attacks the parent had to deal with during the 3-month study period, regardless of the number of children with asthma there were within the family. For example, a family in the experimental group with 2 children with asthma dealt with 4 asthma attacks during the 3-month study period, and a control group family with 2 children with asthma dealt with 5 asthma attacks during the same time period. The purpose of examining these data was to determine equivalence of groups. Table 8 provides the distribution of number of attacks over the 3-month study period by group as measured at T_3.

Table 8: Parental-reported asthma attacks per family over the 3-month study period.

Asthma Attacks	Experimental		Control		Total	
	n=20	(%)	n=20	(%)	N=40	(%)
0	4	(20.0)	6	(30.0)	10	(25.0)
1	8	(40.0)	4	(20.0)	12	(30.0)
2	3	(15.0)	4	(20.0)	7	(17.5)
3	3	(15.0)	1	(5.0)	4	(10.0)
4	1	(5.0)	2	(10.0)	3	(7.5)
5	0	(0.0)	1	(5.0)	1	(2.5)
5≥	1	(5.0)	2	(10.0)	3	(7.5)

The mean number of asthma attacks for the experimental group was 1.85 (range 0 to 10) and 2.10 (range 0 to 8) for the control group. Number of attacks for both groups indicated two attacks or less for 75% of the experimental group compared to 70% of the control group. Examination of table 8 reveals no major differences between experimental and control groups.

In addition to number of asthma attacks, the type of asthma medications used for asthma control was collected. Table 9 provides a summary of medication type used by the group over the 3-month study period. For both groups, approximately half of parents reported that β_2 agonist as well as inhaled steroid were required for control of their child's asthma, thus indicating similar medication regimens.

Table 9: Distribution of types of medications used by group over the 3-month study period.

Medication type	Experimental		Control		Total	
	n=20	(%)	n=20	(%)	N=40	(%)
β_2 agonist	17	(85.0)	16	(80.0)	33	(82.5)
Inhaled steroid	13	(65.0)	10	(50.0)	23	(57.5)
Oral steroid	5	(25.0)	2	(10.0)	7	(17.5)
Other	1	(5.0)	1	(5.0)	2	(5.0)

Oral steroids were required by 25% of the experimental group and 10% of the control group. Sixty five percent of the experimental and 50% of the control group utilized inhaled steroids for asthma management. Other oral medications used included theophylline (experimental group) and ketotifen (control group).

The child's asthma data also included health care utilization in connection with asthma over the 3-month study period, and included visits to emergency, family physician, pediatrician, after-hour clinic visits and hospital admissions. No hospitalizations for asthma for children in the families of either the experimental or control groups were reported. Table 10 summarizes the additonal data obtained.

Visits to the same pediatrician accounted for the majority of health care utilization for both groups. Fifty percent (50%) of families in the experimental group visited the same pediatrician 1 to 2 times, compared to 45% of the control group during the 3-month study period. Reviewing emergency room, family physician and after-hour clinic visits, no major differences were observed in health care utilization between the groups during the study period.

Table 10: Health care utilization for the 3-month study period.

Health Care Utilization	Experimental		Control		Total	
Number of visits	n=20	(%)	n=20	(%)	N=40	(%)
Emergency Room Visits						
0	19	(95.0)	18	(90.0)	37	(92.5)
1	1	(5.0)	2	(10.0)	3	(7.5)
Family Physician Visits						
0	17	(85.0)	18	(90.0)	35	(87.5)
1	3	(15.0)	2	(10.0)	5	(12.5)
Pediatrician Visits						
0	6	(30.0)	9	(45.0)	15	(37.5)
1	8	(40.0)	7	(35.0)	15	(37.5)
2	2	(10.0)	2	(10.0)	4	(10.0)
3	1	(5.0)	1	(5.0)	2	(5.0)
≥4	3	(15.0)	1	(5.0)	4	(10.0)
After-hour Clinic Visits						
0	19	(95.0)	18	(90.0)	37	(92.5)
1	1	(5.0)	1	(5.0)	2	(5.0)
≥2			1	(5.0)	1	(2.5)

4.2.3 Parental Quality of Life

Analysis of the dependent measures involved calculation of descriptive statistics for the measures over time. Table 11 provides the mean, standard deviation and range of results for PACQLQ components in both groups over the three administrations. The Pediatric Asthma Caregiver Quality of Life Questionnaire (PACQLQ) has three subscales: Overall quality of life, Activity Domain, and Emotional Domain. Note that the scores range from 1 to 7, where 1 represents severe impairment in quality of life, activity or emotional domain and 7 represents no impairment.

The PACQLQ results demonstrate higher values for both groups at Time 2, with results decreasing for both groups at Time 3. The activity domain for the experimental group's activity domain shows an upward trend which is maintained at Time 3. The tests of significance of this trend are presented in the inferential analysis section. There appears to be only very slight differences within groups in all domains over time. Also, data show little differences between groups over time as well as in the overall, activity and emotional domains of the PACQLQ.

Table 11: Mean, standard deviation and range results for PACQLQ by time and group.

PACQLQ	Experimental (n=20)			Control (n=20)		
	Mean	S.D.	Range	Mean	S.D.	Range
T_1						
Overall	5.74	1.39	2.54 -7.00	5.58	1.32	1.92 -7.00
Activity domain	5.41	1.70	1.50 -7.00	5.59	1.47	2.00 -7.00
Emotional domain	5.84	1.37	2.00 -7.00	5.58	1.33	1.89 -7.00
T_2						
Overall	5.88	1.37	2.85 -7.00	5.73	1.14	2.62 -7.00
Activity domain	5.76	1.55	1.50 -7.00	6.14	1.05	3.00 -7.00
Emotional domain	5.92	1.38	2.22 -7.00	5.55	1.35	2.44 -7.00
T_3						
Overall	5.75	1.36	3.23 -7.00	5.60	1.69	1.54 -7.00
Activity	5.73	1.68	1.00 -7.00	5.66	1.83	1.75 -7.00
Emotional	5.77	1.34	3.67 -7.00	5.57	1.66	1.44 -7.00

The second measure of quality of life is the Caregiver Perception of Change (CPC) in Child's Asthma. The purpose of this instrument is to evaluate the parent's assessment of the asthma change since the previous assessment and provide a global view of the change in the asthma situation as seen by the parent.

The parent-perceived change in child's asthma over 1 month indicated that both experimental and control groups had similar results, as demonstrated in Table 12. Scores of -1, 0, or +1 indicate no change. Scores between -7 and -2 or between +2 and +7 are considered to have changed. Positive scores indicate parent perceived improvement in children's asthma, and negative scores indicate parent-perceived worsening of the asthma. At the end of the study, the parent-perceived change in child's asthma over the 3-month study period indicated that the parents in the experimental group perceived improvement in their children's asthma compared to no change in the control group parents.

Table 12: Caregiver Perception of Change (CPC) in child's asthma by group over time.

Caregiver Perception of Change in child's asthma	Experimental (n=20)			Control (n=20)		
	Mean	S.D.	Range	Mean	S.D.	Range
Perceived change						
T_2	+0.80	2.59	-4 to +6	+0.25	2.40	-6 to +6
T_3	+2.90	3.19	-3 to +7	-0.85	3.59	-6 to +6

4.2.4 Parental coping

Parental coping was measured using 5 sub-scales of the Parent Perception Inventory (PPI): Help, Concerns, Beliefs, Feelings, and Coping Strategies. Table 13 lists mean scores for each subscales of the PPI at the two administration points. There appears to be little difference at Time 1 between the experimental and control groups for all PPI sub-scales. The Help sub-scale indicated a change at Time 3 for the experimental group and no major change observed for the control group. The Concern sub-scale indicates the same result, with a decrease in mean Concern value for the experimental group and no major change for the control group.

PPI-Help Subscale

A closer examination of the PPI-Help Subscale revealed that the four most frequently asked topics of help were "child's medicines, treatments, condition and knowing when to see the doctor". To date there has been limited study of the PPI and subconcepts which can provide comparative interpretation of the results obtained.

Table 13: Mean, standard deviation and range results for PPI sub-scales by time and group.

PPI Sub-scale	Time	Experimental			Control		
		mean	s.d.	range	mean	s.d.	range
Help	T_1	26.30	8.62	12 -45	30.60	10.61	18 -53
	T_3	24.25	7.50	12 -38	29.50	10.25	18 -53
Concerns	T_1	40.10	24.16	0 -80	40.40	28.57	4 -120
	T_3	34.75	21.15	0 -67	38.80	29.99	4 -120
Beliefs	T_1	23.45	3.64	17 -32	21.90	3.23	15 -27
	T_3	23.30	3.54	18 - 32	21.90	3.18	15 -27
Feelings	T_1	44.75	5.43	33 -52	42.90	13.13	10 -63
	T_3	42.90	13.14	33 -52	45.70	11.14	23 -63
Coping strategies (Number of)	T_1	19.88	6.69	2 -27	19.85	6.65	1 -28
	T_3	20.95	5.28	11 -27	20.20	6.16	3 -28
Coping strategies (helpfulness)	T_1	27.20	12.54	5 -51	30.30	12.84	3 -49
	T_3	28.95	11.17	14 -50	31.75	11.07	5 -49
Coping strategies (How often used)	T_1	38.40	14.39	5 -62	42.15	13.50	3 -61
	T_3	40.50	12.05	18 -60	43.00	13.09	6 -61

As shown in Table 14, there were no marked differences in selected items of informational needs of the parents at the beginning of the study. Previous studies have demonstrated the similar health education needs of parents of children with asthma (Brook et al., 1993; Carson et al., 1991).

Table 14: Parental informational needs from the PPI-Help sub-scale

PPI-Help Subscale	Time	Experimental		Control		Total	
		n=20	(%)	n=20	(%)	n=40	(%)
Child's medicines	T_1	12	(60.0)	14	(70.0)	26	(65.0)
	T_3	8	(40.0)	12	(60.0)	20	(50.0)
Child's treatments	T_1	10	(50.0)	12	(60.0)	22	(55.0)
	T_3	5	(25.0)	11	(55.0)	16	(40.0)
Child's condition	T_1	9	(45.0)	11	(55.0)	20	(50.0)
	T_3	5	(25.0)	10	(50.0)	15	(37.5)
Knowing when to see the doctor	T_1	9	(45.0)	7	(35.0)	16	(40.0)
	T_3	7	(35.0)	5	(25.0)	12	(30.0)

At time 3, data show a reduction in need for information by the experimental group in the following topics: child's medicines, treatments, and condition. There is minimal change in need for information in the control group. Of note is that over 60% (n=12) of the

control group parents stated not having had time to read the Childhood Asthma booklet during the 3-month study period.

PPI Concern Subscale

Total scores for both experimental and control groups demonstrated little difference at the beginning of the study. At Time 3 however, the experimental group parents demonstrated lower scores of concerns as compared to those of the control group.

PPI Beliefs Subscale

Scores for both the experimental and control groups indicated minimal difference at Time 1 and Time 3. The type of treatment, whether home-based or booklet asthma health information appears to have had no effect on parental beliefs.

PPI Feelings Subscale

The Feelings subscale demonstrated changes for both experimental and control groups. The experimental group exhibited a decrease in positive affect whereas the control group demonstrated an increase in positive affect.

PPI Coping Strategies subscale

As shown in table 13, the number of coping strategies were quite similar between the experimental and control groups at Time 1 and at Time 3. A closer examination of the type

of coping strategy used brought out a frequently used coping strategy utilized by both groups. It was observed during the home visits that 9 out of 20 (45%) parents smoked in the experimental group compared to 5 out of 20 (25%) control group parents who identified smoking as one of their coping strategies. This is noted in particular since cigarette smoke is a recognized asthma trigger.

For the helpfulness of coping strategy listed, parents reported quite similar results between groups and unchanged over time. On the other hand, the frequency of utilization of coping strategies appears to have increased somewhat more in the experimental group than the control group over time. This will be verified by inferential analysis.

4.3 INFERENTIAL ANALYSIS

The most common assumption made in data analysis is that each set of observations is a random sample from a normal distribution (Larsen & Morris, 1986). In this study, a probability curve was plotted on a graph to test for normal distribution of the PACQLQ data. The results are shown in Appendix L indicating that the data obtained were not normally distributed. Since it is difficult to assess normality of small samples, both non-parametric (Wilcoxon) and parametric (t-test) methods were used for analysis. Due to small sample size and non-normal distribution of data, the Wilcoxon results are reported first since they are the appropriate tests to be used in this situation, and the t-tests are reported after, for comparison purposes. Also, the subsequent inferential analyses sections are organized according to the three research hypotheses to be tested.

4.3.1 Test for similarity of groups on baseline data

Wilcoxon Rank Sum W and t-tests for independent samples were performed for each of the measures of quality of life and coping. Test results yield no significant differences between experimental and control group at the start of the study (Appendix M and N).

4.3.2 Influence of Health Education Program

Table 15 provides the results of the Wilcoxon Rank Sum W Test for PACQLQ between the experimental and control group for Time 1, Time 2 and Time 3. There are no statistically significant differences between the experimental and control groups for overall quality of life as measured by PACQLQ. No significant differences were found between the experimental and control groups for both the activity and emotional domains. Independent samples paired t-tests produced no significant differences with agreement using paired t-tests.

Table 15: Wilcoxon Rank Sum W Test for PACQLQ over time.

PACQLQ	Experimental Mean rank	Control Mean rank	W	p
T_1	22.05	18.95	441.0	n.s.
T_2	22.38	18.63	447.5	n.s
T_3	21.48	19.52	429.5	n.s.

Wilcoxon Matched-Pairs Signed Ranks Test and t-tests for paired samples were performed to determine significant differences in parental quality of life within group over time. There were no statistically significant differences within the experimental or control groups at the two administration periods of 1 month and 3 months ($p = 0.37$ and $p = 0.83$ for the experimental group and $p=0.75$ and $p=0.76$ for the control group). In summary, there were no statistically significant differences in parental quality of life as measured by PACQLQ as a function of group or time. Paired t-tests generated similar results.

However, there were significant differences observed in the Caregiver Perception of Change in Child's Asthma. The parents in the experimental group perceived an improved change in their child's asthma ($p=0.01$) as compared to the control group ($p=0.23$) as measured by the Wilcoxon Matched Signed-Rank test. Paired samples t-tests yielded similar results ($p= 0.006$ for experimental group) and ($p=0.22$ for the control group).

Table 16 summarizes the results of the Caregiver Perception of Change in Child's Asthma over the 3-month study period. The perceived change is answered in reference to Time 1, the time at which the parent received the asthma health education information.

Table 16: Caregiver Perception of Change in Child's Asthma

Caregiver Perception of Change in Child's Asthma	Experimental (n=20)			Control (n=20)		
	Mean	S.D.	p	Mean	S.D.	p
Perceived change						
T_2	+0.80	2.59		+0.25	2.40	
T_3	+2.90	3.19	0.006	-0.85	3.59	n.s.

In summary, table 17 presents results of observations for testing the influence of the home-based asthma health education program on parental quality of life for group effect and time effect.

Table 17: Significance of parental quality of life measures for group and time effect.

	GROUP EFFECT	TIME EFFECT
Parental Quality of Life		
CPC	p=0.01	p=0.006
PACQLQ	N.S.	N.S.

Parental Coping

Inferential testing was performed to detect significant differences (two-tailed, at $p<0.05$) for the group and time effects for the sub-scales of the PPI. No differences were observed for group effect. However, results of the Wilcoxon Matched-Pairs Signed Ranks Test yielded significant differences for time effect in the experimental group results on the PPI Sub-Scales showing a reduced need for information (help) ($Z= -2.02$, $p=0.04$), reduced concerns ($Z= 2.38$, $p=0.02$) and increased utilization of coping strategies ($Z= -2.01$, $p= 0.04$). Paired t-tests showed similar results except for the concern scale which was not significant ($p=0.09$). Table 18 summarizes the results for testing the influence of the home-based asthma health education program on parental coping.

Table 18: Significance of parental coping measures for group and time effect.

	GROUP EFFECT	TIME EFFECT
Parental Coping		
PPI - Help	N.S.	p=0.04
Concerns	N.S.	p=0.02
Coping Strategies - How often used	N.S.	p=0.04

No statistically significant differences were observed when determining the influence of the home-based health education by group. However, significant differences were observed for time effect indicating that the home-based health education program influences parental coping over time.

4.3.3 Relationship between quality of life and coping of parents

Pearson product-moment correlations were calculated to examine linear relationships between quality of life and coping. Table 19 summarizes the results of the Pearson correlations between studied variables. Results of the PPI sub-scales yielded a Pearson correlation coefficient of $r = -0.31$ ($p=0.05$) for the PPI Help Sub-scale with the PACQLQ.

The negative coefficient indicates an inverse relationship meaning that as need for informational need increases, quality of life decreases; or inversely, as need for information decreases, quality of life increases as illustrated in figure 5. The PPI Concern scale is also inversely correlated with quality of life ($r = -0.49$; $p=0.002$), thus indicating a similar inverse relationship.

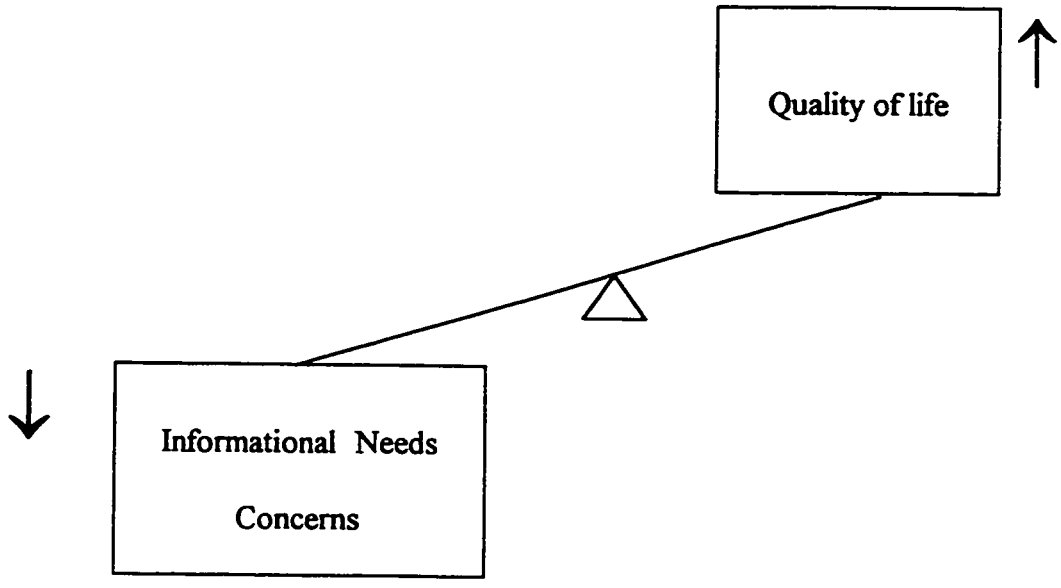

Figure 5: Relationship between informational needs, concerns and quality of life.

4.3.4 Relationship between sociodemographic data and quality of life and coping

Table 19 summarizes the results of Pearson correlation coefficients calculated between the sociodemographic data collected and parental quality of life (PACQLQ) and coping (PPI sub-scales). Results did not yield significant linear relationships between the sociodemographic variables of age and education of parent, family size, family income and number of children with asthma per family and quality of life and coping variables. However, there were significant Pearson correlation coefficients between family income and age of parent ($r=0.41$, $p<0.01$) and between family income and education of parent ($r=0.39$, $p<0.01$).

Table 19: Correlation matrix between PACQLQ, PPI and Sociodemographic Data at baseline (N=40).

	PACQLQ	PPI							Age of Parent	Educ of Parent	Family size	No.children with asthma	Family Income
		Help	Concern	Beliefs	Feelings	Coping Strategies (Number)	Coping Strategies (Helpful)	Coping Strategies (How often)					
PACQLQ	1.00												
PPI													
Help	**-0.31***	1.00											
Concern	**-0.49***	0.48	1.00										
Beliefs	-0.04	0.14	-0.24	1.00									
Feelings	0.17	-0.21	-0.39	0.42	1.00								
Coping strategies (Number of)	-0.06	0.41	0.39	-0.22	-0.33	1.00							
Coping strategies (How helpful)	0.05	-0.24	-0.33	-0.06	0.32	0.56	1.00						
Coping strategies (How often used)	-0.12	0.44	0.25	-0.20	-0.25	0.88	0.61	1.00					
Age of parent	0.11	-0.08	-0.06	0.01	0.01	0.10	0.07	0.03	1.00				
Education of parent	0.16	-0.03	-0.24	-0.12	0.11	0.08	0.11	0.05	0.11	1.00			
Family size	0.11	-0.03	0.03	0.10	0.14	-0.25	-0.07	-0.23	0.24	-0.28	1.00		
No. of children with asthma per family	-0.25	-0.16	0.12	-0.20	-0.09	-0.24	-0.06	-0.11	-0.16	-0.24	0.30	1.00	
Family Income	0.06	0.21	-0.02	0.05	0.02	0.03	-0.02	-0.07	**0.41****	**0.39****	0.10	-0.12	1.00

* $p<0.05$
** $p<0.01$

CHAPTER 5

DISCUSSION

The main purpose of the present study was to determine the influence of a home-based health education program on quality of life and coping of parents of children with asthma. The results of the study indicate that the home-based health education program did not influence overall parental quality of life but did influence sub-concepts of parental coping. While unmet needs for information and asthma-related worries were associated with decreased quality of life, neither coping strategies nor sociodemographic variables were associated with the quality of life outcomes. Following examination of the study sample, the results of analyses testing stated hypothesis are reviewed and placed in the context of the current literature. Limitations of the study are presented as well as clinical implications and directions for future research.

5.1 SAMPLING PROCEDURE

Although the study sample size was small (N=40), the families in the experimental and control groups appeared to be evenly balanced for the known confounding variables of sociodemographic data and child's asthma data. The specific variables which appeared to be equivalent across the two groups included age and gender of parent, family size, family income, employment and marital status, number of asthma attacks per family, asthma medication and health care utilization. This apparent balance allowed for comparison between the two groups.

5.1.1 Characteristics of the sample

More than half of the parents in the present study sample were young (35 years or less), female, married and educated beyond the high school level. The characteristics of the subjects were similar to those described in other studies of parents of children with asthma (Brook et al., 1993; Duffy & Halloran, 1987). The number of children with asthma per family was also comparable with other studies (Duffy & Halloran, 1987), whereas the children were older (mean 9.3, s.d. 4.5) in the Brook et al. (1993) study. It would appear that in many respects, the families studied in this project were similar to those described in other publications on the topic. The fact that parents in this study were relatively experienced in their child's asthma management may have influenced the quality of life measurements. Perhaps a sample taken from parents who had a newly diagnosed child with asthma may have produced a different result. As well, since many of the families were comprised of more than one child with asthma, controlling for this number may have had an effect. Since the present study was conducted in a northern community which is generally underserviced with respect to a variety of health care providers, the sources for asthma information may have been limited.

5.2 HEALTH EDUCATION PROGRAM ON QUALITY OF LIFE AND COPING

It was hoped that the home-based health education program provided to parents in the experimental group would have produced a marked improvement in quality of life and coping. Although specific quality of life measures did not change for either group, an

improvement in the parent's perception of child's asthma severity was observed and scores on sub-scales measuring informational needs and concerns decreased at three months for the experimental group.

Interestingly, parental quality of life as measured by the PACQLQ did not seem to be affected by the intervention. The current literature suggests that asthma health education is effective in reducing parental concerns (Duffy & Halloran, 1987), but no studies in which parental quality of life was assessed as an outcome measure were found. The lack of studies to compare this result with is probably due to the fact that in the past, there were no appropriate tools to measure parental quality of life; the PACQLQ is one of the first. Possible explanations for the absence of change in overall quality of life may include the unexpectedly low statistical power for the design because of larger than predicted standard deviations for the PACQLQ. The group of parents selected had children with chronic stable asthma, therefore since the asthma was stable, the well-being of the parent did not overtly change. As well, these parents were familiar with the impact of asthma on their family life, and no marked changes in quality of life would be detected in the three months evaluated.

A significant change in Caregiver Perception of Change in Child's Asthma survey was observed in the experimental group, while the control group was unchanged. This finding points to the potential influence of asthma education on the parent's perception of change in their child's asthma. Perhaps the home-based asthma education resulted in parents acquiring a better understanding of the condition as well as feeling reassured or made to feel more comfortable with their child's asthma. Social desirability bias may have been operating

however, since the intervening nurse also did the follow-up interviews, parents may have been reluctant to state that the intervention had made no difference or had made things worse. However, further investigation is needed to determine whether the observed results relate to the effects of the specific nursing intervention tested or represent methodological artifact.

The asthma health education program appears to have addressed informational needs of the parents as demonstrated by decreased PPI Help sub-scale scores. This result parallels the findings of Deaves (1993) which found improved parental knowledge following home-based health education sessions provided by a nurse health visitor.

In this study, the types of information needed by parents included (in order of importance): the child's medication, how to treat asthma, what is asthma, and when to see the physician, which have been shown as the most prominent needs in other studies (Brook et al., 1993; Carson et al., 1991). The home-based asthma education in this study, appeared to meet parental needs for information, probably reflecting the parental needs assessment done within the Hymovich model.

Accessibility of the intervening nurse may have been key to the intervention's success in reducing needs for information. When parents in this study identified their usual sources of asthma information, they included people (rather than written materials or agencies). Specifically named were physicians, pharmacists, relatives and spouses and nurses. Nurses were named by approximately 38% of the parents, whereas all of the parents (100%) listed physicians as usual sources of asthma information.. Clinical nurse specialists in asthma

education or community health nurses may not be readily accessible to parents of children with asthma. According to the parents, they used community agencies as information sources quite infrequently (10% of parents), perhaps because these services are generally open during business hours, and are therefore difficult for working parents to access. Written material was cited by only 7.5% of the parents. Since the majority of parents in the control group indicated not having had time to read the pamphlet, this points to the inadequacy of relying on written information as a substitute for face-to-face educational contact.

The Concerns sub-scale of the PPI for the experimental group also showed significant decreases over 3 months, but was relatively unchanged for the control group; asthma-related concerns were reduced over time in the parents receiving the intervention. Townsend et al. (1991) concluded from their qualitative study that worries and concerns were the main burden of the disease, therefore the reduction of concerns associated with the program is an important finding. It is possible that the health education delivered to the experimental group was able to specifically target their concerns better than the "hit-and-miss" approach of handing written materials to parents who may or may not have had time to read them.

An estimated 18-23% of all children with asthma are reported to be exposed to parental cigarette smoking (Meltzer, Hovell, Meltzer, Atkins, & de Peyster, 1993). In the present study, 45% of the parents smoked in the experimental group compared to 25% in the control group. Murray & Morrison (1989) reported in 415 non-smoking children with

asthma seen in a pediatric department, asthma symptoms were more severe if one parent was a smoker. In a subsequent article, these same authors reported in 1993 that if parents are aware that smoke will aggravate their child's asthma, the child will be exposed to less cigarette smoke resulting in less severe asthma. Another study concluded that maternal smoking is associated with higher rates of asthma, an increased likelihood of using asthma medications, and an earlier onset of the disease (Weitzman, Gortmaker, Walker, & Sobol, 1990). The percentage of parents who smoked in the present study did not change between baseline and follow-up data collection. This may reflect the absence of specific health teaching geared to promoting smoking cessation.

Providing information on the effect of cigarette smoke as a recognized asthma trigger can assist the parent in making decisions regarding their smoking habit. A nurse conducting a home-based asthma health education program can offer information and support for those parents considering smoking cessation, and thus potentially assist the parent in replacing smoking as a frequently used coping strategy with one such as exercise or relaxation.

Frequency of use of coping strategies as measured by the PPI increased in the experimental group, but not in the control group. However, it is interesting to note that the number and helpfulness of strategies in the parents' coping repertoires did not show changes in either the experimental or control groups. The intervention may have increased parents' awareness of their ability to cope with their children's asthma (i.e. it may have reinforced existing strategies without adding new ones). The absence of change in the PPI sub-scales of feelings, beliefs, and coping strategies (type and number), like the lack of difference in the

quality of life measure pre- and post-intervention, might be explained by the small sample size. Again, it should be noted that this was a group of parents with chronic stable asthma who probably had long-established ways of dealing with the illness that were unlikely to be easily changed. Figure 6 provides an overview of the findings with respect to the outcomes of the asthma health education program tested.

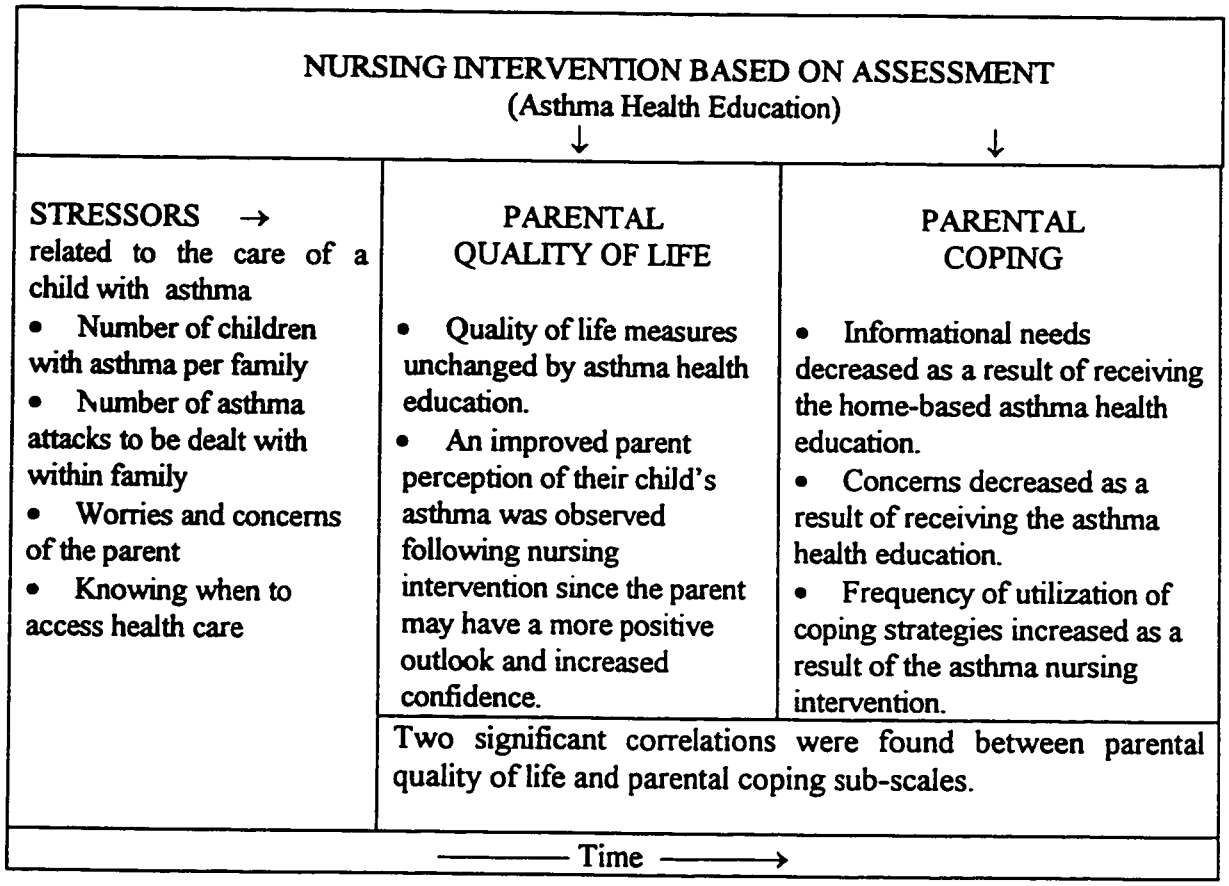

Figure 6: Parental quality of life and parental coping resources in response to stressors and nursing intervention.

In the context of the Hymovich conceptual framework, contributing factors to the overall stress related to the care of the child with asthma include number of children with asthma in the family, number of attacks and unpredictable nature of asthma, the worries and concerns of the parent and knowing when to access health care. Following receipt of the needs-based asthma health education, quality of life measures did not change. However, the caregiver perception of change would then be unexpectedly significant which leads to further inquiry as previously mentioned. Parental coping results were consistent with the Hymovich model which guided this study.

5.3 RELATIONSHIP BETWEEN QUALITY OF LIFE AND COPING

Some evidence for a significant relationship between quality of life and coping was also found in this study. Two significant correlations were found between overall quality of life and coping sub-scales. Informational needs and concerns were inversely related to quality of life: as information needs and concerns decreased, quality of life and well-being of the parent increased. These associations are consistent with Hymovich's theoretical framework in that according to Hymovich and Hagopian (1992) feelings of adequacy in performing treatments, preventing complications and meeting daily needs are important components of one's ability to cope with the care of a chronically ill family member. No relationships were found between the use of coping strategies and the quality of life measures. Since the parent in this study has been managing their child(ren)'s asthma over time, and only children with chronic, stable asthma were enrolled, the coping tool did not

necessarily capture the resourcefulness of the parent in adapting to unforeseen circumstances. The parent chose a particular set of coping strategies, such as crying, exercising, walking, talking with others, and the observation in this study was that the particular set of coping strategies did not show a relationship with quality of life or well-being. Perhaps this points to other influences which may not have been captured with the study.

5.4 CONFOUNDING VARIABLES AND QUALITY OF LIFE AND COPING.

In evaluating possible associations between sociodemographic data, coping and quality of life, none of the variables (age and education of parent, family size, income and number of children with asthma) showed significant linear relationships. This may be a reflection of the independence of these variables to one another. The literature does not comment specifically on the influence of age, education, size of family or income on parental quality of life and coping of parents vis-à-vis a child with asthma. However Clark et al. (1993) state that further study of low-income families in terms of access to adequate care, and effective management information is needed. Other characteristics may be present possibly influencing quality of life and coping. The potential for a type II error should be considered since the sample is relatively small, and the characteristics of the sample (i.e. education, age, income, and size of family) is similar.

5.5 LIMITATIONS OF THE STUDY

In terms of the generalizability of the study, the following limitations of the study must be kept in mind: the sample size was small (N=40); the PACQLQ and CPC were relatively untested in the literature leading to a possible measurement bias; in terms of questionnaire administration, the baseline measures were done by paper and pencil, and the follow-up measures were done by telephone; subjects were aware of which intervention they were to receive, either a booklet, or a home visit which may lead to the Hawthorne effect bias; the investigator conducted both the baseline and follow-up data collection therefore creating a potential for social desirability of response.

5.6 CLINICAL IMPLICATIONS

In light of the results obtained and keeping in mind the limitations of the study, some clinical implications may be derived: 1) a needs-based nursing intervention such as home-based asthma health education can potentially meet client needs and influence aspects of parental coping;; 2) parents identified face-to-face with health professionals preferable to written or community-based programs; 3) nurses can provide asthma health teaching in a variety of settings and flexibility enhances reach to clients; 4) home-based asthma health education allows for a wide scope of assessment possibilities, such as identification of triggers such as smoking or pets in the home; 5) nurses trained in smoking cessation can provided information to parents needing and requesting assistance. Nurse clinicians can

provide asthma health education which is appropriate to the client and addresses identified needs.

A home-based intervention meets the accessibility requirements of today's family situation. Community asthma education programs have shown low attendance, and a home-based approach increases the parent's access to asthma information. The nurse can assist the parent in identifying potential triggers of asthma for the child. Since, as the follow-up interviews revealed, the control families stated they did not have the time to read the booklet given to them at the pediatrician's office, this method of addressing parental concerns may be inadequate. A home-based approach ensures that the family sets aside time to discuss concerns and worries with a nurse knowledgeable about asthma. In summary, the home-based approach provides an opportunity for more than one family member to attend, is scheduled at the convenience of the parent(s), allows for identification of asthma triggers, and ensures that time is set aside for sharing of information. The home-based approach also has the potential to reach and target high-risk families through referral from a pediatrician or social worker to a nurse trained in asthma education.

The literature reveals that many disciplines are involved in asthma education: respiratory therapists, pharmacists, physicians, and nurses. The nurse can offer a holistic approach to the family when providing asthma education. Since the pediatrician's time is limited, there is potential for a referral to a nurse who has clinical expertise in childhood asthma. The nurse can spend more time with the family in addressing their concerns, as well as provide follow-up. In addition to the support the nurse provides to the whole family, the

nurse can refer the family to the pharmacist and respiratory therapist who provides valuable asthma information related to medications and their delivery. In order for family-centered care to be fully achieved, the nurse must work in partnership with the family. The nurse must acknowledge that the parent can best communicate their needs and the needs of their child with an open and sharing relationship (Cardoso, 1992). This study focused on the needs of the parent and not the disease of the child. Through caring for the parent, the nurse indirectly assists the parent-child relationship. Through a thorough assessment of needs, the nurse can address the concerns of the parent, and relieve the stress of caring for a child with a chronic illness such as asthma.

Sociodemographic variables in the present study were not found to have a significant association with parental quality of life and coping. Age, education, and size of family do not influence quality of life and coping. The implication is to ensure that nurses caring for families of children with asthma do not carry preconceived notions about a parent's age or education, and the relationship that information has on quality of life and coping.

While home-based education might be seen as too expensive in this era of cost-cutting, data from this study show that a one-on-one approach might actually be cost effective, reaching more families and in particular the high-risk group. In evaluating the cost of asthma in Canada, it was demonstrated that over 50% of the direct cost is attributed to medications. Hospitalization was the next largest category, followed by physician visits. A minimal cost (less than 1%) was attributable to nursing. This points to the fact that nursing services are either underutilized, or not well documented in terms of cost. One

method of tracking the effects of health education in financial terms would be to follow drug utilization., hospitalizations and physician visits. The present 3-month study was not able to capture these outcomes in addition to the ones selected.

5.7 DIRECTIONS FOR FUTURE RESEARCH

In terms of building on the findings of the present study, there is a need for further validation of the PACQLQ to evaluate the sensitivity to psychosocial and educational interventions (personal communication with Dr. Juniper, October 1996). Future studies of interventions like home-based asthma health education beyond a 3-month study period, should be able to capture the seasonal variations of asthma. A multi-site approach as well as greater sample size would enhance the generalizability of the results. Future research should also request that the parent fill out an asthma symptom diary to reduce the potential for recall bias.

Smoking was identified as a frequently used coping strategy. Further investigation is needed to determine the influence of asthma health education on parental smoking. The asthma health education program would benefit from a component on smoking cessation strategies for those parents wishing to quit smoking.

It was also noted that the experience of the parents as revealed in talking and working with these families was impossible to capture with the instruments available. A qualitative approach would be appropriate in order to search for patterns demonstrated by

parents in terms of the experience of caring for a child with chronic illness such as asthma thus answering the question of how nurses can provide better care.

The sparseness of literature in the area does not mean that work is not being conducted in the area of asthma education and quality of life and coping. There is a need for nurses to become diligent in documenting outcomes of nursing interventions. Without this written proof, other disciplines will make decisions regarding the value and future of nursing.

CONCLUSION

In this pretest-post-test control group study, a home-based asthma health education program produced an improved change in the parent's perception of their child's asthma. Improved coping was observed in terms of decreased need for information and lessened concerns, as well as increased utilization of coping strategies. Although no change in parental quality of life was detected, a significant correlation was shown between parental quality of life and parental coping.

Although there were a number of limitations, including small sample size, newness of the instruments used, and potential for social desirability bias, the strengths of the study included minimal loss to follow-up because of the efforts made to track the sample, randomization of the sample yielding comparable groups and utilization of a conceptual framework. The study was one of the first to evaluate home-based asthma health education on parental quality of life and coping.

The present study demonstrates the need and value for greater contact between nurses and families caring for children with asthma. The early discharge from hospital, lack of community health nurses doing home visits, and decreased opportunity for families to use community services all point to the need for nurses to become involved in home visits for families coping with a child with chronic illness such as asthma.

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Appendix A

Sample Size Calculation

Estimated standard deviation of each population	7.5
Minimum difference you wish to detect as significant	6.5

		$\alpha = 0.10$	0.05	0.02	0.01
Power	β	Sample size			
0.80	0.20	17	21	27	32
0.90	0.10	23	28	35	40
0.95	0.05	29	35	43	48

These values are the size of each group required for a two-tailed test with unpaired data. The α values are halved for one-tailed tests.

Northeastern Ontario Family Medicine Program (1995). In-House Sample Calculation Program. Laurentian University Campus. Sudbury, Ontario

Appendix B

Recruitment Poster

VOLUNTEERS NEEDED

TO TAKE PART IN A STUDY OF AN ASTHMA HEALTH EDUCATION PROGRAM FOR PARENTS OF CHILDREN WITH ASTHMA

There is no obligation and confidentiality is assured.

The **purpose** of this study is to determine the **effectiveness of an asthma health education session** for parents of children (up to age 10) with asthma.

Benefits to you include learning more about the control of asthma, triggers, medications, and coping with asthma. **The one-hour session will be geared to your needs.**

The asthma health education session,based on a Lung Association program, is provided by Rose-Marie Dolinar RN, Lung AssociationVolunteer & MScN student University of Ottawa

For further information, please contact Gisèle at reception

Appendix C

Université d'Ottawa • University of Ottawa

Faculté des sciences de la santé
École des sciences infirmières

Faculty of Health Sciences
School of Nursing

INFORMATION SHEET

Name of researcher & institution: Rose-Marie Dolinar, RN, BScN, University of Ottawa
Name of study:

THE EFFECT OF A HEALTH EDUCATION PROGRAM ON
QUALITY OF LIFE AND COPING OF PARENTS OF CHILDREN WITH ASTHMA

This information sheet has been prepared to answer any questions you may have regarding this study.

WHAT DO I HAVE TO DO: Read both this information sheet and the consent form, and call the researcher at the telephone numbers below if you have any questions. **If you would like to participate, your task, at no obligation will be to attend a one-hour asthma education session and fill out a questionnaire before the session. In the mail, you will receive a questionnaire one week after the session and then three months after the session to be mailed by prepaid postage. More detailed information is available on the consent form.**

WHAT IS THE PURPOSE OF THIS STUDY: The purpose of this study is to find out how effective an asthma health education program is, as well as determine the effect the program has on parents' quality of life and coping.

WHEN: The study will start in the Spring of 1996.

HOW DO I ENROLL IN THE STUDY: If you would like to participate, please read over this form as well as the consent form, sign the form and give it to the receptionist.

WHO CAN TAKE PART IN THE STUDY:

(1) you are a parent (mother or father, natural or adopted) of a child less than 10 years of age, with a diagnosis of stable chronic (over 6 months) asthma;
(2) you are a provider of asthma management for your child;
(3) you have never taken part in a formalized asthma health education program and will not take part in any other formalized asthma education program for the duration of the study (3 months);
(4) you can read, write and communicate in English;
(5) you have signed the consent form.

WHAT ARE THE ADVANTAGES FOR ME AND MY CHILD:
The benefits to you will be learning more about the control of asthma, triggers, medications, and coping with asthma.

THERE IS NO OBLIGATION
YOU CAN WITHDRAW AT ANY TIME
CONFIDENTIALITY IS ASSURED

If you have any further questions, contact Rose-Marie Dolinar (705) 566-8986 or Dr. Ginette Coutu-Wakulczyk, School of Nursing, University of Ottawa (613) 562-5800 Ext. 8424.

451, ch. Smyth
Ottawa (Ontario) K1H 8M5 Canada

451 Smyth Rd.
Ottawa, Ontario K1H 8M5 Canada

(613) 562-5473 • Télec /Fax (613) 562-5443

Appendix D

Université d'Ottawa · University of Ottawa

Faculté des sciences de la santé
Ecole des sciences infirmières

Faculty of Health Sciences
School of Nursing

CONSENT FORM

Name of researcher: Rose-Marie Dolinar, RN, BScN
Institution: University of Ottawa
Program: Master of Science in Nursing
Telephone number: 566-8986

AUTHORIZATION FOR PARTICIPATION IN THE ASTHMA HEALTH EDUCATION RESEARCH STUDY:
I, _____ am interested in collaborating in the research study entitled THE EFFECT OF A HEALTH EDUCATION PROGRAM ON COPING AND QUALITY OF LIFE OF PARENTS OF PRESCHOOL-AGE CHILDREN WITH ASTHMA conducted by Rose-Marie Dolinar, student at the University of Ottawa in the Master of Nursing program. **The purpose of this research is to study the effect of a health education program on coping and quality of life of parents with a preschool-age (under 6 years of age) child with asthma.**

If I agree to participate, I will be assigned by chance to either a standard asthma education session, or to a Lung Association asthma education session. Both asthma education programs (standard and the Lung Association) will be provided by the same nurse. My participation will consist of attending one session (approximately 1 hour in length) during which I will receive either standard asthma education or the Lung Association asthma education. The session will be located for the standard group at the physician's office, and the Lung Association group will be provided at the doctor's office or if I prefer, by home visit. **I will also be asked to fill out a questionnaire which asks questions on coping and quality of life before the health education begins, one week after, and then at three months after the asthma health education. The first questionnaire will be given at the beginning of the asthma education session. The one week and three month questionnaires will be filled out and** mailed in by pre-paid postage.

I understand I am free to withdraw from the project at any time, before or during the program, refuse to participate, and refuse to answer questions without prejudice.

I have received assurance from the researcher that the information I will share will remain strictly confidential. I, in turn, assure other participants that I will treat in the same confidential way any information I may obtain in the context of this project. All information obtained will remain anonymous. There are no risks attached to the asthma education sessions. Benefits include learning more about asthma, triggers, and medications.

Any information requests or complaints about the ethical conduct of this research study may be addressed to Dr. Roger Proulx, University Human Research Ethics Committee (UHREC), by calling (613) 562-5800 Ext.4251.

There are two copies of the consent form, one of which I may keep. If I have any questions, I may contact Dr. Ginette Coutu-Wakulczyk, Thesis Supervisor, at the School of Nursing, Faculty of Health Sciences, University of Ottawa, 451 Smyth Road, Ottawa, Ontario K1H 8M5, (613) 562-5800 Ext. 8424.

Participants signature: _____ Date: _____

Researcher's signature: _____ Date: _____

Appendix E

Moses Oakford Method of Randomization

Block Size: 8
Block Number : 5
Sample size: 45

Random Numbers

Start: P27 Col1 Row 1
End: P27 Col 17 Row 12

Allocation: 1:1

Treatment Codes:
H= Home Based
S= Standard Care

Order of Assignment	Patient ID (Name/#)	Date (dd/mm/yy)	Treatment Allocation
1.			S
2.			H
3.			H
4.			S
5.			H
6.			S
7.			S
8.			H
9.			S
10.			H
11.			H
12.			S
13.			S
14.			S
15.			H
16.			H
17.			S
18.			H
19.			H
20.			H
21.			S
22.			S
23.			S
24.			H

Meinert, M. & Curtis, L. (1986). Clinical trials: Design, conduct, and analyses. New York: Oxford University Press.

Appendix F

Air Force Asthma Program

The Philosophy of the Program

The AIR FORCE Asthma Program is an educational program for asthmatic children (age 6-12) and their parents. The program is aimed at:

1. teaching self-management skills to the children so that they can take more responsibility for managing their asthma, and
2. providing parents with the knowledge and skills to help them deal more effectively with asthma and to help their children take responsibility of managing their asthma.

Self-management programs are not meant to conflict with the role of the doctor. The doctor controls the medical management of asthma, while self management techniques merely strengthen the ability of the child to handle day-to-day control of the condition.

The skills learned in this asthma self-management program include recognizing early warning signs of asthma, being aware of asthma triggers and avoiding and lessening their effects, taking medications correctly and on time, beginning preventive measures early in the chain of events that lead up to an attack and taking the proper steps in treating an attack.

Ultimately, as children and parents become more knowledgeable about ways to control their asthma, they will become more capable of joining forces and working together to control the condition.

In simple terms, self management entails those aspects of caring for one's asthma that are affected by one's own actions and attitudes.

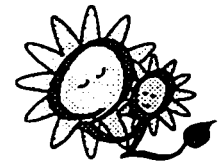
The program is divided into four sessions.

- What is asthma?
- Triggers of asthma
- Treatment of asthma
- Coping with asthma

The program is delivered in conjunction with overhead slides. An accompanying teaching manual is used for lesson planning by learning objectives. Reference material is also included.

PAEDIATRIC ASTHMA CAREGIVER'S QUALITY OF LIFE QUESTIONNAIRE

McMASTER UNIVERSITY
HAMILTON, ONTARIO
CANADA



For further information:

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PAEDIATRIC ASTHMA CAREGIVER'S QUALITY OF LIFE QUESTIONNAIRE

PATIENT ID: _____ **VISIT #:** _____

PT's INITIALS: _____ **DATE:** _____

This questionnaire is designed to find out how you have been during the last week. We want to know about the ways in which your child's asthma has interfered with your normal daily activities and how this has made you feel. Please answer each question by placing a check mark in the appropriate box. You may only check one box per question.

DURING THE PAST WEEK, HOW OFTEN:

		All of the Time	Most of the Time	Quite Often	Some of the Time	Once in a While	Hardly Any of the Time	None of the Time
		1	2	3	4	5	6	7
1.	Did you feel helpless or frightened when your child experienced cough, wheeze, or breathlessness?	☐	☐	☐	☐	☐	☐	☐
2.	Did your family need to change plans because of your child's asthma?	☐	☐	☐	☐	☐	☐	☐
3.	Did you feel frustrated or impatient because your child was irritable due to asthma?	☐	☐	☐	☐	☐	☐	☐
4.	Did your child's asthma interfere with your job or work around the house?	☐	☐	☐	☐	☐	☐	☐

		All of the Time	Most of the Time	Quite Often	Some of the Time	Once in a While	Hardly Any of the Time	None of the Time
		1	2	3	4	5	6	7
5.	Did you feel upset because of your child's cough, wheeze, or breathlessness?	☐	☐	☐	☐	☐	☐	☐
6.	Did you have sleepless nights because of your child's asthma?	☐	☐	☐	☐	☐	☐	☐
7.	Were you bothered because your child's asthma interfered with family relationships?	☐	☐	☐	☐	☐	☐	☐
8.	Were you awakened during the night because of your child's asthma?	☐	☐	☐	☐	☐	☐	☐
9.	Did you feel angry that your child has asthma?	☐	☐	☐	☐	☐	☐	☐

DURING THE PAST WEEK, HOW WORRIED OR CONCERNED WERE YOU:

		Very, Very Worried/ Concerned	Very Worried/ Concerned	Fairly Worried/ Concerned	Somewhat Worried/ Concerned	A Little Worried/ Concerned	Hardly Worried/ Concerned	Not Worried/ Concerned
		1	2	3	4	5	6	7
10.	About your child's performance of normal daily activities?	☐	☐	☐	☐	☐	☐	☐

	Very, Very Worried/ Concerned	Very Worried/ Concerned	Fairly Worried/ Concerned	Somewhat Worried/ Concerned	A Little Worried/ Concerned	Hardly Worried/ Concerned	Not Worried/ Concerned
	1	2	3	4	5	6	7
11. About your child's asthma medications and side effects?	☐	☐	☐	☐	☐	☐	☐
12. About being over-protective of your child?	☐	☐	☐	☐	☐	☐	☐
13. About your child being able to lead a normal life?	☐	☐	☐	☐	☐	☐	☐

Appendix H

Caregiver Perception of Change in Child's Asthma

Since receiving the asthma health education information, how is your child's asthma?

1 [ ] BETTER
2 [ ] ABOUT THE SAME
3 [ ] WORSE

A. You have stated that your child's asthma is WORSE since the health education information. Can you please indicate how much worse by selecting one of the following options?

1 [ ] Almost the same, hardly any worse
2 [ ] A little worse
3 [ ] Somewhat worse
4 [ ] Moderately worse
5 [ ] A good deal worse
6 [ ] A great deal worse
7 [ ] A very great deal worse

B. You have stated that your child's asthma is BETTER since the health education information. Can you please indicate how much better by choosing one of the following options?

1 [ ] Almost the same, hardly better
2 [ ] A little better
3 [ ] Somewhat better
4 [ ] Moderately better
5 [ ] A good deal better
6 [ ] A great deal better
7 [ ] A very great deal better

CODE# DATE: 100

This questionnaire is to help us learn more about what you do when caring for your child and how we can help you. Circle the right number for your answer or fill in the blank.

PART I. CHILD CARE NEEDS

1. Child's age:_____ /_____
(years) (months)

2. Child's sex: (1) male (2) female

3. What is your child's illness, condition or disability?

4. How severe is your child's condition?

(1) not severe (slight)

(2) moderately severe

(3) very severe

5. How old was your child when the condition was diagnosed? _____

(1) under 6mos (4) 4-5yrs 11mos

(2) 6-11mos (5) 6-12yrs 11mos

(3) 1-3yrs 11mos (6) 13yrs or older

5. How are you related to this child?

(1) mother (6) foster mother

(2) father (7) foster father

(3) stepmother (8) grandmother

(4) stepfather (9) grandfather

(5) guardian (10) other_____

7. Does anyone else in your family have the same illness or disability as your child?

(1) no (2) yes

(7a) If YES, is it your child's:

(1) mother (4) grandparent

(2) father (5) cousins, aunts, uncles

(3) brother or sister (6) other_____

8. Parents have asked for help with many aspects of their child's development and care, including those listed below. Please let us know if you want to discuss any of the following topics with the health care team.

TOPIC	(1) Do not need now	(2) Not Sure	(3) Would Like
Physical care of child	1	2	3
Diet or nutrition	1	2	3
Sleep habits	1	2	3
Genetic counseling	1	2	3
Care of minor illnesses	1	2	3
Dental needs	1	2	3
Play or recreation activities	1	2	3
Managing child's behavior	1	2	3
School or learning experiences	1	2	3

TOPIC	(1) Do not need now	(2) Not Sure	(3) Would Like
Physical development	1	2	3
Social development	1	2	3
Emotional development	1	2	3
Intellectual development	1	2	3
Child's condition	1	2	3
Child's medicines	1	2	3
Child's treatments	1	2	3
Knowing when my child needs to see the doctor	1	2	3
Talking to my child about the condition	1	2	3

9. Is there anything else you would like information about? What?

PART II. CONCERNS AND RESOURCES

1. All parents have some concerns. During the past 3 months, how much have you been concerned with the following? Circle the number in the column that best explains your concern.

CONCERNS	(0) Does not apply	(1) Not Sure	(2) Little Bit	(3) Quite a Bit	(4) Great Deal
Extra demands on my time	0	1	2	3	4
Feeling worn out	0	1	2	3	4
Having enough fun and relaxation as I would like	0	1	2	3	4
Having enough time alone with my spouse or partner	0	1	2	3	4
Talking with or understanding my spouse or partner	0	1	2	3	4
Sexual relationship with my spouse or partner	0	1	2	3	4
Making my child comfortable or happy	0	1	2	3	4
Having enough time or attention from my spouse or partner	0	1	2	3	4
Getting out of house with spouse or partner but without children	0	1	2	3	4
Getting out of house by myself	0	1	2	3	4
Getting to do activities together as a family	0	1	2	3	4
Whether I am taking care of my child in the best way	0	1	2	3	4
Having to travel too far for medical help or child care	0	1	2	3	4
The weather effecting what my child can do	0	1	2	3	4
Having enough insurance to meet expenses of child care	0	1	2	3	4
Having the right agencies in the community to provide the care my child needs	0	1	2	3	4
Wondering what my child's future is likely to be	0	1	2	3	4
Worrying about the responsibility of caring for my child	0	1	2	3	4
Having enough money to meet my family's needs	0	1	2	3	4
Having money for extra pleasures	0	1	2	3	4
Having someone to talk with about my worries	0	1	2	3	4
Finding someone to stay with my child	0	1	2	3	4
Wondering about how my child feels about himself or herself	0	1	2	3	4

CONCERNS (Continued)	(0) Does not apply	(1) Not Sure	(2) Little Bit	(3) Quite a Bit	(4) Great Deal
Getting enough sleep for myself	0	1	2	3	4
Talking to my child about his her condition	0	1	2	3	4
Talking with neighbors or friends about my child's condition	0	1	2	3	4
Wondering whether my other children will develop the sama condition	0	1	2	3	4
The cost of my child's medical care	0	1	2	3	4
Wondering whether I will recogr ize important changes in my child's condition	0	1	2	3	4
Getting enough information about my child's condition	0	1	2	3	4
Helping my child cooperate with taking medicines or doing treatments	0	1	2	3	4
My spouse or partner's health	0	1	2	3	4
My own health	0	1	2	3	4
My child(ren)'s health	0	1	2	3	4

2. Are you a member of a parents' association related to your child's illness or disability?

(1) no (2) yes

2a. If YES, how often do you go to meetings?

(1) never (3) sometimes
(2) rarely (4) often

2b. If you go to meetings, how helpful have they been?

(1) not at all (3) somewhat
(2) not very (4) very

3. Do you have someone to take care of your child for a day in case of an emergency (such as if you become ill and cannot take care of your child)?

(1) no (2) not sure (3) yes

4. Do you have someone to take your child for a week or more in case of an emergency?

(1) no (2) not sure (3) yes

5. Do you have a regular baby sitter?

(1) do not need (2) no (3) yes

6. Are you responsible for the care of any other family members:

(1) no (2) yes, WHO?_____

7. How much time do you usually spend taking care of your child's health needs each day?

(1) less than 1 hr (4) 6-8 hrs
(2) 1-2 hrs (5) over 8 hrs.
(3) 3-5 hrs

HYMOVICH'S PARENT PERCEPTION INVENTORY: BELIEFS AND FEELINGS

CODE#

DATE:

1. Parents have different beliefs about things that influence their way of living. Please indicate whether or not you agree or disagree with the following statements. There are no right or wrong answers.

BELIEFS	(1) Agree	(2) Not Sure	(3) Dis-agree
Parents usually need to take care of their own needs before they can help their children	1	2	3
Sometimes parents need to get out of the house to relieve the strain of child care	1	2	3
It is usually better to talk about one's feelings with others	1	2	3
Sometimes just trying to forget something makes it easier to handle	1	2	3
Taking one day at a time is usually better than making long term plans	1	2	3
Sometimes getting away from something makes it easier to handle	1	2	3
I usually have control over things that happen to me or my family	1	2	3
It is lucky that this is my child's only condition	1	2	3
There isn't much that I can do about my child's condition	1	2	3
Sometimes I think of my child's condition as a nuisance	1	2	3
Parents need someone to talk with about raising children	1	2	3
People should try to handle their problems by themselves	1	2	3

2. Listed below are feelings that people may have. Put a circle around the number of the item that best shows how often you have had these feelings during the past 3 months. There are no right or wrong answers.

FEELINGS	(0) Not at all	(1) Not often	(2) Often	(3) Very often
Angry	0	1	2	3
Anxious	0	1	2	3
Confident	0	1	2	3
Content	0	1	2	3
Defeated	0	1	2	3
Depressed	0	1	2	3
Disappointed	0	1	2	3
Frustrated	0	1	2	3
Good	0	1	2	3
Guilty	0	1	2	3
Happy	0	1	2	3
Helpless	0	1	2	3
Hopeful	0	1	2	3
In control	0	1	2	3
Lucky	0	1	2	3
Overwhelmed	0	1	2	3
Pleased	0	1	2	3
Resentful	0	1	2	3
Sad	0	1	2	3
Satisfied	0	1	2	3
Uneasy	0	1	2	3
Other WHAT?	0	1	2	3
	0	1	2	3
	0	1	2	3

HYMOVICH'S PARENT PERCEPTION INVENTORY: COPING (PPICOPE)

CODE# DATE:

1. Parents cope with their concerns in many different ways. There are times when you may have more problems or concerns because of your child's needs. The first column has a list of some ways people cope. Coping means what a person does in order to make the situation better or to try to make oneself feel better.

   1. If you do not use a coping method in the list, circle the 0 in the first column; and leave the center columns blank.

   2. Circle the number that shows how often you used the coping method in the past 3 months when you had a problem related to your child's needs.

COPING	HOW OFTEN				HOW HELPFUL			
	(0) DO NOT DO THIS	(1) Very rarely	(2) Some-times	(3) Very often	(0) Never helps	(1) Sometimes helps	(2) Almost always helps	(3) Always Helps
Cry	0	1	2	3	0	1	2	3
Busy myself with other things	0	1	2	3	0	1	2	3
Talk with someone about feelings	0	1	2	3	0	1	2	3
Ignore/try to forget	0	1	2	3	0	1	2	3
Look at options	0	1	2	3	0	1	2	3
Get away for awhile	0	1	2	3	0	1	2	3
Hide feelings	0	1	2	3	0	1	2	3
Change my expectations	0	1	2	3	0	1	2	3
Blame someone	0	1	2	3	0	1	2	3
Yell/scream/slam doors, etc.	0	1	2	3	0	1	2	3
Exercise	0	1	2	3	0	1	2	3
Ask for help	0	1	2	3	0	1	2	3
Take alcohol or medicine	0	1	2	3	0	1	2	3
Pray	0	1	2	3	0	1	2	3
Blame myself	0	1	2	3	0	1	2	3
Ask questions	0	1	2	3	0	1	2	3
Use advise of others	0	1	2	3	0	1	2	3

COPING	HOW OFTEN				HOW HELPFUL			
	(0) DO NOT DO THIS	(1) Very rarely	(2) Some-times	(3) Very often	(0) Never helps	(1) Sometimes helps	(2) Almost always helps	(3) Always Helps
Try to figure out what to do	0	1	2	3	0	1	2	3
Sleep	0	1	2	3	0	1	2	3
Find help	0	1	2	3	0	1	2	3
Smoke	0	1	2	3	0	1	2	3
Try to laugh or joke about it	0	1	2	3	0	1	2	3
Eat	0	1	2	3	0	1	2	3
Try to relax	0	1	2	3	0	1	2	3
Read about the problem	0	1	2	3	0	1	2	3
Wish problems would go away	0	1	2	3	0	1	2	3
Weigh choices	0	1	2	3	0	1	2	3
Get information	0	1	2	3	0	1	2	3
Try to change things	0	1	2	3	0	1	2	3

1. In the past, what sources have you used for information or help related to your child's problems or needs? Circle all that apply.

   (1) clergy
   (2) Doctor
   (3) Friend
   (4) Nurse
   (5) Teacher
   (6) Relatives or spouse
   (7) Pharmacist
   (8) Other parent
   (9) Social worker
   (10) Nutritionist
   (11) Therapist
   (12) Library
   (13) Newspaper / magazine
   (14) Support group
   (15) Community Agency
   (16) Other

2. How often have there been times when you did not know what to do to get information or help related to your child?

   (0) Never
   (1) Sometimes
   (2) Often
   (3) Always

3. In general, how well do you believe you are coping with (managing) problems related to your child's care?

   (1) Not well
   (2) Well

4. In general, when you have problems related to your child's needs, how often are they things you can change or have some control over?

   (1) Always
   (2) Almost always
   (3) Not very often
   (4) Never

5. In general, how well do you believe you are coping with (managing) your feelings and concerns about your child?

   (0) Not well
   (1) Fairly well
   (2) Well
   (3) Extremely well

6. Would you like us to help you with any problems you are having?

   (1) No
   (2) Not sure
   (3) Yes

7. How satisfied are you with the way you are able to cope with the stresses you have?

   (1) Very dissatisfied
   (2) Dissatisfied
   (3) Satisfied
   (4) Very Satisfied

Appendix J

General Information and Asthma Questionnaire

Code #: Date:

The purpose of these questions is to find out some general information about your family that may be useful in helping you manage your child's care

1. **Number of times in the past that my child has been admitted to the hospital for asthma?**

1b. **How long ago was your child's last admission to the hospital?**

2. **How many children do you have?**
3. **How many children are five years and under?**
4. **How many children are between 6 and 12 years of age?**
5. **How many children are 13 years of age and older**

6. **In general, how has the health of your other children been during the last three months:**

   (1) Poor/Fair (2) Good (3) Very good (4) Excellent

7. **How has your health been during the past three months:**

   (1) Poor/Fair (2) Good (3) Very good (4) Excellent

8. **What is your religion?**
(1) Catholic (2) Jewish (3) Protestant (4) Other
(5) No religion

9. **How often have you attended religious services in the past 3 months?**

(1) Never (2) Rarely (3) Sometimes (4) Often

10. **Are you employed now?**

(1) No (2) Yes

10a. **If yes, what do you do? (Please put the type of work you do, not where you work)**
10b. **Do you work: (1) full-time (2) part-time**

11. **Are you satisfied with your current employment status?**

(1) No (2) Not sure (3) Yes

12. **What is your age?**

13. **How much school have you completed? (Primary, High School, College, or University:**

14. To which ethnic or cultural group(s) did your ancestors belong: (specify as many as applicable): French, English, German, Scottish, Canadian, Italian, Irish, Chinese, Ojibway, Cree, Métis, Ukrainian, Dutch, Finnish, East Indian, Polish, Jewish, Other (specify)

15. What is your family's yearly income?

(1) Under $5,000
(2) $5,000 - $9,999
(3) $10,000 - $19,999
(4) $20,000 - $29,999
(5) $30,000 - $39,999
(6) $40,000 or more

16. What is your current marital status?

(1) Married
(2) Common law
(3) Remarried
(4) Separated
(5) Divorced
(6) Single (Never married)

17. For how many years have you been married?

18. How many times have you been married?

19. If you are separated or divorced, please answer the following questions.

a. For how many years have you been separated or divorced
b. Were you separated or divorced before or after your child's condition was diagnosed? (1) Before (2) After

20a. In the past 3 months, how often have you had to miss work to take care of your child?_____

(0) I do not work (1) less than once a month
(2) 1-4 times a month (3) over 4 times a month

20b Number of attacks (asthma) in the past three months:

21 In the past three months, how many times have you visited the emergency department for your child's asthma?

22. In the past three months, how many times have you visited your family physician and/or pediatrician (or after-hours clinic) for your child's asthma?

23. In the last three months, what asthma medications has your child been prescribed & used

24. Has you child's medications changed in the last three months and how?

Appendix K

Université d'Ottawa · University of Ottawa

Faculté des sciences de la santé
Cabinet de la doyenne

Faculty of Health Sciences
Office of the Dean

CERTIFICATION OF INSTITUTIONAL HUMAN RESEARCH ETHICS COMMITTEE FACULTY OF HEALTH SCIENCES

This is to certify that the Institutional Human Research Ethics Review Committee of the Faculty of Health Sciences has examined the research proposal by **Rose-Marie Dolinar**, student from the **School of Nursing** for the project entitled: **"The effect of a health education program on coping and quality of life of parents of preschool-age children with asthma"** and concludes that, in all respects, the proposed research protocol meets the appropriate standards of ethical acceptability, at a Category 1A level.

MEMBERS OF THE COMMITTEE

Name (Optional)	Position held	Department of discipline
Victor Boucher	Professor	Audiology and Speech-Pathology Program
François Tremblay	Professor	Physiotherapy Program
Claire-Jehanne Dubouloz	Professor	Occupational Therapy Program
Ann Watters	Student	School of Nursing
Jocelyne Tourigny	Professor	School of Nursing
Sylvie Frigon	Professor	Faculty of Social Sciences
Roch Paquin	Member-at-Large	
J. Roger Proulx	Chair	Human Research Ethics Committee School of Human Kinetics

SIGNATURE

23/02/96 — Q. Proulx

Date — Committee Chairperson - J. Roger Proulx, Ph.D.

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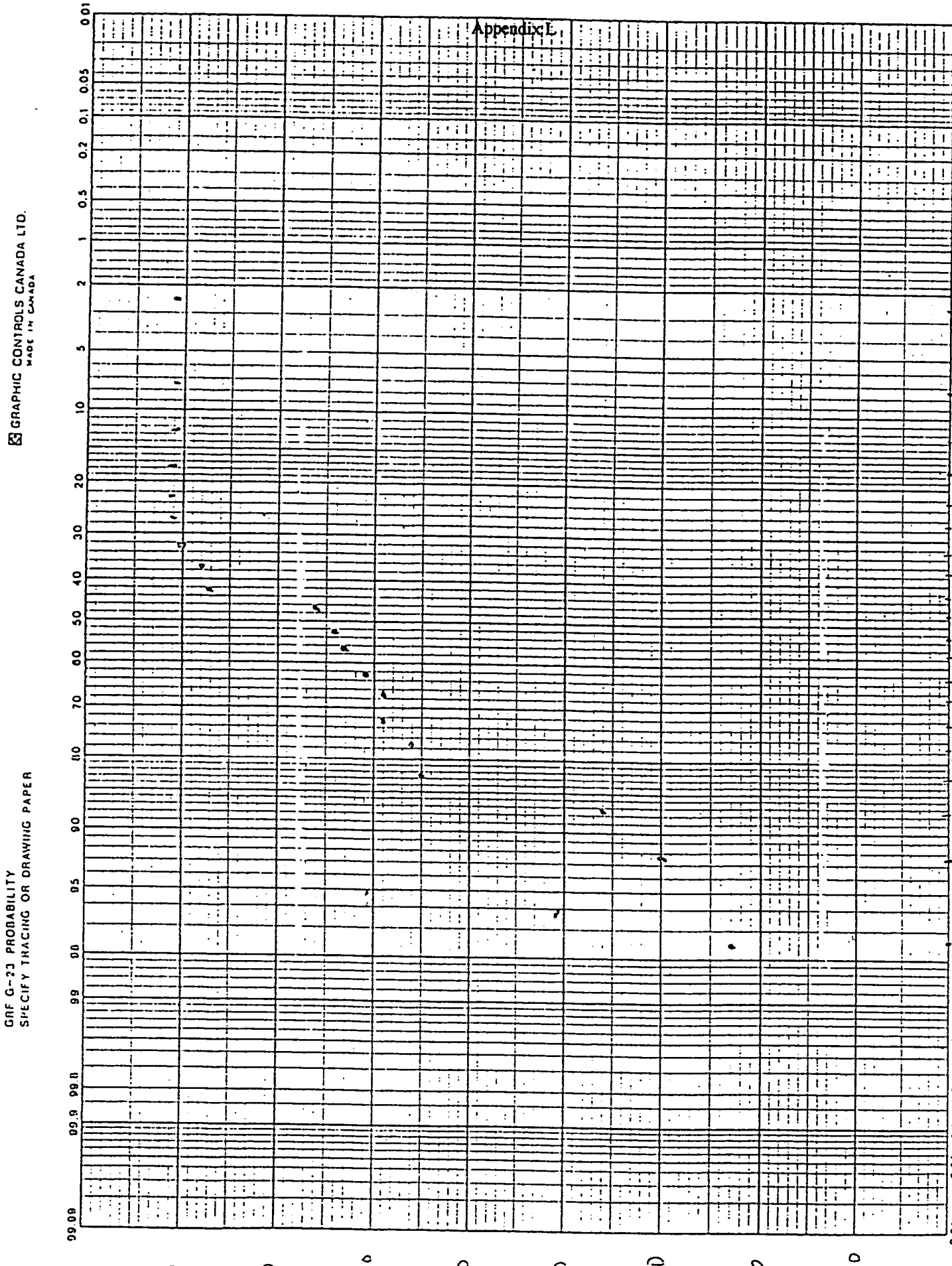
Appendix L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MADE IN CANADA
GRF G-23 PROBABILITY
SPECIFY TRACING OR DRAWING PAPER
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Appendix M

Wilcoxon Rank Sum W Tests for PACQLQ, CPC, PPI and corresponding sub-scales for determination of between-group significant differences at T_1

	MEAN RANK		W	p
	Experimental	Control		
PACQLQ*				
Overall	22.05	18.95	441.0	n.s.
Activity	20.08	20.92	401.5	n.s.
Emotional	22.30	18.70	446.0	n.s.
CPC**	21.63	19.38	432.5	n.s.
PPI***				
Help	18.10	22.90	362.0	n.s.
Concern	21.23	19.77	424.5	n.s.
Beliefs	22.40	18.60	448.0	n.s.
Feelings	21.12	19.88	422.5	n.s.
Coping Strategies:				
a) Number of	20.27	20.73	405.5	n.s.
b) Helpfulness	18.52	22.48	370.5	n.s.
c) Frequency	19.10	21.90	382.0	n.s.

* Pediatric Asthma Caregiver's Quality of Life Questionnaire
** Caregiver's Perception of Change in Child's Asthma
*** Parent Perception Inventory

Appendix N

t-tests for independent samples for PACQLQ, CPC, PPI and corresponding sub-scales for determination of between-group significant differences at T_1

	t	df	p
PACQLQ*			
Overall	0.37	38	n.s.
Activity	-0.35	38	n.s.
Emotional	0.60	38	n.s.
CPC**	0.70	38	n.s.
PPI***			
Help	-1.41	38	n.s.
Concern	-0.04	38	n.s.
Beliefs	1.36	38	n.s.
Feelings	0.58	38	n.s.
Coping Strategies:			
a) Number of	0.02	38	n.s.
b) Helpfulness	-0.77	38	n.s.
c) Frequency	-0.85	38	n.s.

* Pediatric Asthma Caregiver's Quality of Life Questionnaire
** Caregiver's Perception of Change in Child's Asthma
*** Parent Perception Inventory