

THE LIVED EXPERIENCE OF MOTHERS OF
CHILDREN WITH ASTHMA

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I am submitting herewith a dissertation written by Mary Kay Garcia entitled "The Lived Experience of Mothers of Children with Asthma." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

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ABSTRACT

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The purpose of this phenomenological study was to describe the lived experience of mothers of children with asthma. A purposeful sample of 10 mothers was interviewed using a semi-structured interview guide. Interviews were audiotaped and transcribed. Data were analyzed for common themes and descriptive elements using the phenomenological method. A core category, uncertainty, and four process-oriented categories: vigilance, searching for answers, taking charge, and finding a balance emerged.

Uncertainty described the experience of being in a state of enhanced vulnerability without predictability or control over events or outcomes which led to the mothers' feelings of anxiety, frustration, worry, fear, and anger. Mothers dealt with uncertainty by cautious monitoring (vigilance) and a quest for answers, support, and resources (searching for answers). In time, the mothers became

sufficiently assertive to effect change (taking charge). The processes of vigilance, searching for answers, and taking charge were directed toward promoting the normal experiences of childhood while taking the necessary precautions to maintain a sense of control (finding a balance).

Findings indicated mothers need to be included as integral members of the health care team. A timely diagnosis of asthma with understanding, appropriate education, and provision of resources would decrease uncertainty and improve mothers' ability to manage effectively. Further research is needed to identify and overcome the barriers to provision of asthma education and resources by nurses in all settings.

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CHAPTER 1

INTRODUCTION

Mothers of children with asthma face, not only the challenge of meeting the health care needs of their children, but also the challenge of providing the normal experiences of childhood. Schooling is frequently interrupted, family activities may be limited, disturbances in a child's normal sleep pattern are common, and frequent infections can disrupt parental schedules (Townsend et al., 1991). Even though health professionals have emphasized the concept of "family" in their practices, in reality in many cultures and instances, the mother assumes the primary role of caretaking and not the family as a unit (Anderson & Elfert, 1989). A mother's life can be consumed by the disease, and her own needs overshadowed by her child's needs. Nurses must take into consideration the impact of caregiving on women's lives. Understanding the mother's experience is essential if nurses are to intervene effectively and provide adequate resources.

As health care costs escalate, the success of new strategies for the management of care relies increasingly on families to assume more responsibility for the care of the

chronically ill. Health professionals expect that mothers provide skilled monitoring and follow complicated treatment regimes. However, effective health care is not just a matter of giving mothers more information about peak flow monitoring and warning signs or teaching them how to give nebulized breathing treatments. Little thought has been given to the monetary, physical and psychological cost to the woman caretaker (Anderson & Elfert, 1989). Illness management cannot simply be transferred from health professionals to families, mothers in particular, without recognition of the mothers' perspective of the experience.

Little research has been done to document the perspective of mothers of children with asthma within their own reality (Mesters, Pieterse, & Meertens, 1991; Nocon & Booth, 1991). Knowledge about these mothers' lived experience is limited, because most researchers examined only isolated dependent variables such as stress, coping, skills, and knowledge (Peri, Molinari, & Taverna, 1991; Townsend et al., 1991). These isolated factors fail to reflect that people do not experience life as isolated events but within the context of the total experience. The mothers' subjective worlds are often more subtle and elusive than the markers (i.e., emotional resistance, lack of knowledge and skills) by and through which investigators

attempt to interpret their worlds (Kestenbaum, 1982). Techniques of research have revealed limited understanding of the experience as quantitative studies have relied heavily on the use of questionnaires. A common disadvantage of gathering data with a structured questionnaire is that important issues cannot be foreseen and consequently are not included in the questionnaire (Mesters et al., 1991). Quantitative studies conducted from the perspective of the health professional have been less sensitive to mothers' concerns than qualitative methods. Qualitative research attempts to explain the meaning and pattern of responses to this human experience by going back to the experts themselves, the mothers, who experience this phenomenon.

The qualitative approach of phenomenology lends itself to an exploration of the essence of being the mother of a child with asthma. Through phenomenology, understanding can be grounded in the person's perception of reality, as experience is accepted as it exists in the consciousness of the individual (Field & Morse, 1985). This personal, subjective experience is so important to nursing that, according to Watson (1979), the phenomenon of health and the human predicament of coping with illness are best, and perhaps only, understood from an existential-phenomenological perspective. Instead of dissecting people

and dissecting care into discrete acts of giving instructions and providing treatments, the holistic approach to nursing coincides with the phenomenological approach which can offer a foundation for the humanization of health care (Kestenbaum, 1982). The phenomenon to be studied dictates the method, and phenomenology guides one back from theoretical abstraction to the reality of the mothers' lived experience (Field & Morse, 1985). A phenomenological study allows nurses to determine from mothers what a child's illness means to them within the context of their everyday world.

The perceptions of these mothers can provide that piece of subjective reality which seems to be missing but necessary to the nursing process. Understanding issues that are important in the mothers' lives is crucial in developing appropriate nursing interventions and programs targeted at improving overall family functioning. Armed with this knowledge, the nurse can play an important role in continuity service coordination, support care and advocacy (Gibson, 1988).

Problem of the Study

According to Husserl (1970), the lived experience is how the person experiences the everyday world pre-reflectively. In this phenomenological investigation,

mothers' perceptions of the experience of living with a child with asthma were examined. Recurring patterns and themes were analyzed to arrive at the essence of the experience.

Rationale for Study

Asthma is defined as a chronic, persistent, inflammatory disease of the airways characterized by exacerbations of coughing, wheezing, chest tightness, and difficult breathing that are usually reversible, but that can be severe and sometimes fatal. Major factors contributing to asthma morbidity and mortality have been underdiagnosis and inappropriate treatment. Most exacerbations reflect a treatment failure because they could have been prevented if treatment of the disease had been comprehensive and ongoing. The goals of management are the control of symptoms, prevention of exacerbations, maintenance of pulmonary function as close to normal as possible, maintenance of normal activity levels, including exercise, avoidance of adverse medication effects, prevention of development of irreversible airway obstruction, and prevention of asthma mortality (NHLBI, 1992b).

Asthma is a serious chronic condition affecting an estimated 11.7 million Americans; 4.1 million are under the

age of 18 years. For unknown reasons, the reported prevalence of asthma is increasing. Asthma is the most common respiratory disease of childhood and accounts for more school absences than any other chronic illness. Asthma is the most frequent reason for hospitalization due to chronic disease in children and teenagers (American Lung Association, ALA, 1994). In 1989, over 479,000 people were hospitalized for asthma, and 5,150 people in the U.S. died from asthma (NHLBI, 1992a). Between 1982 and 1991, the estimated number of asthma cases increased by 48.6%. The hospitalization rate rose 24.2% from 1979 to 1991. The greatest increases in asthma cases in recent years have been among those under 18 years. The annual estimated cost of treating asthma in those under 18 years is \$712 million (ALA, 1994).

Health professionals have nationally (NHLBI, 1991) and internationally (NHLBI, 1992b) defined guidelines for the diagnosis and management of asthma which includes goals of therapy for asthma which should have decreased morbidity and mortality. However, these goals frequently are not being met. When a child has a chronic episodic illness like asthma, many mothers attempt to seek guidance and treatment from their health care providers. Often these interactions do not necessarily result in the expected attainment of

goals of therapy as evidenced by the increase in hospitalizations and mortality due to asthma (Keenan, 1993). Increases in asthma morbidity and mortality are of international concern because they are occurring at a time when scientific advances have improved the understanding of asthma and provided new therapies. A recognition of these trends led to the development of the "International Consensus Report on the Diagnosis and Treatment of Asthma" in June, 1992. Factors considered in attempting to understand and explain these trends include: environmental exposures, stress, sociocultural factors, access to health care, air pollution, and suboptimal management by primary care providers (Keenan, 1993). The goals of therapy are not being reached, even with all the recent attempts at raising patient and professional awareness (NHLBI, 1991; Sander, 1994). Even though expert panels have been convened to give their perspectives on asthma, the perspective of the patient and family needs to be explored.

Barriers to effective asthma management are many, including the complexity and apparent unpredictability of the disease (Creer, 1982). Due to the chronic episodic nature of asthma and the diurnal cycle of pulmonary function, a mother may be up at night with a wheezing child who then may appear asymptomatic at the clinic visit the

following afternoon. A condition with such ambiguity can affect perception and cause disagreement among providers and parents about courses of action. In a study about the role of uncertainty in chronic illness in children, Jessop and Stein (1985) found that it was essential for physicians and other health care providers, as well as social scientists, to understand not only the logical structure of their own thinking, but be able to understand the structure of the world as seen from the viewpoint of the patient or parent. Failure to do so precludes optimal provider/patient communication and is a forerunner of difficult patients, problems of compliance, and dissatisfied patients.

When a child has asthma, the entire family is affected, but management of the illness most often becomes the responsibility of the child's mother. Being a mother can be challenging on a daily basis without additional complications such as chronic, episodic illness with the unanticipated and frequent crises. Although asthma is a chronic condition, often it is the acute episode that brings the mother and child in contact with the health care system (Taggart et al., 1991). Emergency room visits and/or hospitalizations can financially and emotionally tax a family. Episodic crisis management seems to prevail even though health care providers know that treating asthma as a

chronic condition with routine follow-ups can reduce the severity and frequency of exacerbations, help determine appropriate medication management, and decrease school absenteeism. Speculation regarding barriers to continuity of care include: lack of access to care, lack of ability to discern severity, financial and emotional issues (National Heart, Lung, & Blood Institute, NHLBI, 1991).

When a child has asthma, the role of the child's mother expands to include the extra burden of doctor's visits, breathing treatments, peak flow monitoring, sleepless nights, and general case management. The findings from this study, with a phenomenological approach, will enable nurses to learn from mothers in order to better understand the experience and intervene in more relevant and meaningful ways with mothers of children with asthma. When little is known about a phenomenon, the need for nurse educators and practitioners who can develop appropriate nursing interventions and plan care is difficult to substantiate. Accurate assessment and evaluation of nursing care must be based not only on the perceptions of the nurse but also on verification of the mothers' perceptions. With increased insight, mutual agreement on goals of therapy should be reached and morbidity and mortality decreased. From listening to mothers' stories, nurses can come to a clearer

understanding of the mothers' perceptions and help rather than hinder them as they attempt to "deal with It."

Nursing has a vital role in helping children with asthma and their mothers gain control over the disease rather than allowing the disease to control the patient. Fireman, Friday, Gira, Vierthaler, and Michaels (1981) found that the use of a nurse educator to work with families improved adherence to management plans and reduced asthma episodes, unscheduled hospital and clinic visits, and school absenteeism. However, that study, conducted 14 years ago, generated little change in routine practice. Only a small percentage of patients see a specialist and even fewer a nurse educator. The majority of patients are treated by primary care providers (Keenan, 1993). Unfortunately, the largest threat to the high-risk asthma patient is complacency about the severity of the disease on the part of the patient, physician, and health care system (NHLBI, 1991). Or, as one mother stated so succinctly, "It's sort of, to me, as the one (asthma) that goes through the cracks a lot, because a lot of people do get better, so it's like, 'too bad those ten years were hell. You're fine now'." Awareness needs to be increased regarding the implications of asthma and the potential of nursing to make a positive

difference especially when sensitive to the mothers' concerns and feelings.

Theoretical Orientation

Robert Coles, in the introduction to Rosenberg's (1980) book about the experience of illness, was reminded of something the poet and physician, William Carlos Williams, said to him when he accompanied him on house-calls:

We've got to learn to stop ourselves; we've got to learn to surrender to them--to our patients. They have stories to tell, too--lines of poetry in them; bad dreams and good ones; pictures to give us of their wounds, and their smiles, and the deep worry-lines on their faces. (p. 8)

If nurses do not understand what a person is experiencing in a particular situation, how can they expect to provide effective health care? The qualitative approach of phenomenology attempts to describe accurately the experience of the phenomenon under study and is best suited to answer experiential questions such as, "what is the lived experience of mothers of children with asthma?" Through the phenomenological research approach, the researcher can "go back" to the things themselves to uncover rich storehouses of insight into human life (Munhall & Oiler, 1986). The aim of phenomenology, as well as phenomenological research, is to show the essential features of a process or to understand the general nature of a phenomenon.

Phenomenology is both a philosophy and a research method (Leininger, 1985). Phenomenology, a term coined in the 18th century, is derived from the Greek words *phenomenon* (plural, *phenomena*) and *logos*. *Phenomena*, in general, means the appearance of things as contrasted with things themselves.

Spiegelberg (1960) described phenomenology as a movement because it is not static, but has been growing and changing and formed by various philosophers. Kant (1724-1804) made this a cornerstone of his philosophy when he taught that individuals can only know it as it appears to them. The mind is actively involved in the object it experiences and organizes experiences into definite patterns. Kierkegaard (1813-1855), a Danish philosopher, began the existential school of philosophy focusing on the nature and meaning of human experience.

Husserl (1970), a German philosopher influenced by Kierkegaard, is viewed as the founder of the phenomenological approach which is principally a systematic and full exploration of consciousness. After Husserl's son died in World War I, he thought that science needed a philosophy that would restore its contact with deeper human concerns. Thus, phenomenology grew out of a critique of positivism when inappropriately applied to human concerns.

More than mere sense data or observable behaviors are admissible data. Husserl directed others to suspend theoretical understandings in order to renew observations of peoples' experiences in the everyday world. Heidegger (1962) was an established scholar when he became Husserl's assistant and used the phenomenological method to explore being and time. The German phase of phenomenology ended with the Nazi years and interest in phenomenology moved to France.

Sartre (1963) was the first French philosopher to reactivate phenomenology. His goal was to understand man and Sartre believed that nothing could be more exact and rigorous than to recognize human properties in man. Merleau-Ponty (1964), a colleague of Sartre, was more scholarly and concerned about science. Merleau-Ponty wanted to show that a science of human beings was possible. The science of perception was his most cherished thesis. The phenomenological approach becomes an attitude, a way of looking, an attempt to return to the things themselves.

According to Misiak and Sexton (1973), the phenomena of consciousness are so numerous as to encompass events, experiences, memories, feelings, moods, thoughts, images, fantasies, persons, things, mental constructs, and the like. These phenomena are all enlisted and explored through the

phenomenological method. As Duffy (1986) pointed out, "phenomenologists use a descriptive approach to understand human beings in their own culture in order to determine the essence of their behavior" (p. 238). The goal is not to discover the cause of the event but to describe the experience as it is lived (Field & Morse, 1985). Phenomenological research does not attempt to affirm theory, but rather understand a human experience by examining the data of experience and its meaning from the person as well as the essence of the phenomenon. Davis (1978) recommended support of the phenomenological approach in nursing research because nursing is primarily a social and interpersonal act between the nurse and patient.

Becker (1992) emphasized that the phenomenological viewpoint is based on the following premises: experience is a valid and fruitful source of knowledge and the basis of behavior; and everyday worlds are valuable sources of knowledge. Phenomenological assumptions, according to Becker, include:

1. People are active, intentional subjects who are aware of their worlds.
2. Each person is inherently tied to a context and to other people, and these factors help define the person.
3. A person is a unity of mind and body, a perspectival scholar, and a co-creator of meaning who embraces and transcends thrownness by exercising situated freedom.

4. Unique experiences generate common themes that illuminate the essential structures of life.
5. Experiential time and space differ from clocktime and measured space. (pp. 23-25)

An active, experiencing person is aware of self and the world, and lives intentionally to construct a meaningful life. The worlds or situations in which a person lives must be understood to fully understand the person. The essence of human nature is the mind-body unity, and meaning is created between person and world. Perspectivity means that any knowledge is from a particular, limited viewpoint. Thrownness refers to people being born (thrown) into a given world, that is, a well established culture and a life formed by factors outside their control. Situated freedom lies between complete freedom and complete determinism because in any given situation people can make choices. Although each person is different and irreplaceable, knowing the common aspects of human experience can lead to an understanding of the essential themes of unique experiences. To phenomenology, time and space exist as they are experienced. The same hour by the clock can seem too long when spent in a boring lecture and too short when spent in enjoyable company. The same two chairs can seem too far apart when occupied by close friends and too near when occupied by antagonists (Becker, 1992).

Research Question

Using a phenomenological approach, the following question was asked: What is the lived experience of mothers who have children with asthma? The focus of the study was twofold: (a) to explore common components of the phenomenon and, (b) to develop a description of the experience.

Orientational Definitions

According to Leininger (1985), orientational definitions are explicit guides to study the domain or areas related frequently to the theory. The orientational definitions for this study are the following:

1. Asthma is a chronic episodic lung condition which is characterized by inflammation and bronchospasm and evidenced by coughing, wheezing, chest tightness, or shortness of breath (NHLBI, 1991).
2. A child with asthma is a person under the age of 18 years who has a diagnosis of asthma made by a physician.
3. Health care professionals include physicians, medical assistants, nurses, respiratory therapists.
4. Lived experience is a personal situation which is identified and described by each research informant.
5. Mother of a child with asthma is a woman over the age of 21 years who lives with and cares for a child with asthma.

Summary

The purpose of the study was to explore and describe the phenomenon of the experience of having a child with asthma as perceived by mothers of children with asthma. The researcher used a qualitative method, phenomenology, to describe the informants' lived experiences. Only through a deeper understanding of the mothers' perspective of the experience can health care delivery become more sensitive to mothers' needs and thus more effective.

CHAPTER 2

LITERATURE REVIEW

In reviewing the literature, three areas have been addressed. First is an historical overview to acknowledge that the definition of asthma now being used is not the same as it has been defined previously. The word, asthma, carries many connotations. Following the historical overview, more recent studies about asthma have been described. Finally, a noncategorical approach to coping with chronic illness has been reviewed because of the many commonalities experienced by parents who have children with chronic illness (Stein & Jessop, 1982).

Historical Overview

Today, asthma is defined as a chronic persistent inflammatory disease of the airways manifested in increased reactivity. The airway hyper-reactivity causes recurrent episodes of shortness of breath, wheezing, and coughing. These episodes, or as they used to be called, attacks, usually develop as a result of exposure to various triggers such as allergens (i.e., house dust, mold, pollen) or irritants (i.e., smoke, fumes), viral respiratory

infections, exercise, or emotional stress (National Heart, Lung, and Blood Institute, NHLBI, 1992b).

Treatment of asthma should be individualized and can be complex. The basics include: (a) avoidance of triggers, (b) use of bronchodilators for control of acute symptoms, and (c) prophylactic use of anti-inflammatories to deal with the underlying problem of inflammation. Currently, self-monitoring of pulmonary function with a peak flow meter is recommended as a gauge to determine efficacy of medications and to define the need to adjust the regimen per a protocol determined with the health care provider (NHLBI, 1992b).

Many misconceptions and myths continue to influence perceptions of asthma. The term, asthma, comes from the Greek language and means "to pant." References to the symptoms that comprise asthma date back to Hippocrates (460-370 B.C.), although it was not until the 2nd century that Aretaeus provided a detailed description of asthma. According to Rosenblaat (1976), Aretaeus described both the physical changes and the psychological states that were thought to accompany asthma episodes. In the 12th century, many of the same psychological and physical changes were echoed by Maimonides in his treatise on asthma, Tractus Contra Passionem Asthmatis. Maimonides discussed features

of asthma and individual differences in treatment (Munter, 1963). Despite these early references to asthma, sizable gaps, myths, and questions about the nature of asthma have remained in the 20th century. Conflicting viewpoints have been especially strong regarding the medical versus psychological nature of asthma. In a report of a task force on asthma assembled by the National Institute of Allergy and Infectious Diseases (NIAID, 1979), this dichotomy was summarized. The NIAID Task Force Report quoted an influential clinician from the early part of the century, Sir William Osler, who wrote "All authors agree that there is, in a majority of cases of bronchial asthma, a strong neurotic element" (p. 118). At the same time, the report quoted Cooke who in an early textbook on allergy wrote that "asthma is an allergy and only an allergy" (p. 118).

Over 50 years ago, French and Alexander (1941), after reviewing various psychological theories of asthma and gathering data from 27 patients with asthma undergoing psychoanalysis, concluded that: asthmatics have a unique personality and dependency conflict over their attachment to their mother. The asthma attack is a form of inhibited suppressed cry for the mother and psychoanalysis would alleviate the symptoms. Their conclusions have proven durable and had the greatest impact of any writings on the

subject of asthma and the psychological factors (Creer, 1982). Despite evidence to the contrary, many followers of this psychological theory still persist. Many nurses who worked pediatric inpatient units years ago will remember being firm about enforcing the "parent-ectomy" policy when a child with asthma was admitted having an asthma attack. Parents seemed to have been given much of the blame if a child had asthma. Removing the parent from the scene was thought to help. This technique was an obvious way of inferring that the parent was contributing to the problem, at least to the psychological component.

Asthma was considered a psychosomatic illness and "smother love" was a frequently used term in referring to the causative factors. The parent-child relationship was considered to be unsatisfactory because of dependency conflicts (Rees, 1963). Mothers were seen as overprotective and smothering in order to compensate for their guilt feelings over their hostility toward their child. The child's sense of independence and autonomy was thwarted and a heightened sense of vulnerability and insecurity was created. Other parents were seen as openly critical and rejecting thus causing the child to feel vulnerable and unloved. Asthma was seen as the way of releasing pent-up feelings and achieving closeness. Although there is a

fittingness to these descriptions, the accuracy of such depictions has been questioned by many researchers (Dubo, 1961; Kaplan and Kaplan, 1959; Mendelson, Hirsch, & Webber, 1956). There has been little attempt to separate current factors from predisposing factors. In other words, if mother is overprotective and the child is dependent, could asthma be the cause of it, instead of the reverse?

Gauthier et. al. (1977, 1978) analyzed through an observational methodology the autonomous strivings of asthmatic children ($n = 40$, $n = 35$ in follow-up) and the mother-child relationship, along with the allergic and psychological variables, and found the children and their mothers to be well adjusted with age appropriate autonomy. Purcell (1963) noted that crying, coughing, or laughing are forms of irregular breathing that can trigger asthma attacks, but there is no evidence that it is a repressed cry for the mother. Jones, Kinsman, Schum, and Resnikoff (1976), using Minnesota Multiphasic Personality Inventory (MMPI) profiles, concluded that it would be premature to impose a unifying theory on those with asthma as no single personality style was unique to asthma.

Creer, Stein, Rappaport, and Lewis (1992) noted that in spite of recent strides in the past 20 years "regarding the pathophysiological basis of asthma and its treatment, much

of the lay public still views asthma as primarily an 'emotional disease'" (p. 808). The medical community has colluded in this view by often classifying asthma as a psychosomatic disease. More recently, though, investigators have found there is an interface between the biology of asthma, behavior, stress, the immune system, and the medications used to treat asthma. The fact that asthma can worsen with stress and improve when stress is relieved has complicated understanding and educational efforts. Creer et. al. presented a transactional model which accounts for the "somatic predisposition for asthma which through interactions with multiple internal and external forces, determines the clinical presentation of asthma in varying degrees of airway disease and disability" (p. 808). The somatic predisposition involves a physical vulnerability to the development of asthma and the inheritance of allergies. Those internal and external forces include neuroimmunology, temperament, and emotional factors as well as medications and their side effects. Asthma is a complicated and frequently unpredictable disorder that continues to puzzle behavioral scientists, physicians, and patients. The impact of asthma on the child and family often influences quality of life issues. Using this transactional model, preventive interventions such as self-management programs have been

developed to reduce the medical and behavioral impact of childhood asthma (Creer et al., 1992).

In the last 20 years, health related behavioral research promoted development of asthma self-management programs, such as Air Power, Air Wise, Superstuff, and A.C.T. (Asthma Care Training) for Kids (Wilson-Pessano & Mellins, 1987). Living with Asthma was developed in 1977 at the National Asthma Center in Denver with the same goal of helping children develop self-management skills (Creer, 1987). These various programs were developed for children from the ages of 5 to 12 years and their families.

Lewis, Rachelefsky, Lewis, de la Sota, and Kaplan (1984) conducted a randomized control trial of the A.C.T. for Kids curriculum. Seventy-six children with asthma from 8 to 12 years of age were randomly assigned to control and experimental groups. The control group received 4.5 hours of lecture on asthma and its management, while the experimental groups of four to seven children received five 1-hour sessions at weekly intervals. Parents and children were in separate groups for most of the time, and the sessions were interactive with the theme of putting the child in the driver's seat. Children and their parents were interviewed prior to the sessions and at 3, 6, and 12 months afterwards. Records of emergency room usage and

hospitalizations were reviewed for a period of one year prior and one year post intervention. Results showed equivalent increases in knowledge for both groups and changes in belief. However, with a 2 X 2 statistical design (self-care/other and pretest/posttest analysis) a significant change in self-reported compliance behaviors was found for the experimental group only ($p < .05$). Using an analysis of covariance to control for differences between groups prior to intervention, significant ($p < .01$) reductions in days of hospitalization and emergency visits for the experimental compared with the control group were seen.

Repeatedly, many of these self-management programs have proved similarly efficacious (Green, Goldstein, & Parker, 1983; Wilson-Pessano & Mellins, 1987). However, much time and energy on the part of volunteers and professionals was spent on trying to recruit parents and children to attend these programs and the dropout rate was high. Other barriers to dissemination seemed to include lack of physician awareness of the programs and referral to the programs. In an attempt to overcome some of these barriers, Open Airways for Schools was developed with the plan of teaching asthma self-management skills during the school day in order to reach more children with asthma (American Lung

Association, ALA, 1992). Open Airways for Schools was designed for students with asthma in grades 3-5 with the goal of increasing knowledge, skills and self-efficacy. Information is to be sent home to be shared with the parents. The program is new and has yet to be utilized in the majority of elementary schools. To decrease morbidity and mortality, patients and families need knowledge, skills, motivation, good medical management, and resources. However, even as researchers and educators try to reduce asthma management to an ABC formula, morbidity and mortality continue to increase at an alarming rate.

Asthma Today

The patient and family are being actively encouraged to become partners with the provider in decision-making, goal-setting, and development of treatment plans. The family's collaborative role with the health care provider is stressed as critical (NHLBI, 1992b). Even the word compliance has been replaced by the word adherence to connote a less passive patient role and more active participation in health care. However, what should be taking place is not always the reality of what is occurring in the clinic or during the office visit. As recent as 1990, adherence to proper medical management varied across studies from 17%-90% (Baum & Creer, 1986; Lemenck, 1990;

Miller, 1982).

Few studies directly address parents' concerns and barriers encountered in establishing these collaborative relationships with health care providers (Mesters, Pieterse, & Meertens, 1991; Townsend et al., 1991). The majority of studies and articles on asthma are focused on the pathophysiology, treatment, psychosomatic issues, and patient education (Creer, 1987; Dubo, 1961; Horn & Cochrane, 1989).

One study designed to examine parental perceptions of childhood illness was completed by Peri, Molinari, and Taverna (1991). A sample of 460 parents of 230 preadolescent children were given a modified version of Creer's asthma problem behavior checklist. The sample consisted of one group of 84 parents of 42 children with atopic symptoms (asthma, bronchitis, hay fever) and a second group of 376 parents of 188 children without atopy or any other serious disease. Data were analyzed using a descriptive comparative method. The percentage of positive responses to the survey items by parents of children with atopic symptoms were compared with positive responses by parents of healthy children. Results indicated both groups viewed their children as capable of autonomously managing their disease and medical facilities were viewed as a

primary resource. Children, especially those with atopic problems, were not perceived as altered by their illness, but family relationships were. Factors causing the greatest difficulties included disagreement over treatment, anxiety caused by the disease, and sacrifices made by family members as a result of the illness.

Nocon and Booth (1991) studied the social and personal impact of asthma on the lives of those with asthma and their families. Informants had experienced some impact to varying degrees in different ways: employment, schooling, physical activities, social interaction, personal relationships, and emotional well-being. Spearman rank correlation coefficient was used to show that the overall social impact correlated positively with severity of asthma and was significant ($p < .05$) in cases of adults and children under 5 years.

Mesters et al. (1991) used a qualitative and quantitative approach to do a needs assessment prior to development of an asthma education program. The target population consisted of parents ($n = 42$) of asthmatic children up to 4 years of age. A written survey and six focus group interviews were used to discuss parents' experience with health care, belief and knowledge of general aspects of asthma, medications, and preventive measures. Simple frequencies were calculated for the responses to each

question. Results of the questionnaire and interview were combined for each separate aspect of asthma. Important misconceptions that could have contributed to nonadherence such as anxiety about addiction and side effects of medications were revealed during discussions. The researchers noted the value of using both survey and focus groups as a means of discerning discrepancies between responses. Some of the discrepancies noted included: knowledge about medications, preventive care, and measured and perceived satisfaction with health care.

Townsend et al. (1991) evaluated the quality-of-life burden of asthma for 100 pediatric patients with moderate asthma, and one of each of their parents in order to construct two health related quality-of-life questionnaires. Since perceived burden can vary by viewpoint, the patient and parent were given separate quantitative surveys for assessment. Prior to being administered, an extensive item pool was generated and reviewed by parents and professionals to determine if all aspects of the disease and associated problems were included. The patient list identified 77 items dealing with three categories: respiratory symptoms and fatigue, emotional function, and limitations in physical activity. The parental questionnaire listed 69 items dealing with interference of the disease in the day to day

activities of parents. Parents and patients were interviewed separately, and the interview consisted of three parts. Respondents were first asked to volunteer asthma related problems by category. Then the interviewer asked whether each of the items from the item pool was a problem and, if so, to rate the impact of each item identified as problematic. A 5-point Likert scale with responses ranging from "does not bother you much" to "bothers you very, very much" was used. A "wishes" category enabled patients to identify areas in which they would like to do something, but participation in the activity was restricted or limited due to asthma.

Townsend et al. (1991) concluded that, for patients with moderate asthma, symptoms of asthma formed the largest component of the burden of disease and more than half listed various emotional factors that were at least a moderate bother to them. The three major components of the burden of the disease which troubled parents included: worry and concern about the disease, the medications used to treat it, and their inability to relieve their child's symptoms. Anecdotal feedback from respondents indicated they had rarely been asked about the day to day problems, and that it would have been a novel but sensible approach in helping them cope. The generalizability of the study findings was

limited because it was a convenience sample of families who had a child with mild to moderate asthma who had been referred to a specialist most often in a private practice setting. At time of publication, data regarding reproducibility and responsiveness of resultant instruments were not available (Townsend et al., 1991).

MacDonald (1996) used ethnography to describe the meaning of asthma to mothers of children with asthma. The overall theme that emerged was "mastering uncertainty." Eight mothers, from 26 to 42 years of age, with children ages 3 to 10 years, were selected by convenience sampling to participate in the study. Three mothers were interviewed once, and five mothers were interviewed on two separate occasions. Open-ended questions and statements offered the mothers the opportunity to describe their experience of living with children with asthma. Descriptive, structural, and contrast questions were used to elicit information. The participants were asked to describe the 24-hour period when their child was having an asthma attack and how their need to watch their child differed now from when the child was first diagnosed. Field notes were taken, interviews taped and transcribed. Analyses included uncovering domains, taxonomies, components of meaning, and cultural themes. After themes were identified, three mothers were asked to

verify the interpretations.

The mothers in MacDonald's (1996) study expressed their experiences in terms of self by describing internal self, actions, and passage of time. The mothers described their ability to cope with uncertainty as having mastered uncertainty. Passage of time started when the mothers first recognized their children were not well and continued to the "present" time. The major themes that emerged to define mastering uncertainty were expressed in passage of time as: appearance of symptoms, diagnosis, acquisition of knowledge, and learning to live. The themes that emerged within the internal self included: inability to read cues, self-doubt, fear, frustration, fatigue, loss of self, trapped, taking hold, self trust, and increased self-esteem. The mothers' actions were described as repeated questioning, vigilance, persistent, assertive, and assisting others. The mothers described how they periodically returned to an earlier feeling (i.e., self-doubt, frustration, or being trapped) but the feeling was of shorter duration and less intensity. The process was described as moving backwards and forward rather than linearly. Mothers wanted to be considered integral members of the health care team, but they did not have a sense of partnership. While the mothers viewed nurses as advocates, they did not view them as teachers or counselors.

Initially, mothers were reported to have naive trust in health care providers, but if discrepancies or ambiguities were recognized, trust was lost and uncertainty heightened. Mothers wanted recognition of their day-to-day struggles. Mothers experienced a time when they had acquired knowledge and competence and used them to secure some element of control in their lives.

The day to day problems and feelings have been described in a very personal and penetrating way by Clarke (1992) in "Memories of Breathing: A Phenomenological Dialogue: Asthma as a Way of Becoming." In this dialogue between Clarke and her teenage daughter who has asthma, their views of what it is like to have asthma and to be the mother of a child with asthma were expressed. The daughter, Sasha, described her fear, the ambiguity of asthma, the isolation, tears, concealment, the hospital, and even asthma as a way of being in the world. Clarke described her feelings about the night, the watching and waiting, the anguish, the comfort in ritual, and just being there. Asthma has had a pervasive effect on how they relate to each other and the meanings they now associate with certain cues. The report a very moving narrative of a relationship influenced by asthma.

The previous studies (Clarke, 1992; Mesters et al., 1991; Townsend et al., 1991) have shown that asthma impacts

not just the physical health of the person with asthma, but also the schooling, physical activities, social interaction, personal relationships, and emotional well-being. The family interactions, employment, level of anxiety, and stress in the family are affected when a child has a chronic episodic illness such as asthma. Parents who have children with diabetes, epilepsy, and other chronic conditions are dealing with complicated treatment regimens, frequent health care encounters, and all that that entails. According to Anderson and Elfert (1989), while the treatment of diseases varies according to diagnostic category, families caring for a chronically ill child over time share similar experiences.

A Noncategorical Approach to Chronic Illness

Clinical diagnosis may not be the central issue in describing an individual with an illness. In "What Diagnosis Does Not Tell: The Case for a Noncategorical Approach to Chronic Illness in Childhood" by Stein and Jessop (1982), data from two studies, one institutional and one population based (the Pediatric Ambulatory Care Treatment Study and the National Health Examination Survey-Cycles II & III), were used to test the usefulness of diagnostic groupings in examining correlates of illness. Pless and Pinkerton (1975) in Chronic Childhood Disorder: Promoting Patterns of Adjustment proposed a conceptual framework focused on the

commonalities across disease categories rather than diagnostic labels and dimensions of illness (e.g., stability, visibility) that may cross diagnostic boundaries and be related to psychological and social adjustment. Analyses of variance with the diagnostic groupings as the independent variable and a range of social, psychological, and educational measures as dependent variables revealed only one significant difference and that was the pattern of interaction with the health care delivery system ($F = 7.49$, $p < .001$). A child whose condition was less severe, or in better control, would have fewer interactions with the health care system than a child with a more severe or out of control condition. The clinician's overall burden index (COBI) revealed the most differences among groups as measured by the provider's perception of burden involved in care of the child. Results indicated more variability within diagnostic groupings than between them and suggested that the familiar medical diagnosis label is not a helpful categorization in the examination of social and psychological variables.

Jessop and Stein (1985) found that visibility of disease and its constant or changing quality is a better indicator of social and psychological functioning than diagnosis. The lack of visible difference between a child with chronic illness and one without such a condition makes it more

difficult to recognize or acknowledge the chronic condition. This uncertainty seemed to account for more psychological disturbance on the part of the mother and greater perceived impact on the family. The findings of their study documented that the inability of individuals to structure their situations in stable ways due to unpredictable events creates insecurity of the deepest kind.

Mishel (1988) constructed a middle-range nursing theory of uncertainty in illness that offers an interactionist perspective for the process of determining meaning in the illness experience. The primary antecedent variable, the stimuli frame, has three components: (a) the symptom pattern or degree to which the symptoms present with enough consistency to have a recognizable pattern, (b) event familiarity or the degree to which the situation is habitual and contains recognized cues, and (c) event congruence or the degree to which the expected and experienced is consistent in illness-related events. The stimuli frame is influenced by two variables: cognitive capacity and structure providers. Cognitive capacity refers to the individual's information-processing capabilities. Structure providers are the resources available to assist the individual in interpreting the event and include educational level, credible authority, and social support. When stimuli cannot be processed to form

a cognitive schema, uncertainty results. Uncertainty in illness was described as having four forms: (a) ambiguity regarding the state of the illness, (b) complex treatments and care, (c) lack of information about diagnosis and seriousness, and (d) unpredictability of the course and prognosis.

Uncertainty can be appraised as either a danger or opportunity according to Mishel's (1988) theory. If appraised as an opportunity, coping strategies to maintain the uncertainty are utilized. When it facilitates hope in situations where certainty is negative, buffer methods such as denial, avoidance, and neutralizing may be employed. If appraised as a danger, two coping tracts are available to the individual: (a) mobilizing strategies such as direct action, information seeking, and vigilance, and (b) affect management which includes the methods of faith, disengagement, and cognitive support. If the coping strategies are successful, adaptation will occur. Adaptation has been operationalized as psychosocial adjustment, recovery, life quality or health. Uncertainty was identified by Ruppert (1992) in her phenomenological study of the lived experience of wives whose husbands were hospitalized in critical care units. Whether illness is acute or chronic, uncertainty seems to be a pervasive theme.

When a parent receives a diagnosis of a child's chronic illness, (i.e., asthma, epilepsy, or diabetes) that lacks visibility, the reaction to the diagnosis can be met with mixed feelings. Austin (1979) used her experience as the mother of a child with epilepsy for the basis of "Stages in a Family's Reaction to Epilepsy in a Child" in which she discussed the similarities of her experience with the grief reaction of parents with terminally ill children. Although the loss is not of the child to death but to a seizure-free existence, Austin's disbelief and anger are experienced in the stage of growing awareness. Austin noted the similarity to the chronic grief of parents with a mentally handicapped child for the sadness remains even after acceptance of the diagnosis. But those with epilepsy can lead productive and independent lives even though it is an unpredictable disorder which can cause seizures and put them in physical risk, danger, and cause possible rejection by society.

The stages that Austin (1979) described in an autobiographical case study format included: disbelief, anger, demystification, and conditional acceptance. Austin offered appropriate nursing interventions for each stage. As the nurse assesses what stage the family is in, the nurse should be able to intervene effectively, anticipate possible behavior, and recognize the need for mental health

consultation if warranted for the family. According to Austin, sharing information with parents about stages can help them to see a progression in their adjustment. Austin's article can lead one to conjecture about possible commonalities across disease boundaries, especially with chronic episodic illnesses.

In an ethnographic study, Anderson and Elfert (1989) described women as caretakers when managing chronic illness in the family. An in-depth understanding of families' experiences of caring for a chronically ill child was obtained through participant observation combined with interviews in the first phase. Thus, questions were formulated for exploration in ethnographic interviews with a larger number of families. Over five years, 45 families were interviewed. In the second phase, the investigators were able to build on and verify concepts developed in the first phase. The concept of "competent mother" came into focus from the birth of a healthy child. Having a child with a health problem put the mother's competency into question. Mothers began to question themselves and what they did wrong. According to the findings, the issue of competency not only shapes "the ways in which a child's illness is managed, but is the background against which a woman makes sense of the illness" (p. 738). The researchers

noted how the caretaker role was constructed and that even as families took more responsibility for a child's care, the women were expected to be the caretakers and coordinators of health care. In relationship with health professionals, the societal notion of women as caretakers has been reinforced. Anderson and Elfert concluded that the research findings pointed to the need for health professionals to recognize the impact of caregiving on women's lives.

Hamlett, Pellegrini, and Katz (1992) investigated the impact of childhood chronic illness within a family context. Sixty mothers with 6- to 14-year-old children were interviewed. Half of the mothers had children with asthma or diabetes; the other half had healthy children. Instruments included the Child Behavior Checklist, Family Environment Scale, an amended form of the Interview Schedule for Social Interactions, and the Project Competence Life Events Questionnaire. These instruments examined family functioning, extrafamilial social support available to mothers, and child life stress events in relation to the child's psychological adjustment and illness events. Mothers of children with asthma reported a greater number of internalizing behavior problems in their children and perceived less adequate social support as well as a greater number of stressful events. Methodological limitations to

be considered in reviewing the findings included the small number of children with chronic illness, especially with diabetes in the sample. Regression analyses showed that family functioning, maternal social support, and chronic illness were significantly ($p < .03$) related to the child's psychological adjustment. The results suggested the importance of family member competencies and social support in coping with crises and changes in the child's illness.

Wuest and Stern (1990) used a grounded theory method to study families with a child having otitis media. A convenience sample of 30 was drawn from 12 families in Canada having a child under 10 years of age diagnosed with otitis media with effusion. Wuest conducted 1-hour informal interviews with each family during which each member was asked to talk about his or her experiences with middle ear disease. Wuest and Stern participated in analyses of data and found three variables that influenced the position of the family on a continuum of learning to manage including effects of the disease on the child, disruption to family life, and relationship with the health care system. Learning to manage was not viewed as a linear process of stages to be mastered but rather as a continuum of passive to active behaviors. The researchers labeled the major dimensions of learning to manage as acquiescing, helpless

floundering, becoming an expert, and managing effectively. The family moved forward and retreated along the continuum in response to the effects of the disease, amount of disruption, and relationship with the health care system. The child's symptoms brought the family in contact with the health care system. Then, the effects of the disease and this contact resulted in a series of actions and reactions that disrupted family life and may have increased their motivation to improve their management skills.

According to Wuest and Stern's (1990) findings, the amount of disruption was contingent on three factors: position of the child in the family, experience with illness, and disposition of the child. During the acquiescing phase, the child was entrusted to the professional, and parents learned by trial and error how to ease the symptoms until they received medical help. During the phase of helpless floundering, the family became disillusioned with the health care system that they thought would have been able to cure their child. As the child did not get better and stay better, parents became uncertain about the appropriateness of the interventions and how long the problem would continue. Families experienced living in chaos, unwelcome advice, a breakdown in social support along with repeated episodes of otitis media disease.

In an effort to understand what was happening, parents in Wuest and Stern's (1990) study underwent the process of becoming experts. This process involved learning the rules, perceptive knowing, and experimenting. Learning the rules involved acquiring more information about the disease process and formal and informal working of the health care system. Perceptive knowing was the awareness of the ability to interpret cues (early warning signs or symptoms). Experimentation occurred as the family members juggled or exchanged roles, attempted use of medication to provide comfort or prevent progression of disease, and learned the connections between activities and illness. This experimenting is a form of self-care that enhances the family's sense of control, competence, and self-esteem. Families who managed effectively rearranged roles and responsibilities, negotiated with health care professionals, and minimized the effects on the child.

According to Wuest and Stern (1990), otitis media disease does differ from chronic illness in that it has an expected time span, as it is assumed that the child will outgrow it. Also, the first time a child has an ear infection, the incident is viewed as episodic and not the beginning of long term illness. Parents rarely received a definitive diagnosis of their child's condition and only

gradually became aware that this was more than an occasional problem. This state of uncertainty prevented many families in the study from developing management strategies and caused much frustration as they attempted to make sense out of what was happening. The goal of the families appeared to be to survive the experience with minimal effects on the child. The families hoped for the end of the disease and a return to normal, whereas, in chronic illness usually an attempt is made to establish a new normalcy. In this study, most parents did not consider their adaptation strategies as normal. Instead, the parents tried to explain the differences (such as a need to speak louder) to the child with a hearing problem. A concern to parents was that others could not anticipate special care because the disability was invisible. This invisible and episodic nature of the condition created an element of uncertainty and caused the families to have greater difficulty monitoring the condition. The researchers concluded that health professionals needed to recognize that middle ear disease is not trivial and that individual families needed support in their efforts to manage with emphasis on early intervention.

Some parallels or similarities exist between families in Wuest and Stern's (1990) study and families with children

who have asthma. Often families with children with asthma do not receive the diagnosis of asthma at first; they hope their child will outgrow it; and asthma is episodic and invisible. Also differences exist. Although asthma does not necessarily have a downward trajectory as some chronic illness does, it is a chronic illness. While some children do seem to "outgrow" asthma and the airway obstruction is reversible, the threat to life is real.

Normalization was mentioned briefly by Wuest and Stern (1990) as a characteristic of many families dealing with a true chronic illness. After a review of the literature, Knafl and Deatrick (1986) concluded that there are four criteria for defining and recognizing the concept of normalization in a family. The family will:

1. Acknowledge the existence of the impairment.
 2. Define family life as essentially normal.
 3. Define social consequences of the situation as normal.
 4. Engage in behaviors designed to demonstrate to others the essential normalcy of the family.
- (p. 219)

Bossert, Holaday, Harkins, and Turner-Henson (1989) examined strategies of normalization. From a sampling frame of 912 chronically ill children, 365 children and their parents, usually the mother, were randomly selected and interviewed in the home. The children were ages 10 to 12

years and had a chronic condition not affecting communication, vision, hearing, or intellectual ability. A noncategorical approach focusing on commonalities across disease categories was used. The parent was questioned on the child's health history, school and home activities, ongoing care, the neighborhood, and parental activities and child-rearing philosophy. Children were interviewed about extracurricular activities and use of free time away from school. As a final question of the medical history interview, parents were asked if there was anything else they would like to add. These responses were analyzed by two pediatric nurse researchers using the qualitative process of theoretical coding.

According to Bossert et al. (1989), a frequently recurring theme was normalization and two dominant variations were identified: strategies used to normalize the chronically ill child's life, and strategies used to normalize the lives of siblings or family in general. In normalizing the child's life, the following strategies were most frequently mentioned: viewing the child as a child; altering the prescribed therapeutic regimen; advocacy with the school system; and normalizing the child's interaction with society. In normalization of family life, the strategies included: planning equal time with all children;

family changes to accommodate the child's needs or decreasing reminders of differentness. Finally, measures involving siblings in the care of the ill child or measures used to normalize parents' lives were significantly lacking.

Bossert et al. (1989) emphasized the need for professionals to be able to ascertain the difference between the concept of normalization and denial, although they share many of the same attributes. In normalization, the condition is acknowledged. Normalization strives to promote an ordinary lifestyle under extraordinary circumstances. The researchers concluded that normalization of life for a chronically ill child is a worthwhile goal and nurses should be aware of the meaning and strategies that families use to achieve it. Guidelines for promotion of normalization were given.

Venters (1981) investigated familial coping with cystic fibrosis. Based on the perceptions of parents representing 100 families managing cystic fibrosis for several years, the findings revealed coping strategies utilized to minimize illness related hardships were associated with long term adequacy of family functioning. This exploratory study was one component of a broader study. Parental responses for this one component were limited to parental responses solicited by written questionnaires yielding demographic

information as well as a quantitative family functioning score measuring cohesion, communication, and satisfactions of family members. In addition, the larger study solicited semi-structured interview data which, for the purposes of this study, were limited to the practical and emotional impact of hardships that might influence coping behavior.

Almost half (46%) of the families in Venters' (1981) study identified that their greatest source of anxiety was a result of attempts to manage specific hardships which occurred immediately before or after diagnosis. Several sources of frustration were identified, one of the most stressful being the lack of recognition and search for an accurate diagnosis. Many (62%) of the families recalled the diagnosis was initially missed. Another major source of anxiety was the inability of many (63%) families to anticipate the severity of their child's condition. However, most (89%) families reported to have established some degree of reorganization within the first year after diagnosis. Chi-square analyses demonstrated that two functional coping strategies were significantly associated with level of family functioning: endowing the illness with meaning ($X^2 = 31.51, p < .001$) and sharing the burdens of the illness ($X^2 = 21.06, p < .001$).

In a study of parental coping with a child with a

diagnosis of cystic fibrosis conducted by Gibson (1988), a convenience sample of 56 parents whose children were 10 years of age or under was chosen. Parents completed a series of open-ended and closed-ended questionnaires which provided information on: (a) parents, family situation and child with cystic fibrosis, (b) parental perceptions of coping, including what was most helpful to them and most difficult for them in coping with the disease, and (c) parental coping behaviors. Responses were analyzed using Lazarus and Launier's (1978) cognitive phenomenological theory on stress and coping as a framework. All parents in the sample experienced a degree of illness-related stress. Three categories of resources to meet the illness-related demands emerged: social support, problem-solving skills, and a system of beliefs. Coping behaviors were both action-oriented and intrapsychic efforts. According to Gibson, implications for nursing included the need for nurses to assess parental perceptions of (a) the illness, (b) the threatening aspects of dealing with it, (c) their ability to cope with the demands, and (d) sources and resources for socioemotional and instrumental support. Recommendations included nursing strategies that could enhance each individual's ability to cope and to resist, reduce, or manage the demands.

Gibson (1995) developed a conceptual model of the process of empowerment in mothers of chronically ill children. In the first phase, the concept of empowerment was researched in the literature and analyzed for measurement and meaning. In the second phase which overlapped with the first, field research was conducted for further analysis of the concept. The study took place over a 12-month period on a neurological unit in a 350-bed children's hospital in the northeast United States. Participant observation and multiple in-depth interviews were done with 12 mothers, ages 25 to 49 years, of neurologically challenged children, ages 11 months to 16 years. The mothers had been identified by the staff as having a sense of mastery over their situation. To capture the process of empowerment, the interviews were rewritten in chronological order. During data analysis, constant interplay occurred between the researcher, mothers, and data.

The model Gibson (1995) developed reveals the mothers' bond with, commitment to, and love for their child. This caring motivated and sustained the process of empowerment. Frustration was a powerful force, a predominant theme, that permeated the process and was critical in helping the mothers to discover reality. During this first phase of the

process of empowerment, discovering reality, mothers responded emotionally, cognitively, and behaviorally. Mothers encountered frustration within the family, health care system, and with themselves. This frustration continued to evoke ongoing cycles of critical reflection which then enabled the mothers to take charge of the situation.

Taking charge was the second component in the process (Gibson, 1995) and entailed: (a) advocating for her child, (b) learning to interact efficiently with the health care system, (c) learning to persist to get the care they needed for their child, (d) negotiating so opinions and requests were heard, and (e) establishing a partnership with health care providers that included mutual respect, open communication, and commitment to a common goal. The final phase of the process was holding on to their sense of power even during changing circumstances.

The outcome of the process was participatory competence (Gibson, 1995). Consequences include: purpose and meaning in life, self-development, satisfaction, and mastery; but the process outcome can also have negative consequences, such as rejection, responsibility overload, and less support. Influencing factors include: beliefs, values, social support, determination, and experience. A surprising

finding was how alone and isolated the mothers were, even though personally empowered.

Primarily, Hodges and Parker (1987) attempted to identify major concerns facing parents with school age children having Type I diabetes, and secondarily, attempted to identify the psychological effects these concerns had on parents. This descriptive pilot study had a sample of 14 adults who agreed to attend a support group for parents of diabetic children. Each discussion was 1.5 hours in length and was audiotaped for a total of 8 hours. Content analysis revealed four major categories listed in order of decreasing frequency: (1) management of diabetic regimen, (2) coping with restraints imposed daily by diabetes, (3) dealing with school problems, and (4) working with the health care system. Coping with concerns had a major psychological effect on parents who expressed fears, anxieties, frustrations, anger, and guilt. Further study was suggested to validate these findings. Implications for nursing included focusing on individual, family, and community (especially teachers) and interventions that would take into consideration the phenomena of concern.

Funnell et al. (1991) explored the philosophy of empowerment as a practical conceptual framework for diabetes patient education. Empowerment has been identified as a

viewpoint and system of values that could influence professional behaviors, attitudes, effectiveness, and satisfaction. For the purpose of developing this framework, the process of empowerment was defined as "the discovery and development of one's inherent capacity to be responsible for one's own life" (p. 38). With empowerment as the desired outcome, the patient education process is designed to improve patients' quality of life by enabling them to take charge of their health through recognition and promotion of personal strengths, informed choices, and personal goals.

Enabling the patient is a departure from the traditional patient education approach designed to influence patient knowledge, attitude, and behavior to enhance compliance with treatment recommendations. The traditional approach represents a medical disease model where the professional is viewed as the expert, powerful provider and the patient is the passive recipient. The empowerment approach is more consistent with the nursing and counseling models, where patients are viewed more as equal, active partners in the treatment program.

Summary

The perception of asthma today may still be influenced by the past. Although asthma is currently defined as a chronic, persistent, inflammatory disease of the airways

with recurrent episodes of coughing, wheezing, and shortness of breath, many misconceptions and myths still persist. The echo of psychosomatic illness and "smother love" can still be heard. Although the psychological basis of asthma has been disputed, little has been done to separate out current from predisposing factors. In an attempt to dispel myths and misconceptions, and reduce the medical and behavioral impact of childhood asthma, preventive interventions such as asthma self-management programs have been developed. Although the programs were often found to be efficacious (Green et al., 1983; Wilson-Pessano & Mellins, 1987) in increasing knowledge and reducing hospitalizations and urgent care visits, their dissemination has been very limited.

Today, patients and their families are being actively encouraged to become partners with the provider in decision-making, goal-setting, and development of treatment plans (NHLBI, 1992b). However, there is a paucity of studies that addressed parents' concerns and barriers to establishment of collaborative health care relationships. The process of empowerment is being examined as a concept especially relevant to chronic episodic illness management and may lead towards more participative encounters. Findings from the studies reviewed have shown that asthma

impacts not just the physical health of the person with asthma, but also the schooling, physical activities, social interaction, personal relationships, emotional well-being, family interactions, employment, and level of anxiety and stress in the family.

Other chronic illness studies were reviewed with the intent of examining commonalities that cross disease categories. The medical diagnosis label was not a helpful categorization in examining social and psychological variables and more variability existed within diagnostic groupings than between them. Lack of visibility and stability of illness was indicated as involving a greater need for vigilance due to the uncertainty of the condition (Jessop & Stein, 1985). The responsibility for this vigilance is usually assumed by mothers. Women are expected to be the caretakers and coordinators of health care with little recognition of the impact of caregiving on their lives. The concept of uncertainty emerged as a major theme in the experience of mothers of children with asthma (MacDonald, 1996) and again with parents of children with chronic childhood otitis media. While chronic childhood otitis media differs from true chronic illness in that it has an expected time frame and families do not usually try to normalize it, many similarities to childhood asthma exist in the experience of learning to manage.

CHAPTER 3

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

This study was designed as a phenomenological investigation of the lived experience as perceived by mothers of children with asthma. The mother's experience was fundamentally important, not simply as a subjective accounting of a pre-existing objective reality, but because this lived experience is reality as represented in the mother's experience (Kestenbaum, 1982). A clearer understanding of those perceptions can facilitate more appropriate interventions. Instead of dealing with people as nonpeople, exposure to existential ideas can help the nurse view the patient holistically and establish an "I-thou" relationship (Munhall & Oiler, 1986).

Phenomenology is congruent with nursing's holistic approach to the person as this approach does not reduce individuals to measurable, observable objects independent of their historical, cultural, and social contexts. Phenomenology seeks to take the researcher back to the experience so that understanding can be grounded in the patient's perception of reality. Nursing has a goal to understand those individuals in their care in order to know how to care for them and

others with similar experiences (Leininger, 1985). The phenomenological approach lends itself to an exploration of the essence of the experience of having a child with asthma.

Spiegelberg's (1960) method of analysis was the procedure used for data analysis. The data included field notes and transcriptions of audiotaped interviews given by mothers who had a child with asthma. Within each interview, the mothers were asked to describe the experience of having a child with asthma.

Setting

Although this study was primarily conducted in a large metropolitan area of approximately 3 million people in the southwestern United States, one informant was from the East coast and one was from the West coast. The interviews were done at mutually agreed upon sites, most often either the informant's or researcher's home or another location where privacy could be assured. In either case, the setting was informal thereby providing a relaxed atmosphere, which afforded as much privacy as possible. To protect the privacy and confidentiality of the informant, interviews were conducted with only the researcher and informant present in the room. A quiet place where conversation would not be overheard assisted in the development of rapport and trust which is essential in the relationship between the

informant and researcher. The interviews were audiotaped and field notes taken by the researcher.

Population and Sample

Purposeful sampling was used by the researcher to select the informants. The phenomenon under study dictates not only the method but the selection and type of informants (Hycner, 1985). Sampling was purposeful because only participants who were experiencing this particular phenomena and deemed to be good informants were recruited. A good informant is one who is undergoing the experience and able to reflect and provide detailed experiential information about it (Morse, 1991). Informants must be willing and able to examine critically the experience and their response as well as willing to share this information. Those unable to express their response and/or are unwilling to share this information would not be considered good informants. Names were obtained from the membership of the asthma support group coordinated by the researcher and from other acquaintances, neighbors, or colleagues. Often the person interviewed offered the name of another acquaintance who had a child with asthma. If any names were obtained from private physicians or school nurses, agency permission forms were completed. All informants were at least 21 years of age so that the developmental issues of adolescence would

not be an issue. The informants were English-speaking mothers who had a child with asthma under 18 years of age living with them. Race was not a selection criteria. The interviews lasted approximately one hour, because most informants had a great deal they wanted to say.

While there was no way to predict the required sample size beforehand, the final sample size was justified by the completeness of the data. Themes and core categories emerged as data continued to be collected until no new information was obtained and saturation was achieved. The criteria of increasing the sample size until redundancies of data emerge was based on the recommendation of Parse, Coyne and Smith (1985). Parse et al. suggested, "adequacy of the sample is achieved when the researcher experiences redundancy in descriptions. Redundancy is repetition of statements regarding the phenomenon under study" (pp. 18-19). In other words, the researcher was not hearing anything new. The researcher assessed the amount of information obtained to ensure adequacy, relevance, and completeness. No thin areas existed, and the resulting theory was complete (Morse, 1991). A thin area would be a category, theme, or issue that was glossed over and not fully explored. The researcher had the ability to recognize these thin areas and probe for additional information.

Protection of Human Subjects

Application was made to Texas Woman's University Human Subjects Review Committee. Potential risks of embarrassment due to improper release of information, anxiety, or fatigue were acknowledged. The following steps were taken to decrease anxiety and fatigue: interviews were conducted in private; adequate time was allowed for questions and concerns. The informant was free to interrupt the interview at any time either to rest or stop the interview. If a rest period was needed, the interview was stopped until the informant wished to continue. The researcher remained after the interview to answer any questions or discuss any concerns. Confidentiality was protected by placing only a number, no name, on each form, field note, and audiotape. The informant was not identified by name anywhere in this research study. All audiotapes were kept in a locked file cabinet, and they will be destroyed no later than 2 years after completion of the study.

When approval from the Human Subjects Review Committee was received, the researcher telephoned potential informants and asked if they would be interested in joining the study. The research study, time commitment, and involvement were discussed with them as was the option to withdraw. The researcher told the potential informants that their

participation involved answering questions related to their feelings and perceptions of managing their lives with a child with asthma. The mothers were informed that these discussions would be audiotaped and that measures to protect their identity would be taken.

The researcher read a description of the study (see Appendix A) to all persons who indicated a willingness to participate. If the potential informants agreed, the researcher provided a written consent form for them to sign and have witnessed which allowed the researcher to conduct the study (see Appendix B). Additionally, the researcher provided the informants with a written audiotape consent form which when signed and witnessed allowed the research interview session to be recorded by audiotape (see Appendix B). Persons who did not express a willingness to participate were thanked for their time and attention and were reassured that their child's care would not be affected in any way based on participation or nonparticipation in this study.

Instrument

The researcher asked informants questions which followed a semi-structured interview format. The instrument used in this study was an interview guide (see Appendix C). The first part of the guide is a very short demographic data

form that was used to collect information including age, marital status, years of education, employment status, number of children, age of child with asthma, age of child with asthma at diagnosis (see Appendix C).

The researcher interviewed the informants using open-ended questions. Reflective and clarifying responses were offered by the researcher. According to Giorgi (1985), "the original data consist of naive descriptions, prompted by open-ended questions, of experiences of situations by subjects unfamiliar with the researcher's theories or biases" (p. 9). Reflection of content is a way of letting the informant know that what was said was heard and understood. Reflection of feelings signifies understanding, empathy, and respect for the informant. Clarification is an attempt to put into words vague thoughts or ideas that are implicit or explicit in the informants statements. Tentative questioning such as "I'm not sure what you mean. Are you saying that...?" or "Could you go over that again?" help clarify feelings, ideas, and perceptions and can provide explicit correlation between them and the informants' actions.

Advantages of the interview approach include the opportunity to identify possible misinterpretation or inconsistency, clarify responses, probe for additional

information, and pursue the topic in depth with greater detail than other methods allow (Waltz, Strickland, & Lenz, 1984). A relatively unstructured interview provides the freedom to explore various topics with each informant based on particular responses. The actual questions to be used in each interview may differ because of the various experiences and perceptions of each informant. The phenomenological method involves retrospective descriptions of lived experiences. Questions should lead informants to reflect on, and describe the experience as a whole, and specific moments as they are presently remembered. This open-ended interview process is facilitated by providing for a quiet environment where interruptions will not occur and where the researcher is receptive and able to listen in a nonjudgmental manner (Field & Morse, 1985).

The following questions were used to elicit basic core variables and start with a grand tour question:

1. Please tell me what it is like to be the mother of a child with asthma.
2. Please describe how you felt when you were told your child had asthma.
3. What was your experience like before and after diagnosis?
4. How have others, family, friends, health care

professionals played a role in your experience of being a mother of a child with asthma?

5. Is there anything else you would like to tell me about this experience of being the mother of a child with asthma that we have not talked about?

Additional probes to be used included phrases such as, "please give me a specific example" and/or "please tell me more about that." The open-ended question allows informants to express responses in their own words thereby increasing validity (Leininger, 1985).

Validity and reliability issues of qualitative research studies have been questioned often since the interview responses of the informants are considered the data in phenomenological studies. Validity refers to the truthfulness and the data are the informants' responses. The researcher assumes that the informant is telling the truth. Associations are made and assumptions verified "to get inside the informant's skin" so that the topic may be understood from the informant's perspective (Field & Morse, 1985). The description of the phenomenon was validated by examples from the data, often direct quotes from the mothers (Burns & Grove, 1993). Prior to the final draft, some of the mothers were contacted to ensure that the essence of their experience had been accurately and fully captured

(Lincoln & Guba, 1985). This informant review further ensured completeness of data and that all aspects of the experience were described (Hycner, 1985).

Reliability refers to the ability of another researcher following the study methodology to obtain similar results. Guided by the phenomenological approach, preconceptions need to be kept in abeyance through bracketing so that the richness of the experiences can be contemplated without researcher bias. Bracketing is the process of consciously being aware of any preconceptions or bias so they can be set aside knowingly or suspended to prevent contamination during contemplation of the data. Influences on reliability include the subjectivity of the researcher and replicability of the study findings. These concerns about reliability can be controlled somewhat by the previously mentioned bracketing bias, transcribing interviews verbatim, reporting precisely the strategies used to collect, analyze, and report data, and seeking reaction to working analysis from selected informants. This member check was recommended by Lincoln and Guba (1985) as a validity check.

Agreement between the researcher and a judge, a doctorally prepared nurse with experience in phenomenological analysis, was a goal at each phase of data analysis. Auditability was enhanced by listing for each

theme cluster, the subsumed meanings and their original numeration in order to clarify transitions (Hycner, 1985).

Data Collection

By choosing a phenomenological approach, the researcher adopted an understanding-descriptive method. This method supported the accomplishment of three objectives: "(1) the phenomenological return to the things themselves, (2) the investigation of phenomena in a meaningful way, and (3) the relinquishing of the grip maintained by the technological attitude" (Colaizzi, 1978, p. 57).

After approval from the Texas Woman's University Human Subjects Review Committee, names were obtained from a support group coordinated by the researcher and from acquaintances and colleagues. Every informant was approached individually, either by telephone or personal meeting. Each informant was told the purpose of the study, and asked to participate in an audiotape recorded interview. Interviews lasted approximately one hour and informants had the opportunity to ask questions of the researcher regarding the study after the interview was over. Questions, or any possible misconceptions the informants may have had regarding asthma treatment that needed to be addressed were addressed only after the interview. In this way the interview did not become a health education dialogue or

counseling session and defeat the purpose of the research. Collection of data was done by audiotaping the interviews. As soon as possible after completion of a tape recorded interview, the tape was replayed listening carefully to the questions and tone of responses as well as content. The tapes were coded by number and transcribed word for word by the researcher or a typist. Pauses were denoted in the transcription as well as exclamations, crying, and laughter. Field notes were taken by the researcher during and immediately after the interview. Field notes supplemented the audiotapes and included observations about the setting, nonverbal body language of the informant, and any associations or reflections the researcher may have had during or after the interview.

Demographic data collected in the beginning of the interview included age, marital status, education, employment status, number of children, age of child with asthma, and age of child at time of diagnosis. The second part of the interview began with the question, "Please tell me what it has been like for you to have a child with asthma." From that grand tour question, follow-up questions arose requesting clarification and explication of specific instances that the informant may have described in general terms. These questions were not meant to lead but rather to

encourage a fuller description of the lived experience as perceived by the informant. Finally, mothers were asked if they would like to mention anything else before close of interview and recording was considered complete. To enhance validity of responses, active listening was used and periodic restatement of meaning in order to assure what was heard was what was meant. Active listening is a way of empathetically responding to the feelings of another while being aware of one's own thoughts and behavior. Active listening can be especially helpful when responding to another's feelings at high levels of intensity and assisting with self-exploration.

Pilot Study

A pilot study was conducted which included a total of three informants. All met the criteria, mothers of children with asthma and agreeing to tape recorded interviews about their experiences and feelings. Selection of the informants was from acquaintances, neighbors, and members of a support group for parents of children with asthma and allergies coordinated by the researcher in the Southwestern United States. The three informants were interviewed to review the research protocol. All informants were initially asked extensive demographics and then to describe what it was like to be a mother of a child with asthma. This pilot question

was followed up with further probes to elicit specific examples and further detail. The tape recorded interviews were transcribed and analyzed to reduce the data to its most essential structure. Some of the common themes that started to emerge included: confusion, fear, ambivalence, taking precautions, and receiving support. In the final analyses, all data resulting from the total sample was examined using Spiegelberg's (1960) method of analysis. Based on these findings the grand tour question remained, "Please describe what it is like to be the mother of a child with asthma." The demographics were shortened to a few essential questions and many of the more quantitative questions about number of days missed from school, emergency room visits, number of medications and the like were not asked. Mixing quantitative and qualitative data seemed confusing to both researcher and mothers.

Treatment of Data

Tape recordings, transcriptions, and field notes were analyzed by the researcher for recurring themes and patterns in the responses of the informants. The content analysis involved bracketing, coding, and grouping of coded responses into concept categories or theme clusters. A qualitative researcher begins with no a priori hypothesis regarding these experiences as yet undefined by those in the situation

to be studied.

Each step of the analysis was guided by two concerns: (1) to characterize the essential meaning of the mother's description and what it reveals about the nature of the experience, and (2) to remain as faithful as possible to the mother's original characterization. Based on meditative thought, phenomenological analysis is founded on intuiting (Spiegelberg, 1960). Intuiting involves logical insight based on careful consideration of representative samples. Contemplative dwelling with the data is the undistracted reading and rereading of the transcripts to be open to both tacit and explicit messages in the data in order to uncover the meaning of the lived experience for the informant. In examining the particulars of the experience, the researcher arrives at the essence or the meaning of the experience.

Spiegelberg (1960) set forth the following seven essentials of the phenomenological method:

1. investigating particular phenomena;
2. investigating general essences;
3. apprehending essential relationships among essences;
4. watching modes of appearing;
5. watching the constitution of phenomena in consciousness;

6. suspending belief in the existence of the phenomena (i.e., bracketing);
7. interpreting the meaning of phenomena. (p. 659)

First, investigating particular phenomena involves intuiting, analyzing, and describing. These processes are closely related but discrete although occurring simultaneously. Intuiting is done through quiet reflection on the descriptions which allows the essences of the phenomena to be grasped by the researcher who is openly looking, listening, and feeling. The second operation in investigating is analyzing and that is "the general examination of the structure of the phenomenon according to their ingredients and their configuration" (Spiegelberg, 1960, p. 671). Analyzing explores the distinguishing characteristics of the phenomenon and its connections and relation to other phenomena. An integral part of intuiting and analyzing is describing which focuses attention on the major characteristics of the phenomenon. Thus, this selective process culminates in an elaboration of the meaning of the elements and structure of the lived experience.

Secondly, investigating general essences occurs by examining particulars and reflecting on remembered experiences of the informants. These particulars are the

stepping stones in arriving at the general essences (Spiegelberg, 1960).

Third, apprehending essential relationships involves imaginative variation. This process has two operations: (1) omit certain components within each essence of the phenomenon, and (2) replace certain components with others. These activities will help determine what is not essential and can be omitted and what is compatible with the nature of the essences of the phenomenon and should be included. In this way, a deeper understanding of the fundamental meaning of the phenomenon can be achieved (Parse et al., 1985).

Fourth, watching modes of appearing involves looking at the way in which things appear. Spiegelberg (1960) used the example of a cube. The aspect or side of the cube that presents itself to the viewer is the side from which one knows the whole. From that perspective, the other sides are shaded and have different degrees of clarity and distinctness.

Fifth, exploring the constitution of phenomena in consciousness occurs through a process of integrating the unfamiliar with the familiar similar to the process of becoming acquainted with a strange hotel room or beginning to form the impression of a new acquaintance's personality (Spiegelberg, 1960).

Sixth, before even beginning, and throughout the interview and analysis of data, the researcher needs to recognize self-preconceptions and then suspend or "bracket" and set them aside. In this study, the awareness of bias was especially imperative, since the researcher is herself a mother of a child with asthma. Phenomenological reduction is done by suspending previous knowledge or experience through bracketing (Spiegelberg, 1960).

Finally, interpreting concealed meanings of phenomena is the intuitive leap necessary to go beyond what is given. These seven steps lead to the identification of structural descriptions of that phenomenon (Spiegelberg, 1960).

Summary

The domain of the study was stated as: what is the lived experience of mothers who have a child with asthma? Mothers over the age of 21 years, English speaking, and who have a child with asthma living at home with them were interviewed and constituted a purposive sample. The interviews were audiotape recorded and transcribed. The descriptions were analyzed using Spiegelberg's (1960) essentials. The essentials and the method used in the inductive analysis of the data included:

1. investigating particular phenomena;
2. investigating general essences;
3. apprehending essential relationships among
essences;
4. watching modes of appearing;
5. watching the constitution of phenomena in
consciousness;
6. suspending belief in the existence of the phenomena
(i.e., bracketing);
7. interpreting the meaning of phenomena. (p. 659)

Findings are reported in Chapter 4 and discussed in Chapter

5. Conclusions, implications, and recommendations for
further study also are included in Chapter 5.

CHAPTER 4

ANALYSIS OF DATA

A phenomenological approach was used to explore and describe the lived experience of mothers of children with asthma. Data were gathered using audiotaped interviews that were subsequently transcribed and analyzed. A description of the informants and study findings organized according to their thematic categories and supportive descriptive elements are presented.

Description of the Sample

Ten mothers related perceptions about the lived experience of having children with asthma. Informants ranged in age from 27 to 53 years with children from ages 19 months to 17 years. Three of the mothers had two children with asthma, and seven of the mothers had one child with asthma. All were Caucasian and married. Six were employed outside the home, three were self-described homemakers, and one helped with her husband's business. Most informants were college educated, with some informants having completed graduate work. Informant characteristics are described in Table 1.

Table 1

Demographic Characteristics of Informants (N = 10)

No.	Age	Ethnic- ity	Family		Educa- tion (Yrs.)	Occupation	Age of Child with Asthma (Years)		Child's Age at Diagnosis (Years)	
			Mari- tal Status	# of Chil- dren			#1	#2	#1	#2
1.	42	C	M	3	18	Psycho- therapist	14	-	7	-
2.	35	C	M	2	15	Homemaker	11	7	5	2
3.	40	C	M	2	16	Homemaker	7	4/6mos	6	3/6mos
4.	38	C	M	2	12	Works for Spouse	2	-	3	-
5.	35	C	M	3	18	Teacher	5	-	3	-
6.	31	C	M	2	17	Teacher	6	-	5/2mos	-
7.	36	C	M	2	16	Homemaker	7	-	4	-
8.	27	C	M	1	16	Teacher	1/7mos	-	0/7mos	-
9.	42	C	M	2	18	Adminis.	12	10	3	8
10.	53	C	M	2	15	Adminis.	17 ^a	-	5	-

^aAdopted as infant.

Findings

Eight mothers were initially interviewed regarding their experiences as mothers of children with asthma. Interviews were transcribed. As analysis progressed, two additional mothers were interviewed to permit the investigator to confirm conceptualizations derived from analyzing the earlier interviews.

From the informants' descriptive expressions obtained during the interviews, emerging themes were identified. Using Spiegelberg's (1960) analytical process, the task of identifying categories was done by conceptualizing the essence of the phenomenon from the expressive descriptions. A search for themes in the descriptions yielded categories of the lived experience which included the core category of uncertainty that was the innermost pervasive quality of the experience. Within uncertainty, the process categories of vigilance, searching for answers, taking charge, and finding a balance were identified. These categories emerged from the data as informants described a process oriented toward dealing with the uncertainty and finding a balance which promotes the normal experiences of childhood while taking the necessary precautions to maintain a sense of control. The categories are schematically represented in Figure 1.

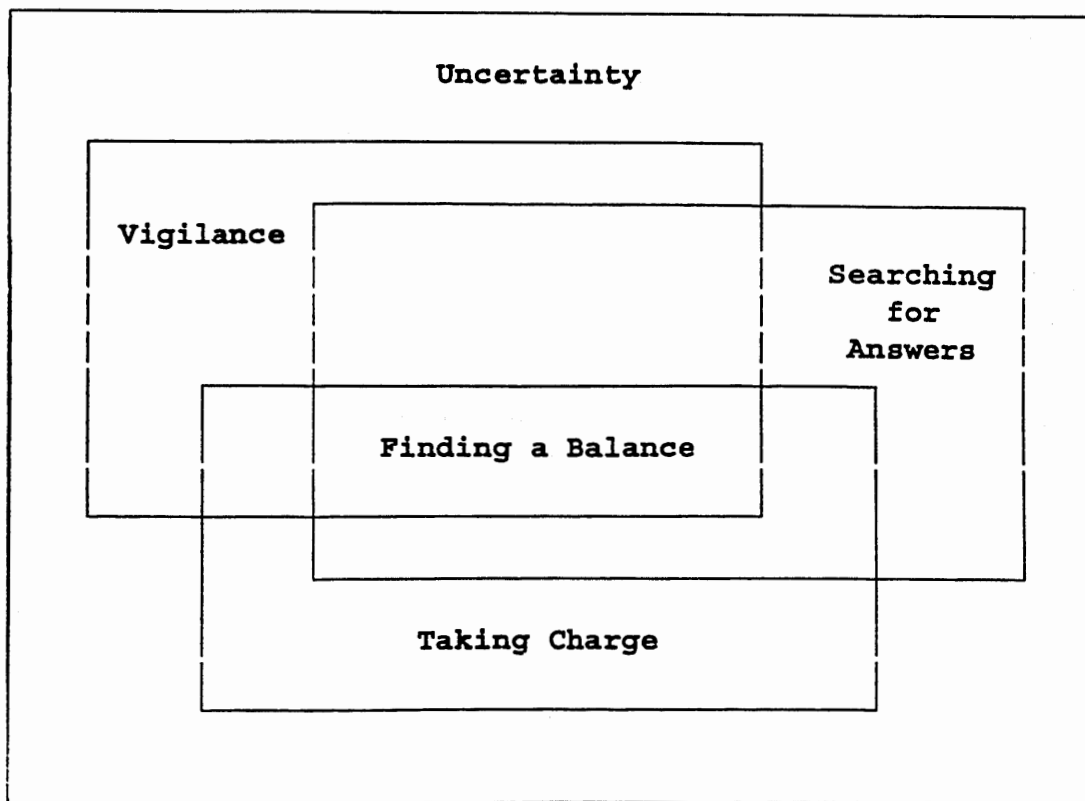


Figure 1. Schematic model of phenomenon

Categories were comprised of descriptive elements clustered from a common theme. Each category, representing a single theme, is presented with the descriptive elements derived from the interviews. The descriptive elements were derived through contemplative dwelling with the data (Table 2). Identification of these elements resulted from commonalities in the descriptions given by the informants. Conceptual descriptions for each category are presented in the language of the researcher in Table 3. The descriptions attempt to capture the essence of the described experiences.

Table 2

Categories within the Phenomenon: Descriptive Elements

Category	Descriptive Elements
<u>Core Category</u>	
Uncertainty	<ol style="list-style-type: none"> 1. Ambiguous symptoms 2. Lack of predictability 3. Lack of information 4. Complex treatments
<u>Process Categories</u>	
Vigilance	<ol style="list-style-type: none"> 1. A different kind of listening 2. A life on hold 3. Avoiding the hospital
Searching for Answers	<ol style="list-style-type: none"> 1. Frustrating encounters 2. Naming it 3. Networking
Taking Charge	<ol style="list-style-type: none"> 1. The final straw 2. Finding her voice 3. Establishing a partnership 4. Advocacy
Finding a Balance	<ol style="list-style-type: none"> 1. Acknowledging the differences 2. Varying routines 3. Packing the drugstore 4. A sense of control 5. Keeping up

The discussion of the findings follows the schematic model with the model serving as an organizing framework to clarify the discussion of the described experiences. However, the model is not meant to provide a theoretical

Table 3

Conceptual Descriptions of Categories

Category	Conceptual Description
<u>Core Category</u>	
Uncertainty	A state of enhanced vulnerability without predictability or control over events or outcomes
<u>Process Categories</u>	
Vigilance	Act of cautious monitoring
Searching for Answers	A quest for answers, support, and resources
Taking Charge	Process of becoming assertive to effect change
Finding a Balance	Promoting the normal experiences of childhood while taking the necessary precautions

explanation of the experience or imply a static experience easily categorized. Rather than a linear process of stages that are mastered, the lived experience of mothers of children with asthma is an emerging process. Vigilance, searching for answers, taking charge and finding a balance are interactive processes that emerge and re/emerge throughout the experience. The unfolding of the phenomenon

as humanly experienced by the informants is presented using the related descriptions that weave their personal stories.

Uncertainty

The underlying core category in the descriptions of the informants was that of uncertainty in illness. For the mothers, the experience of uncertainty was pervasive. Anxiety, fear, and worry accompanied the mothers' attempts to manage unfamiliar, incongruent events. Disruption to normal family functioning was profound. Uncertainty was reduced after the mothers developed an understanding of the signs, symptoms, and treatment of asthma. However, due to the unpredictability of the disease and the complexity of treatment, uncertainty remained throughout the experience.

For the informants, knowing what was wrong with their children was preferable to not knowing, but for most mothers the process of arriving at any degree of certainty was lengthy and agonizing. Elements descriptive of the category were: (1) ambiguous symptoms, (2) lack of predictability, (3) lack of information, and (4) complexity of treatments.

Ambiguous Symptoms

The first element, ambiguous symptoms, caused the mothers to struggle in their attempts to make sense of their children's illnesses. Rashes, ear infections, allergies,

coughs, and runny noses were the norm for most of the children long before the diagnosis of asthma. The ambiguous and inconsistent presentation of symptoms necessitated many visits to the health care providers. All of the mothers talked about each illness being treated as an isolated episode initially, and only later did a pattern become apparent. This descriptive element was exemplified by two mothers in the following statements:

Other kids would have a runny nose for a day or two and be fine. And no one understood that my son would get so much sicker, so much longer. They thought I was overprotective. He'd go to school for two days and be sick for 3 weeks. It was a constant cycle. We went from crisis to crisis. It was a nightmare.

My experience mostly was with sick children and not knowing what was wrong with them. For several years, my oldest son always got coughs that would not go away . . . used every cough medicine and then the neb. He (physician) never used the word asthma.

In some cases, when the children would be struggling to breathe at night, but have improved by the morning, the mothers began to doubt their own judgment. The nocturnal nature of asthma seemed to work against the mothers' credibility, for one informant recounted:

It always happens in the middle of the night and by the time I bring him to the doctor's (the next day), I think the doctor thinks I'm lying to him because he's not even wheezing or he can just hear a little bit of a wheeze, and I just said, "You need to come home with me, I wish you were there at night when we need you." Because I don't think he really understands.

Mothers found asthma to be a subtle, and hidden disease; even family members and some health care providers were often inclined to discount the mothers' concerns. Two mothers described such episodes:

The doctor said "Don't baby her. You're being over-protective. She's not wheezing" She was using her inhaler every 15 minutes Same day, took her to another doctor and he admitted her to the hospital.

His first Christmas Eve, I took him to the doctor. My husband told me I was nuts. There was nothing wrong with him. Don't you love it (laughs). She (the doctor) prescribes all this medicine and says, "Now you need to make sure you listen to him at night, or sleep with him, cause he could stop breathing."

Those were commonplace instructions given to the mothers, and none of them ever questioned if children who could stop breathing during the night were well enough to go home.

Another informant felt confused by the contradictory and ambiguous messages she was getting. Her child was ill enough to be hospitalized and yet, the informant stated:

I did not realize what a serious problem she had. I felt it inside, but I was made to feel like it was no big deal, she'll outgrow it, but you get such conflicting messages because there you are twice in the hospital.

Lack of Predictability

The mothers struggled with the anxiety of never knowing when, where, or why an asthma episode might occur. One informant articulated:

. . . never knowing when it's going to start up, that it could be any day. Is this just a typical runny nose, and cough, or is this going to develop into another trip to the hospital? And when might it hit?

Night time caused the most concern, as another mother expressed in the following statement:

You pretty much don't know what's going to happen. One day he could be fine and then . . . in fact, this happened recently, we put him to bed and he was fine and in the middle of the night he just couldn't breathe. . .

The unpredictability of asthma episodes was a concern that never completely went away. This descriptive element was exemplified by the following statements from three mothers:

I don't want to get to the point where I'm too confident, because something could happen at any moment . . . I'm just scared . . . it'll catch us off guard. The next time it gets out of control, she may not be under my care anymore.

I know I can control the treatment a lot better, but I still can't control when it's going to happen or how bad it's going to be.

I even wonder about when he's older, a lot . . . I read about these adults that die from asthma.

Mothers struggled with their inability to determine the severity of each episode. A mother recounted that in the beginning she thought she was going crazy:

. . . because of just worrying so much, and going through so many periods of thinking your child was going to die in the night, and not make it, and not knowing what to do, and you know the only thing you had to desperately hang on to was what the doctor was telling you to do, and that wasn't enough.

Uncertainty and fear would often persist throughout the night as mothers attempted to discern the severity, and one mother shared a common experience:

We're always at the point where should we take him to the emergency room? But by the time, it's like okay, one more breathing treatment, after this one, if he's not doing better . . . we're taking him in. Well, it always happens, because it's getting lighter in the morning and he starts doing better . . .

The unpredictability of timing and severity was a source of anxiety to all the mothers. An informant spoke of the worry being "paralyzing" as she described this experience:

There is nothing more frightening than trying to get to a hospital or doctor's office with a child who can't breath in the back seat and then not knowing when that will happen again.

Lack of Information

The lack of information about diagnosis and severity was a major frustration for the informants. The mothers knew that they had sick children, but in the beginning they knew little else. Most mothers experienced lengthy diagnosis delays which increased their level of anxiety as expressed by these two informants:

Not knowing what I was dealing with, that's what I was dealing with . . . I thought I was going crazy, I thought I was losing my mind.

She was not a well child for two years. It was constant visits to the doctor . . . it was just very frustrating. Feeling completely in the dark, not

knowing what questions to ask . . . What should I be looking for? What should this child be doing?

In the beginning, even if allergies were recognized, it all seemed nebulous. No clear instructions were given, other than possibly to keep the children away from dust, and begin medication when coughing started. One mother described:

. . . years of hearing this cough in the middle of the night, staying up with her all night, trying to get her to have this theophylline, which she despised, and calling the doctor. Asthma was not either explained or mentioned specifically. It was allergies. We didn't go beyond that.

The mothers found that they lacked knowledge, not only regarding what was wrong with their children, but also regarding the medications being used to treat their children. The following exemplar describes this experience:

It was absolutely, such, just totally, just teeth gritting, hair pulling frustrating to not know, what am I'm dealing with? I'm giving this child this medication, I don't know what it's doing to her, but it's making her crazy . . . I had all these medications and I didn't know what I was doing with them. I didn't know what to look for. I didn't know when should I see her getting better, when should this medicine take effect . . . I still wasn't linking it to asthma. That word was never said to me and I was just kind of going along in a fog . . .

The informants were trying to understand. One of the mothers described that time as "living at the doctors." The mothers were coping the best way they knew, by taking their sick children to their health care providers.

Complex Treatments--Making a Contract with the Devil

The informants often found themselves confused and ambivalent regarding the medications used to treat asthma. There was not a simple one-size fits all prescription. Treatment needed to be individualized, for what was effective for one child with asthma did not necessarily work for another child with asthma. Also, mothers found that the treatment that was effective in the past was not necessarily effective for that same child during the next episode. One mother described this quandary:

One minute you feel like you know everything, and the next minute, I guess when you're trying everything and nothing seems like it's working...

Some of the mothers found the complexity, and uncertainty of treatment especially difficult when the health care providers gave them responsibility for treatment options. The mothers worried about the risk-benefit ratio and attempted to balance the benefit against the risk of serious side effects. This was not an easy balancing act. An informant stated:

I'm not a doctor and I don't know. But sometimes that is a pressure, did I make the right call? Should I give him .75 or is .5 going to be enough to get him through the night. She (the physician) gives us play with him because she feels like we can see it and we know. We try . . . if it's ever the wrong call, I feel it would be a real problem.

Although the mothers readily admitted that their children

needed the medications to breathe, the side-effects of the medications worried the informants. As two mothers described:

I'm always terrified of giving him steroids and, they (the physicians) told me that I should be thrilled that there are steroids.

Another major concern of ours is the steroid use. That is a real, real concern of ours . . . we read about what steroids can do . . . but I'm afraid . . . Are we curing his asthma to give cancer?

While the long term effects of steroids were usually the biggest concern, the immediate side effects of some of the other medications were extremely troubling. In the beginning, the mothers had a difficult time distinguishing whether the behavior of their children was a result of the asthma, medication side effects, a phase, or just plain misbehavior, as voiced by two mothers.

It's one thing for your child to be sick, but it's another thing when the medication that's supposed to help him is making him worse. He didn't know if he was coming or going. He was like an entirely different child, and it was so hard, because I'd try everything to get him to sleep.

We went through years of just trying to figure out the right amounts that he was to take . . . so he didn't have a lot of side effects.

To further complicate the issue, even when the children were doing well, the mothers usually had them on maintenance medications and had a love-hate relationship with the treatment. A mother described the experience:

I've always had the philosophy to only put my kids on drugs if they absolutely need it. And it was very, very hard to keep my older daughter on Slobid knowing that it affected her handwriting and gave her stomachaches all the time, gave her headaches all the time, make her hyper all the time, but yet still knowing that she had to be on it because of, if we took her off of it she would start wheezing. I mean it's like you're making a contract with the devil or something (laughs) almost.....

Vigilance

Vigilance was the first process category identified within the described experience. Informants described a process of listening for cues, checking on the children, having their lives consumed by monitoring their children for symptoms, doing round-the-clock treatments, and in some cases, being super-vigilant to avoid emergency department visits or hospital stays. Siblings became resentful, and relationships with spouses became strained. The degree of vigilance was related to the degree of uncertainty. Vigilance intensified when a child was ill and decreased when the child was well, but it was a constant throughout the experience. The descriptive elements of vigilance included: a different kind of listening, a life on hold, and avoiding the hospital.

A Different Kind of Listening

As the mothers learned the cues of an approaching asthma episode, they found themselves listening in a special

way to their children with asthma. One mother called it "the cough you hear three floors away." Other exemplars voiced by three mothers included:

When I hear him coughing, that's when I'll ask him are you okay? That's usually the sign that it is kicking in....

. . . he coughs, I shake. That's your first sign (cries).

His kind of asthma starts with a cough and then will build from there to the wheezing and shortness of breath, and you have to be really in tune.

The mothers expressed concern about being alert to the earliest warning signs, so they could start treatment as soon as possible. Since the episodes frequently started in the middle of the night, a mother expressed this common experience:

I could not come to bed at the end of the day without going upstairs and checking on the kids first to make sure that they were breathing or still alive or you know something like that. I couldn't do it. I could not even turn the intercom off at night . . . it's gotten a lot better....

A Life on Hold

Initially, the high degree of uncertainty regarding predictability, and severity, and the complex treatment regimens severely restricted and disrupted family relationships and any social life the informants might plan. Even when the mothers gained knowledge and competency in managing asthma, life could still be put on hold to monitor

a sick children, especially if they weren't responding according to plan. When uncertainty was high, mothers managed their fear, worry, and anxiety through vigilance to the exclusion of all else. The mothers felt a need to stay home, and monitor their children's condition, and often administer breathing treatments every few hours. Exemplars from three informants were:

In the beginning during those two years, we were very restricted because she was sick all the time.

Now there has been a number of times where we have planned an evening out, where we have canceled it, and not gone, because they have been sick, or come down with something . . . it limits you going, and being out as a couple.

I would never let a sitter administer medication. So, if we go out it's around the medicine schedule.

It was not unusual for the asthma, the medication, or the side effects to keep the mothers awake for much of the night, as noted in the following exemplars voiced by three mothers:

It's worse than having a newborn baby, because not only are you monitoring, you've got to be awake enough to put the medication in. You'd have to be alert while you're doing it, and you're exhausted, but yet you're trying to stay up....

It's just like I wake up to listen, see if I hear him. I'm not a sound sleeper anymore at all....

So we spent about two months on liquid ventolin, where we didn't sleep at night at all . . . and my husband and I were both working full time and getting maybe a hour or so sleep at night, and having to take care of a sick baby on top of it.

While mothers tried to tell their other children that they were "lucky" not to have asthma, the mothers perceived that the healthy siblings frequently felt resentful. One mother described the typical affect on sibling relationships:

. . . there's always been a little bit of jealousy there, because . . . he has told us that his brother always gets so much attention....

The marital relationship often showed the strain of the mother's increased focus on the child with asthma. One mother reported having been in couples counseling for problems that she felt were exacerbated by having a child with asthma. Another mother described the first year of having a child with asthma:

Last year was so difficult and traumatic, and even though my husband was really good it was a really big strain on our relationship and we're kind of trying to rebuild the relationship. Cause when you have a child between you in bed....

When the asthma was really uncontrolled, mothers talked about being consumed with the care of this child. Four informants expressed common feelings:

The days to me were a fog. It took me a while to clue in to what was going on. You know it's hard....

I just think of a black fog, I was just so worried about it. I couldn't even think or . . . wasn't even conscious of anything else in my life except that....

I felt depleted, exhausted, my needs weren't being met. I felt like a cabbage....

I look back and think, why didn't I do anything . . . you just don't think it can get any better...

A shift in relationships and roles was described. Most of the mothers were primary caretakers of their children and this was a fairly common sentiment:

I always end up having to deal with the sick things. I'm the healer. My husband just can't deal with it. I mean he tries, but it's me who has to be all strong. You end up taking care of the husband as another child, and you find yourself protecting the husband from dealing with certain aspects of the disease. You end up making the medical decisions it was my responsibility, my burden....

Some of the mothers viewed themselves as more competent in caring for the child and only recently started feeling comfortable enough to relinquish some of the control to their spouses. Even the few mothers, who had spouses who shared in child care, found themselves to be the primary communicators with the health care providers and schools.

Avoiding the Hospital

Many of the informants had negative experiences in hospitals, and even those who had not, preferred caring for their children at home. To avoid emergency department visits or hospitalizations, mothers were willing to be hyper vigilant which meant round-the-clock monitoring of symptoms, administering breathing treatments, and doing whatever it took to keep their children out of the hospital. Exhaustion was to be disregarded. One mother described the experience whenever her child started getting sick:

I don't sleep. I will stay up and listen to him breathe . . . when he's really bad . . . I can put him on the machine every two hours, and that is what has kept him out of the hospital . . . and I will put him on steroids if he is not responding to the machine.

Asthma is an expensive illness, and for some of the mothers, finances were a consideration in treatment options, and their anxiety increased about whether they were making the right decisions. This anxiety is apparent in the following mother's comment when the family was without insurance:

Financial strain is really difficult knowing what's the right thing to do. He really had a bad time in the middle of the night when he couldn't breathe and we didn't have any money or insurance cause my husband was laid off. So we did all those things (the doctor had told us last year), and we made it through the night, but by morning I was so scared, I should have taken him to the hospital. I know I'll never do that again.

Another mother who had to work to have the little insurance they did have, found that the unreimbursable expenses were exorbitant. Her insurance wouldn't cover hospitalization and she described that experience:

In August his medication alone was \$1,500..... Last week I spent \$250, when he gets that sick, he's on his nebulizer every hour through the night with the decadron and everything. And that's how she (the physician) keeps him out of the hospital..... So since December it's been in excess of \$8,000 (out of our pocket) so it's frustrating from that aspect, because like how much longer can we keep going at this rate? But we don't have a choice, so what can we do.....

Searching for Answers

The third category identified searching for answers as a quests for answers, a diagnosis, emotional support, and resources. Initially, because of their unfamiliarity and inexperience, mothers looked to external sources of information and accepted as true whatever the physicians told them. However, as time progressed, most of the health care encounters only increased the mothers' uncertainty. The categorical elements included frustrating encounters, naming it, and networking.

Frustrating encounters

In the mothers' attempts to discover what was wrong with their children and how to treat them, they first looked to their health care providers for the answers. Concerns were negated. Questions went unanswered, and a diagnosis was not forthcoming. Initially, the mothers experienced a great deal of frustration in their dealings with health care professionals. Four mothers expressed these feelings in the following exemplars:

She (the physician) wouldn't listen to me . . . I kind of get the impression that she doesn't think your opinion counts.

I felt like we were a number, and that he (the physician) really wasn't taking the interest in my child that he should have. I think that's why he

didn't realize what was wrong. I mean, my child would get so sick.

One doctor told me . . . there was nothing wrong with him and I should not keep bringing him in for these minor little things....

The pediatrician's response was "oh, don't bring her in" which tends to make you feel like it's not that big a deal, don't worry about it, you know, you're overreacting....

One mother talked about how she thought women were afraid of being called over protective, of offending physicians, and they wouldn't want to see them. Initially, when the mothers' concerns were minimized or negated, many of the mothers lost both confidence in themselves and any sense of control. Their children's illness had no meaning for the mothers who were receiving crisis episodic care with little preventive focus. Instead of decreasing the uncertainty, the health care providers were increasing it. One mother gave a metaphorical description:

It was like riding in the back of a truck over a bumpy road and a winding road and you didn't know what turn was coming up.

Naming It

All of the mothers were told at one time or another that their children had reactive airway disease (RAD), which meant nothing to them. Only two of the mothers received the diagnosis of asthma within the first few months of the first episode. Both of them asked directly if their children had

asthma. One of these mothers had a child with very severe asthma and a physician who was very available to her and open with her about the life threatening aspect of his condition. The other mother had asthma herself and recognized the symptoms, although she still had unanswered questions after the diagnosis. The rest of the mothers struggled for years without really knowing what was wrong with their children. When they did get the diagnosis, it was met with a mixture of guilt, sorrow, and relief. The mothers were relieved to know what was wrong and that it was not worse. Some mothers had worried about their children having cystic fibrosis. Some of the mothers felt guilty, especially if they had had childhood asthma. Most of the mothers reported experiencing grief, but not as much at diagnosis as they did later throughout the course of the experience. At different times, losses would be experienced when the children's activities had to be limited because of asthma. The following exemplars reflect four mothers' immediate experience of receiving the diagnosis:

I think I knew, but I was hoping that wasn't what they were going to tell me. Yet, I was relieved in a sense because, I didn't know what was wrong with him.

I wasn't surprised because I knew it had to be something like that, but after they diagnosed it as asthma, and I learned what to do, and how to take care of it, it was a relief. And at the same time, (it) made me sad because I didn't want her to have it, because I knew her dad couldn't admit that she had asthma. He wouldn't admit that....

I wasn't happy he had asthma . . . I guess I kind of blamed myself for a while that he had asthma. Especially, when he'd get really sick.

And then having asthma myself, I felt a little bit guilty.

One mother anticipated the diagnosis, but not the explanation, and related this experience:

It wasn't a shock . . . I asked him (the physician), "Do my children have asthma?" At that point, I must have known and I wanted clarification from him. I wanted a diagnosis . . . It was a shock when he told me that asthma was caused by a mother's smothering a child with overprotection of her love . . . I came home and cried for the better part of the day, because I felt extremely guilty that I had somehow caused this....

This informant received reassurance from her husband and most friends that she was not responsible for her children's asthma. But, from time to time, others still alluded to the cause being emotional, and she felt guilty. While only one mother was told directly by a health care provider that the asthma was due to "smother love," all the mothers referred to their fear of being considered over protective or neurotic by family, health care providers, or friends. Fortunately, this mother confided in a friend and was given this advice:

I shared it ("smother love" concept) with a friend of mine who has asthma herself, and of course, she told me that it was ridiculous, and not to listen to it, and that I needed to start finding out about asthma. So I did, I started reading.

For all of the mothers, the diagnosis of asthma was important in their attempt to deal with it. Two mothers explained what it meant to them:

I said to her (physician) "Isn't it asthma"? And that's when she said "yes that's what it is but we call it RAD". I guess it just made it clearer to me what I was having to deal with. Probably made more sense to me . . . I guess it did make a difference.

But once we got a label, a name for what was wrong, and we were told it's not going to go away tomorrow, everything became a little bit easier. I was able to get information, but up to that point in time--it was just grasping at straws....

While the diagnosis was an important step, giving it a name did not confer instant knowledge and understanding. The mothers found there was a difference between the first time they heard asthma mentioned, and when they finally understood the meaning of having children with asthma. But for most of the mothers, giving it a name at least gave them a place to start.

Networking

The informants started talking to others about their experiences in an attempt to learn more and gain support. Many mothers felt very isolated going through this experience. Often the most frightening time for the mothers was in the middle of the night. One mother expressed those feelings in the following way:

Even with a totally supportive family and husband, like I feel I have, you're still alone. I don't know

whether it's fear. There's just this bond with your child. You want it to be okay. There is something about a child not being able to breathe that's probably the worst thing you can ever go through. Pain while it's terrible, you can comfort; you can get them to think about other things. Not being able to breathe is so basic and it's hard not to panic yourself. I think the feeling of aloneness would come no matter what. It has with me.

Informants were not all fortunate enough to receive support from their spouses in the beginning. Most of the spouses were not as available to the mothers as could have been hoped, either because they travelled or distanced themselves as a way of coping. Since the majority of mothers were the primary caretakers, getting up at night with their sick children, the fathers did not always see the severity of the episodes. Especially in the beginning and shortly after the diagnosis, many mothers experienced what these two mothers described:

My husband didn't know what asthma was either. He thought that I was just worrying too much and being paranoid, so he was denying it . . . I felt like I was on my own totally.

My husband early on, I'd say was in denial . . . He didn't realize the intense severity, the life-threatening aspect of it until he saw how hunched over our child would get . . . unable to breathe . . . my husband was like freaked out.

In an attempt to find support, some of the informants did turn to family, but the response was very mixed. Many mothers found that their extended family (even when there was a family history of asthma) were not comfortable

acknowledging the severity of the episodes or dealing with the complexity of the breathing treatments. Most of the mothers did talk to their families about what was happening, and the rarely mentioned family history of respiratory problems, and sometimes deaths, started to be revealed. Even mothers who in their own childhood had asthma themselves seemed at little or no advantage in understanding how to care for their children.

I think in the beginning, I wanted reassurance that my baby would be okay. I feel like I was running blind not knowing what I was doing. Not necessarily having asthma does it make it easier when it's your child . . . I was a first time mom and so to me it was just like a nightmare come true. The last thing you want is for your child to get sick. I spent a lot of time with my mom looking for support, looking for advice, what should I do.

One mother, whose parents were unsupportive, found support from other family members:

It was a lot of sharing, networking with my sister-in-law, my sis, by this point there were other children in the family that were going through it. Anytime something would show up in the newspapers, or health magazines . . . just sharing that information. My sister went to a support group, when her child was diagnosed with it . . . that's when it really started coming together.

Having a diagnosis made it easier for the mothers to find meaning in their experience. Sharing experiences and information, whether it was done informally, or in a support group seemed to give the mothers much needed reassurance and information, as noted by three mothers' exemplars:

I don't have any friends with children with asthma, so that's what was neat about the support group, and when you hear you're not alone, and there are other children worse off than yours, and they're handling it....

I needed to hear that there were other moms going through it, and it was okay that they were getting through it fine . . . they were playing soccer and going to school. I guess I needed to hear those things to reassure myself that we were going to make it through it.

The school nurse gave me the flyer on the support group. That's how I found out about that and from there I got names of books and names of people and began a self-education process. Um, my doctor still didn't seem to think that there was anything else I needed to know about it....

The mothers' quest for answers, outside of the health care arena, seemed to be fueled by feelings of frustration that their children were not getting any better and their questions were left unanswered. As the mothers started looking for support and answers, they found allies in school nurses, pharmacists, friends who happened to be respiratory therapists or working for pharmaceutical companies, as well as acquaintances who had children with asthma and knew of resources (i.e., newsletters and books). This mother described the importance of a book:

Dr. Plaut (author of Children with Asthma: A Manual for Parents) and I visited many nights together, I'm talking about the book. (laughs) that book, those books were probably the most comforting thing because I just read those books over and over . . . it was just me. I didn't know anybody with asthma.

Another mother was given the name and address of a non-profit organization called Mothers of Asthmatics and

wrote away for their newsletter.

It was through the MA Report that I learned about preventive medications, spacers, peak flow meters, and nebulizers. Because up to that point, I didn't know you could have a nebulizer at home and I didn't know about preventive medications.

Networking opened their eyes, and they began to understand the meaning of having and caring for a child with asthma. Networking offered them support and information and, in many instances, material assistance as well. Many of the mothers mentioned how fortunate they felt that someone had given an extra nebulizer to the school so the children with asthma at school did not have to bring their own nebulizers back and forth every day.

Many times networking was started as the mothers tried to make sense of their experience and equipped them to ask their physician if their children had asthma. One mother related:

I started reading about asthma knowing in the back of my mind that's what it was, but that's what we weren't calling it. And then I knew what to start asking for.

For some, a diagnosis and hospitalization galvanized their process of self-education as these two mothers described it:

We came home from the hospital, threw everything in the door and headed straight for Bookstop and bought everything I could find on asthma. I read in the bibliographies any of the suggested publications. I subscribed to MA, Aircurrents, I got the 800 number for National Jewish Hospital. I was on the phone to them if I had any questions, or anything I didn't really understand.

We just during that few weeks time period we read everything we could get our hands on and you know opened our ears to everything about asthma.

One mother expressed what seemed to be the common experience:

It was networking that really got me where I was. That was the key, in conjunction at the same time getting linked up with a good pediatrician and a good allergist. But the networking, mothers saying "this is how I deal with it, this is what I look for, this is what I do when this comes up." So it just all happened to fall in place at the same time.

Another mother expressed some anger, that she had at this point:

I've made a lot of progress but I think I have a little bit of anger, resentment there because I've had to do it. No one said this is what you need to do . . . I had to go to each place . . . and then I was given a lot of support and information at each of those places (ALA, other non profits) but . . . I had to do the footwork . . . I think it could have been different . . . that stuff could be at the doctor's office. . . . He doesn't have any kind of handouts on asthma, and yet he's got a whole room full of rental nebulizers.

When well-meaning friends made comparisons of the informants' children to children with mild asthma who outgrew it, the comparisons were perceived as unhelpful. While most mothers viewed school nurses as supportive, only one mother reported recognizing other nurses as knowledgeable and supportive, and that was only if she could get them to have a little patience and talk to her.

Taking Charge

Taking charge was the process of becoming assertive to effect change. Initially, all mothers were passive recipients of care who relied on their health care providers to be the ultimate experts and make sound decisions. Through questioning, the mothers had gained knowledge, gathered support, and resources, and gained confidence in their intuitive feeling that their children "just weren't getting any better." As frustrating health care encounters multiplied and concerns were ignored, the mother became assertive in meeting their needs. The descriptive elements included: the final straw, making their voices heard, establishing a partnership, and advocacy.

The Final Straw

After a time, the realization that their children were not getting better was impossible to avoid. For almost every mother there seemed to be a demarcation or defining moment when it was the "final straw" or they just realized they needed to be assertive and persist in finding the best care for their children. For some mothers, hospitalizations caused them to rethink how they were managing:

When I don't know what I'm dealing with, I've lost control of the situation . . . and I need to see someone else because as much as I'm trusting my doctors, I'm not that trusting. I'm not going to be an outside observer and totally put myself, my child's life in their hands, which is what I did for those

three hospital visits....

Another mother decided after the first hospitalization, that she had to make some changes.

I made a vow to myself, if she came out of this . . . I'm not going to let her go through this again. I'm not going to let any physician talk down to me any more. I'm going to find out all I can about this illness . . . From the first hospitalization on, I became much more aggressive. It just wasn't going to happen anymore.

Many of the mothers remember just reflecting, "my child's not getting any better" and the combination of frustration, loss of faith in the health care provider, and increasing self-confidence seemed to fuel this shift of control. For some mothers it meant doctor-shopping. One mother described her frustration:

Finally, I got so fed up, I could not face another year of viruses, and sickness and ear infections and I couldn't do it anymore. I had also learned in the MA Report about asthma specialists . . . I found one . . . and I called him up and I interviewed him.....

For some of the mothers, the "final straw" was intolerable medication side effects, as two mothers described it:

They wouldn't listen to me, which was frustrating because I was the only one who knew what was going on . . . I guess I was just at wits end, I knew he could no longer take that medication. It was horrible for him . . . for two months he hadn't slept normally. I just finally had to be strong and say we can no longer do this.

I made the final decision to see a specialist to . . . get the medication straight.

Finding Her Voice

As the mothers doctor shopped and networked, they found the people who would listen to them and help them. At the same time, a transformation occurred as the mothers became people who would insist on being heard. Not all the dialogues were positive, but their persistence got the mothers the attention they desired. One mother related a conversation with her child's physician:

You are not going to come in here for two minutes and send me out to the pharmacy. You can sit here, I want you to really check my child and listen to me about what I'm going through..... I want you to talk to me about this medicine.....

Another mother expressed a common view:

I've realized that if I don't stand up and ask these questions, nobody else will . . . And so many people are afraid or intimidated, by doctors . . . but you're the one who has to live with it day to day and if they make a decision and you either don't agree with or don't understand it. You're stuck. You're the one who has to live with it. They're not the ones who are sitting in your house doling out the medicine, making the choices and doing all these things.

Anger was apparent in almost every interview. The anger was stemming from frustration. Learning to manage asthma had been such a difficult journey, and most of the mothers felt it could have been made easier by health care providers who had just listened and given them some answers. These mothers expressed some of that anger, as explicated by one mother:

I had a voice . . . that's what asthma taught me; that these doctors were human too and I had rights. They

had knowledge, but sometimes I had to jerk their choke collars to get the knowledge out of them and get them to pay attention to me.

Establishing a Partnership

Achieving control was facilitated by finding health care providers who would listen, acknowledge concerns, and include the mothers in the health care decision-making process. The mothers usually doctor shopped until they were able to establish a partnership. Some mothers talked about finding someone they "connected with" or it finally "clicked." The seeds for participatory competence were planted. Three mothers described the experience:

I felt listened to, I could ask questions, and not feel stupid about it. He'd give me honest answers. I felt in control. I felt I had a say. I knew where things were leading....

He (MD) will admit, "you understand her better than I do . . . you get in touch with me or one of my partners at any time." I felt like I had a life line. I could get in touch with somebody who believed . . . I'm as much a part of the management team as he is.

"If you have a concern, you bring them in." Questions were answered before I could even ask them. There was a lot of guidance and instruction given.

The mother, who initially had used the metaphor of being in the back of a truck on a winding road, now felt "in the driver's seat with the allergist." Most of the mothers felt that asthma was now "manageable" since they were working in a collaborative relationship with their health care providers. The mothers' feelings were validated

and they spoke in terms of goals and plans for their children, as voiced by two mothers:

We started our mutual goal to keep him out of the hospital and keep him from having emergency type office visits and in the past year we have met that objective . . . through working together Before it was more like well, you've finished your hospital stay, finish this medicine and we'll see you next time.

He was very accessible to me, very communicative, very knowledgeable and emphasized wellness asthma checks. He validated my feelings . . . I have a plan.

Through networking and reading about asthma, most of the mothers had learned about new procedures, or treatments that would benefit their children. Although the mothers were not all in equally collaborative relationships, they had learned ways to initiate discussions to effect change. The following are exemplars from two mothers:

I talked to his doctor about using intal, and she said "fine."

I said, "Now, I read about this peak flow meter" She said "Oh yeah that would help you, here's one." So, a lot of the things I had, I had to ask for in the beginning.....

One mother now faxes peak flow charts to her child's physician so he can review them prior to the appointment. Time is not wasted, and the discussion of plan can start promptly with the visit.

Advocacy

All of the mothers felt compelled to speak on behalf of their children, and this need extended beyond just being a

voice for the children with the health care provider. The mothers advocated at the schools, so the best interests of their children would be taken into consideration. Often the mothers' concern reached beyond that of caring just for their individual children; they gave yearly asthma presentations for the teachers. One mother's approach was very direct:

I said, "Whatever you don't know, I will teach you (the school nurse)." And a bunch of us got together and bought a nebulizer for the school. It now belongs to the school, and she works very well with us.

After having gained a great deal of information, many informants found themselves counseling friends who had children with asthma. The following exemplars from two mothers describe the experience:

I strongly urge them to get Plaut's book, Children with Asthma, and any other information they can get and read it. I tell them, "You cannot ask an intelligent question . . . unless you know what questions you need to ask."

I tell a lot of moms, "It's worth the effort to find a physician you can connect with," but I think when you're going through the treadmill, you don't think it can be any different.

When the mothers went beyond an individual level of advocacy, anger seemed to fuel that transition, as these two mothers described:

I turned my anger and frustration into making sure that others in my community did not have to go through what I went through. I became a center for what I needed that wasn't there.

I would do something to make sure other mothers wouldn't have to go through this . . . four and a half years of confused state . . . (never) being referred on to other physicians, books, anybody talking to me . . . There was a lot of anger at that point . . . It was really only incompetence and misguidance that landed her in the hospital.

Finding a Balance

Vigilance, searching for answers, and taking charge interact continuously and form the foundation upon which mothers strive to find a balance within the uncertainty that accompanies having a child with asthma. Mothers tried to achieve a balance which promoted the normal experiences of childhood while taking the necessary precautions. Finding a balance was a process that was delayed until diagnosis was made and the necessary knowledge and competence had been gained for asthma to be considered manageable. At that point, the situation was viewed as more of a challenge and less of a threat. Due to the chronic episodic nature of asthma, routines had to be flexible and based on the day-to-day condition of their children. The categorical elements included: acknowledging the differences, varying routines, packing the drugstore, a sense of control, and keeping up.

Acknowledging the Differences

The informants were well aware that their children looked and acted normally, but when exposed to certain

triggers, the children could become seriously ill very quickly. These limitations were losses quietly grieved by the mothers. One mother described the experience:

We're real fortunate when we find friends that don't have dogs and cats inside their homes . . . Naturally I'm the mom who has all the kids at my house all the time, which is fine with me but, the child likes to go other places too.

He spends the night I will usually ask him just take your sprays, take your medicine along with you, just in case.....

The informants did not try to hide their children's asthma from others, who might be in a position to care for their children, even if it limited their activities, as exemplified by one mother.

A lot of his friends' parents are concerned to take him, because when they take him places, you have to take a bag of medicine . . . I don't think he gets as many invitations to go overnight or on all day activities as he would if people didn't know he was sick.

The mothers made every effort to minimize the restrictions in their children's lives. One mother gave an example of how she dealt with her son's allergies:

I learned years ago to send him his little cookies, or I would go make a white cake, send cupcakes for himself, or send a few for anybody else that didn't want chocolate. I mean you just deal with that, same thing at school.

Varying Routines

The mothers lived with uncertainty, but a way of feeling a sense of control was to develop routines. One

mother described that developmental process:

It's hard at first, I had to keep a schedule, and write down the times, and check it off, and I felt like all I did was give medicine, but once you get use to it, it gets a little bit easier. It just becomes part of your routine . . . we've adjusted some of the medicines . . . you make those adjustments to keep from having to spend your whole life doing medicine.

Two other mothers, as they described their days, seemed to find comfort in the regular aspect of the routine.

. . . the daily ritual is in the morning he gets on his nebulizer with his Intal, one bottle of Intal and .75 of Ventolin and two puffs of Asthmacort and then at school he does that twice and then at night again.

I take it so for granted . . . I walk in the kitchen, before I even start making breakfast, I'm dishing out all these pills, and I forget, I'm so unconscious, I do it every day . . . except for dishing out the drugstore, it's just like anyone else's day.

The mothers have routines of giving preventive or maintenance medication, but also have plans they put into effect when their children start getting sick. For one mother, getting into a routine was a way of detaching and being able to function during crisis:

We're just kind of in a routine . . . His type of asthma is extremely fatal and we just have to blank that part out. And we just deal with it from the start.

Due to the episodic nature of asthma, most of the mothers experienced periods of time when their children would be off all medications and free of symptoms. In some ways, these periods made it all the more difficult to restart a medication routine. When the children were sick,

they would usually take medications without objection, but the mothers encountered resistance with maintenance medications. None of the mothers enjoyed reminding, cajoling, or forcing their children to take medications. Since many asthma medications are inhaled, it means using a nebulizer or inhaler with spacer. One mother recalled a common experience:

My son says, "Oh, Mom, I don't want to do it." They hate it and I'm sure he hates me bugging him about it.

Episodic denial, and wishful thinking were both described by two mothers:

I notice when we go off the medicine for a while, I go right back into denial. I go right back in thinking, gee, they're fine. I don't have to think about this anymore.

I know I should be really used to it, and I don't know if I will ever get that used to it, because I am waiting for him to outgrow it, and I don't see any signs of it.

The often repeated phrase, "maybe he'll outgrow it" was considered and reevaluated in a more realistic way by most of the mothers who expressed sentiments similar to the following statement from one mother:

Some people say he'll outgrow it. Well, that's not a goal right now. Our goal is let's keep him out of the hospital and let's keep the office visits down to the regularly scheduled every three month visits.

Packing the Drugstore

Packing the drugstore was a form of taking precautions so that family activities could be maintained. The mothers

were willing to do whatever they could to assure their children the normal experiences of childhood and family life. Having a positive attitude and minimizing limitations because of asthma was deemed an important strategy. The following exemplars from three mothers describe the experience:

The month of June they were both off all medication and it was great, I thought, you know, we can live a normal life, but . . . when we went on vacation, I still packed everything, because I know I have to. We even went camping one time last year and took the . . . plug-in nebulizer, found a campsite next to a coke machine building and my husband ran an extension cord, I mean we have learned to adapt and go ahead and do things anyway. And that's been good, that I can see that you can do that, Um, but I still would rather not have to.

It just became a way of life. You just always had a lot of medication around . . . It's like brushing your teeth and combing your hair . . . You take your own pillow and encasing. I'll always say, "do you have your meds?"

Any time we go anywhere for a day or two, I take a huge thing of, everything out of the medicine cabinet, and believe me, it has paid off over and over again . . . people see me and they'll go . . . there's so and so with her drug cabinet under her arm, but I've gotten use to that. You just can't let it limit you, you just have to learn as much as you can and be as smart as you can and make everything as portable as you can and then just get out there and do it.

Sometimes, the restrictions of having to be "plugged into the nebulizer" every four hours was too much of a restriction for the parents to carry out and travel plans had to be canceled. At times children were sick and missed parties. The best laid plans did not always work out. It

was a balancing act that took experience, practice, creativity, and luck.

A Sense of Control

While the uncertainty of asthma never goes away, most of the mothers had come to have more confidence in their ability to maintain some control. Reestablishing this sense of control over their lives was a part of finding that balance. By this time, most of the mothers had effective management plans and worked in partnership with their health care providers. The mothers perceived managing asthma as more of a challenge with more options to choose from to keep it under control. Control is a relative word, and meant different things to each mother, but one mother summarized it:

You know, you can't get rid of it, but . . . a feeling of control is knowing that you can take something or know to do the right thing and get over it, instead of being so out of control that you have to go to the emergency room or to a doctor to get over it.

Two other mothers also described common feelings:

I felt like as soon as I learned as much as I could learn about asthma and as soon as I felt that we had some sense of sanity or some sense of control over it, that's when I felt like I was coming out of the fog....

There is still the anxiety, and being frightened, but there is something about knowing that you are really doing as much as you can.

Only two mothers had little sense of control. One

informant was still hoping her child would outgrow his asthma. The child's grandmother had steroid-dependent asthma, and the long term medication side effects so worried the mother, that she chose to live with a level of poor control rather than use steroids to achieve control. It was a conscious choice she made. The second mother had a child who had only recently been diagnosed with very severe asthma and was still learning.

Keeping Up

Being able to regularly attend school and participate in sports was a goal the mothers had for their children. To ensure attendance at school or daycare like other children, the mothers worked closely with the schools. The transition from home to school was anxiety-provoking, at least in some part because the children had an invisible disability. Mothers were concerned that because their children might look fine, the teachers could fail to recognize the seriousness of an episode and not act appropriately to help. One mother's experience was similar to the others:

Each year . . . I would have to go to school and give my standard asthma spiel to the teacher to make sure she understood what he needed and when he needed it, and not to make him feel weird about it . . . Give him space and time to do it (his medications) and about P.E. and premedicating.

The mothers also made certain that both the teachers

and school nurses knew their children's early warning signs and how to contact them if the children started having problems. The mothers made every effort to have their children in attendance even when the previous night may have included little sleep and the nebulizer had to accompany the child to school the next day.

Participation in sports was a concern for the informants. Grieving was done again, when choices appeared limited or extremely difficult to accommodate. Some of the mothers discussed it with their health care providers and got different messages, as expressed by two mothers:

The saddest thing--it still brings tears to my eyes, was that I kept telling the allergist that I wanted him to be able to run and jump and be a normal child. He said "you may have to reevaluate, you may have to adjust what you wish for this child." But I remember at the time thinking, you have these hopes and dreams for your child and then a doctor to suddenly say to you "You may not be able to achieve those things" but it hasn't been hard because he makes his own choices.

He's had a real hard time playing baseball and I will do everything I can to keep that child playing because that is his love in life. We're even going to try basketball . . . the doctors say "let him be like any normal child, he can do it," so we're going to try it.

Most of the mothers had the same sentiments these two mothers expressed:

I try to encourage her to do what she likes, if she's interested. If she were interested in doing soccer with asthma, I'd probably go "oh my God!" but . . . I would say OK, well load up on the medicine and go out and get after it, but I wouldn't try to hold her back.....

People say don't let it inhibit him, but my big thing is finding things he can succeed at.

The mothers wanted their children to be children who happened to have asthma and not defined by their asthma. To help the children focus on their strengths and feel they could achieve their dreams, one mother described a common approach:

I point out friends of mine who are adults that have asthma and we will see athletes on TV you know like in the Olympics and we'll say oh, yea they got a gold medal but did you know they have asthma?

Communicating normal expectations and achievements was a way of constructing a positive future for their children.

Summary of Findings

Analysis of the interview transcripts from the 10 mothers yielded categories within the phenomenon of the human experience of having children with asthma as described by mothers. Contemplation of the categories and their descriptive elements led the researcher to the following summary description of the phenomenon:

The experience of having a child with asthma is marked by uncertainty, and the processes of vigilant monitoring, searching for answers, and taking charge of the situation are directed towards finding a balance which promotes the normal experiences of childhood while taking the necessary precautions.

Uncertainty was identified as the core category upon which the phenomenon was based. Each mother experienced continual uncertainty about her child's condition. Although the degree of uncertainty varied, it never totally went away. Initially, the mothers were unfamiliar with the ambiguous, and unpredictable, recurring symptoms. The mothers felt like they were living at the doctors' offices, but received confusing and contradictory messages. Seeing their children struggling to breathe at night and not being able to predict the outcome or when another episode would happen again were sources of boundless anxiety. The mothers found the medications and treatments complicated and side effects on occasion intolerable.

Fear and worry fueled a vigilance that was necessitated by the lack of stability and visibility. The mothers put their lives on hold when their children started getting sick. Hyper vigilance included round-the-clock observation and breathing treatments to avoid hospitalizations. Exhaustion was disregarded. Initially, the lack of information created a feeling of "being in the dark," which when combined with the demands of hyper vigilance had the mothers "going along in a fog." Marital relationships were strained as attention was focused intensely on the child with asthma. Healthy siblings resented the extra attention the child with asthma was receiving. The disruption to the

family system was incredible.

The mothers mobilized to search for answers, arrive at a diagnosis, and network. Their first stop in the search was at the health care providers. However, for most of the mothers, these health care encounters turned frustrating when concerns were minimized and little information was shared. When the condition was finally diagnosed as asthma, the mothers felt a mixture of relief, guilt, and sorrow. The diagnosis did not confer instant meaning, but was the key to finding the meaning. Once they had a name, the mothers found it easier to network. Mothers looked for information and support from friends, relatives, school nurses, support groups, bookstores, and non-profit organizations. The mothers no longer trusted their health care providers to have all the answers. Networking gave the mothers many of the answers and more questions to ask.

Frustration that their children just were not getting any better was the underlying catalyst for taking charge. The mothers recalled defining moments when it was "the last straw" and they realized they had to take back some control over the situation. This frequently involved doctor shopping as the mothers persisted in trying to find the best care for their children. Not only did mothers want to find health care providers who would listen to them, the mothers found their voice and insisted on being heard. The mothers

went about establishing partnerships with health care providers which, at their best, included mutual goal-setting and decision-making. The mothers felt compelled to speak on behalf of their children, not just to their health care providers, but also to school nurses and teachers. Often the advocacy went beyond helping their own children to helping friends as well as other mothers and children. Advocacy seemed fueled by anger at the injustice of the treatment the mothers had received, wanting to insure that no one else had to struggle as they did for information, and to make sense of the experience.

Initially, the mothers were not able to balance the illness demands and any sense of normalcy. Finding a balance was delayed until there was a diagnosis of asthma and the necessary competence had been gained for asthma to be considered manageable. At that point, the situation was viewed as more of a challenge and less of a threat. The mothers were able to acknowledge the differences but attempt to minimize the restrictions. Routines were established, but varied according to the day-to-day condition of the children. Mothers tried to maintain normal family activities even if it meant "packing the drugstore" to go on vacation. The mothers tried to insure that their children kept up by regularly attending school and participating in sports. For the children to have successful experiences in

these areas, the mothers maintained close communication with the schools, premedicated before sports, and tried to keep the asthma under control. Having a sense of control was achieved by most of the mothers and contributed to their finding a balance which promoted normal childhood activities while taking the necessary precautions.

CHAPTER 5

SUMMARY OF THE STUDY

Asthma is a chronic episodic respiratory disease that can be devastating to a child and disruptive to the family system. Unanticipated and frequent crises can be emotionally, physically, and financially taxing for the family. Although the entire family is affected, management of the illness most often becomes the mother's responsibility. The need exists for nurses and other health care providers to gain insight into the experience of the mothers of children with asthma. An understanding of the human experience is essential in order to plan with mothers and implement effective care for children with asthma and their families. The purpose of the study was to explore and describe the phenomenon of the experience of having a child with asthma as perceived by mothers of children with asthma.

Summary

The lived experience of mothers of children with asthma was explored using the qualitative method of phenomenology. Data were collected from mothers who had children with asthma living in the southwestern, eastern and western

United States. A purposeful sample of 10 mothers participated in the study. Sampling ceased when redundancy in the data was achieved. Informants were interviewed by use of a semi-structured Participant Interview Guide (see Appendix C). Each interview was flexible in order to allow informants to fully explore perceptions in describing the phenomenon. Interviews were audiotaped and transcribed. Each transcript was analyzed using the phenomenological essentials set forth by Spiegelberg (1960). Contemplative dwelling with the data resulted in uncovering of categories descriptive of the phenomenon. Categories were shaped by the descriptive elements which emerged from further analysis of the data. Essential relationships between elements within categories were apprehended through imaginative variation. From watching, modes of appearing relationships between categories emerged which resulted in the following summary description of the phenomenon:

The experience of having a child with asthma is marked by uncertainty, and the processes of vigilant monitoring, searching for answers, and taking charge of the situation are directed towards finding a balance which promotes the normal experiences of childhood while taking the necessary precautions.

Agreement between the researcher and a doctorally prepared nurse with experience in phenomenological analysis was sought during various phases of data analysis. Two informants verbally provided feedback to the working analysis in order to validate the findings. The reviewers confirmed the description of the collective experience as being very similar or identical to their own.

Discussion of Findings

Uncertainty exists, not only with asthma, but with epilepsy, diabetes, cystic fibrosis and other chronic illness, when the symptoms are unfamiliar or unpredictable. The processes of vigilance, searching for answers, taking charge, and finding a balance have been reported, in some form, either separately or together, in studies of asthma (MacDonald, 1996) or studies of other chronic illness (Bossert et al, 1989; Venters, 1981; Wuest and Stern, 1990). Findings from this phenomenological study of mothers of children with asthma would support the relevance of a non-categorical approach to chronic illness which focuses on similarities and dimensions of illness (e.g., stability and visibility) as advocated by Stein and Jessop (1982).

The overriding uncertainty experienced by the informants was similar to findings of previous studies (Jessop & Stein, 1985; MacDonald, 1996). Informants

described the ambiguous symptoms, lack of predictability, lack of information, and complex treatments that according to Mishel (1988) characterizes uncertainty in illness. While uncertainty has been reconceptualized as an opportunity by Mishel (1990), all informants viewed it as a threat to varying degrees. With time, knowledge, and competency, the situation became somewhat more of a challenge and less of a threat; however the life threatening potential of an asthma episode was never forgotten. In contrast to the ethnographic study of MacDonald, the informants never considered themselves to be mastering uncertainty but only to be managing it. Mishel and Sorenson (1991) found the ability of mastery to be weakened as a coping mediator under conditions of uncertainty. The informants accepted that some uncertainty would always remain.

As mothers repeatedly sought health care for their ill children, they received confusing and contradictory messages. Concerns were frequently trivialized. Patterns were not recognized, and little information was given. Recognition and early accurate diagnosis would have relieved a major source of frustration. Venters (1981) reported similar findings with cystic fibrosis families. Also, Wuest and Stern (1990) had similar findings with chronic otitis

media families.

Lack of understanding of asthma signs, symptoms, and triggers was just one part of the informants' quandary. Treatments could be equally complicated with intolerable medication side effects. Little information was received about what to expect and what other options were available. Medication concerns were also reported by Townsend et al. (1991). The mothers desperately wanted someone to listen and provide them with information and guidance.

Mothers reported learning to listen for early warning signs of asthma as reported by MacDonald (1996). The degree of vigilance was related to the degree of uncertainty. For, as noted by Jessop and Stein (1985), the uncertainty due to lack of stability and visibility of asthma leads to increased vigilance. Initially, when they were not sure of what was wrong, and later when their children had asthma episodes, the need to be vigilant was more intense. Marital relationships were frequently strained, and healthy siblings became resentful of the extra attention given the child with asthma. Altered family relationships were reported also by Peri, Molinari, and Taverna (1991) and Bossert et al. (1989). Finding support, lessening the uncertainty through diagnosis, information, a management plan, and an accessible health care provider all served to relieve the mothers of

some of the stress.

The role of searching for answers as a coping mechanism in dealing with uncertainty has been perceived similarly by subjects in previous studies. Multiple researchers (Gibson, 1995; Venters, 1981; Wuest & Stern, 1990) discussed this quest for information and support as a way of making sense of the situation. The mothers first looked to their health care providers for answers. According to Mishel (1988), a trusted credible authority can serve to decrease uncertainty. However, as the diagnosis was delayed, there was a loss of trust, and uncertainty and frustration increased. With the arrival of a diagnosis, the mothers expressed feelings of relief, guilt, and sorrow. Grieving occurred throughout the experience as losses were encountered. Denial was only mentioned in respect to the spouses, which is in contrast to Austin's (1979) initial stage of disbelief experienced when parents had children with epilepsy. Probably due to the delay, many of the mothers already suspected asthma or something worse; to have their concerns acknowledged as legitimate was a relief. However, when a diagnosis was given, other accurate information did not necessarily accompany it. The "smother-love" theory (French & Alexander, 1941; Rees, 1963) was advanced in one instance. All mothers were concerned

about being viewed as overprotective.

Having a diagnosis was a key to effectively networking to find answers, support, and resources. Surprisingly, family was not necessarily supportive, even if there was a family history of asthma. Also, mothers who had asthma in childhood were mistakenly assumed to have an advantage. Information and support derived from sharing experiences with other mothers was a predominant theme. Mothers often had a feeling of aloneness that was alleviated by attending support groups and becoming aware of other resources. However, when well-meaning friends made comparisons of children with mild asthma who outgrew it to the informants' children, these comments were not perceived as helpful. This would reinforce Pless and Pinkerton's (1975) findings that more variability exists within diagnostic groupings than between them. Mothers viewed most school nurses as knowledgeable and supportive, but few other nurses were recognized as resources. The informants did feel angry that they had to search for the answers. The mothers would have preferred their health care providers to have given them some guidance including printed information and resources. No mothers reported being referred to asthma management classes, even though they have proven efficacious (Green, Goldstein, & Parker, 1983; Wilson-Pessano & Mellins, 1987).

Frustrating health care encounters and increasing self-confidence propelled the mothers into taking charge of their situation. This process of taking charge, becoming assertive to effect change, was similarly observed by Gibson (1995) as one component of the reconceptualized interactive model of empowerment. MacDonald (1996) referred to taking hold as a transformative process in order to get some control in their lives. Advocacy, the need to be listened to, and heard, and the importance of establishing partnership care were elements identified by both Gibson and MacDonald. However, in MacDonald's study the mothers did not have a sense of partnership with the health care team, but felt they were being labelled as demanding and obtrusive.

Through the processes of being vigilant, searching for answers, and taking charge, the mothers attempted to find a balance which promoted the normal experiences of childhood while taking the necessary precautions. This process of finding a balance included utilizing the coping strategies of establishing varying routines and maintaining a sense of control. Modifying routines and maintaining a sense of being in control were similarly described by Miller (1983) as coping tasks of chronically ill adults. Since asthma is an invisible illness, mothers took great pains to explain the condition to others and acknowledge the differences.

Jessop and Stein (1985) suggested that when the chronic condition is not visible, uncertainty is increased because of the difficulty in monitoring the changes in the child's condition. Rather than try to demonstrate normalcy, mothers tended to explain differences. A similar process was observed by Wuest and Stern (1990). However, while the families of children with chronic otitis media hoped for an end to the disease and return to normal, the mothers of children with asthma who set return to normalcy as a goal, delayed developing effective management strategies.

Once asthma was considered manageable, mothers regained a sense of control. Some strategies of normalization as described by Knafl and Deatruck (1986) and Bossert, Holaday, Harkins, and Turner-Henson (1990) were utilized by the informants in the attempt to continue normal family activities and vacations, and ensure that their children could keep up in school and sports. Mothers wanted their children to be children who happened to have asthma, but were not defined by the asthma.

Conclusions and Implications

When a child has asthma, the entire family is affected, but management of the illness most often becomes the responsibility of the mother. In an era of escalating health care costs, where mothers are increasingly expected

to provide skilled monitoring and administer complicated treatment regimes, the need exists to include the mother as an integral part of the health care team. Health care professionals must begin to recognize the impact of caregiving on women's lives. Understanding the mother's experience is essential if nurses are to plan and implement appropriate interventions to assist the mother in caring for the child with asthma. Conclusions and implications for practice reached from the findings of this study include:

1. Having a child with asthma is a life-altering experience for mothers.

The experience is characterized by uncertainty which is dealt with by using the process-oriented strategies of being vigilant, searching for answers, and taking charge in order to work towards finding a balance. Mothers are worried, anxious, and frustrated when they do not know what is wrong with their children. The mothers want someone to listen and not trivialize their concerns. Findings indicated that nurses need to listen to mothers and respect their expert knowledge. The nurse-mother relationships can then be based on shared expertise. Assessing mothers' perceptions of the illness and what is threatening in dealing with the illness can help nurses to understand the meaning that event has for the mother. The nurse's efforts can then be directed toward

planning with the mother to resist, reduce, or manage the uncertainty. When the nurse is viewed as a resource, problems and learning needs can be identified by the mother (Funnell et al., 1991). Appropriate education (ideally, with both parents) can begin to develop a partnership which includes teaching problem-solving and assessment skills.

2. Delaying the diagnosis of asthma is a disservice; however giving the diagnosis without accurate information and appropriate support is insufficient.

The term reactive airway disease (RAD) means little to the mothers. Telling them that their children will probably outgrow it does nothing to help the mothers manage the condition effectively. Mothers are likely to receive the diagnosis with feelings guilt, sorrow, and possibly relief. Mothers perceived the fathers to be in more denial. Findings from this study also indicated that asthma is still viewed by many to have an emotional cause. Practice implications include the need for recognition by health care professionals of a timely diagnosis of asthma with understanding and acknowledgement of the feelings often associated with the diagnosis. Trying to include the father in the discussion might help him to accept the diagnosis and allow him to be more available to support the mother. Exploring the mothers' beliefs and attitudes about asthma

can help to dispel any myths and relieve some of the guilt. Nurses should plan sufficient time to answer questions and provide printed information, resources, and continuing support.

3. Mothers indicated that resources such as support groups, books, and nonprofit organizations had been helpful but were not provided by most primary care offices or hospitals.

The findings from this study indicated that the mothers were angry that they had to search for almost all the information on their own. The practice implications include the need for primary care offices and hospitals to provide patient education materials and resources to families who are caring for children with asthma, or any chronic illness.

4. Mothers are very ambivalent about medications and especially dislike having to give their children the maintenance medications.

According to the findings of this study, ambivalency about medications is a neglected but important issue. Health care professionals need to explain carefully the expected actions of medications and differentiate between acceptable and unacceptable side effects. Open communication needs to be encouraged so other options can be explored if the side effects are intolerable for the family.

Printed information should always be given with verbal instructions. Families need to be encouraged to ventilate their feelings about forms of treatment and preventive medications in order that barriers to adherence to the management plan can be identified and overcome. Development of a joint treatment plan for maximum benefits with least adverse effects should be a goal.

5. The demands of intense vigilance are exhausting and are given little regard by health care professionals. The disruption to family life is equally intense.

The findings of this study indicated that too little attention has been given to the affects of caretaking demands placed on mothers. Practice implications include the need to do periodic family assessments of the impact of asthma on the family system. Assessment should include how parents are coping with the demands of the illness and to whom they can turn for socioemotional and instrumental support. Nurses need to encourage mothers to have spouses or extended family accompany them to appointments so that more of a shared competence is engendered. Establishing some evening office hours could enable working fathers to bring the children in and be included in the management process. Health care professionals need to increase their contact with mothers during times of crisis and intense

vigilance. Nurses need to be sensitive to the mother's needs and assess her level of comfort, anxiety, or exhaustion in attempting to meet her child's health care needs. Telephone calls from the nurse would be a way of offering support or home visits could be considered. Providing the appropriate tools (peak flow meters, nebulizers, prednisone, education, up-dated management plans) to decrease uncertainty and improve management is imperative. Referral for specialty care and counseling when indicated should be offered.

6. Some expert mothers engage in community advocacy.

Practice implications would include trying to identify and support the advocacy efforts of these mothers. One possibility would be establishing a training program for them to maintain a telephone tree to support novice mothers who would benefit from sharing experiences with an experienced mother.

7. School nurses have worked effectively with the mothers, but other nurses have missed the opportunity to teach, counsel, or advocate for mothers of children with asthma.

This finding indicated a strong need for nurses in emergency centers as well as inpatient and outpatient facilities to assess educational needs, at the very least

identifying teachable moments, and make available to mothers and children printed information and resource listings. Referral to support groups and asthma management programs is ideal. Training may need to be provided for nurses to become comfortable as asthma educators and even to start support groups or teach asthma management programs.

8. Mothers want to promote normal childhood experiences while taking the necessary precautions.

Finding a balance was a sustaining factor in the experience. Practice implications include simplifying medication schedules to interfere less with normal activities and, when possible, transferring children from nebulizer to inhaler with spacer to reduce restrictions and assist the mothers in maintaining normal family activities. Mutual goal-setting and joint development of peak flow based asthma management plans can increase the sense of control and enable the mothers to make informed choices. Specific educational resources for schools, daycare centers, and babysitters are available and should be shared with mothers. Nurses need to take the time to assess if the mother has been able to find a balance and identify any barriers that need to be overcome. Wellness asthma checks should include questions about attendance at school, participation in sports, sleeping through the night, normal activities,

routines, and precautions. Nurses need to acknowledge that coping with asthma is difficult, but try to point out the strengths in the mother's situation to support a positive attitude. Open communication should be advocated, and mother's efforts to promote the normal experiences of childhood while taking the necessary precautions should be encouraged.

Recommendations for Further Study

Further research is needed that addresses all aspects of the experience of having a child with asthma. This preliminary study revealed specific areas in which research could be conducted.

1. Since this study only explored the phenomenon from the perspective of mothers, further investigation of the perceived experience of fathers and siblings is warranted.
2. Differences in the experience based on demographic variables such as marital status, income, culture and ethnicity might reveal an even richer and broader description of the experience. Further qualitative studies of the experience of having a child with asthma among minority populations as well as the uninsured and underserved who have limited access to health care might yield data that would be helpful in understanding

the rising mortality and morbidity rates.

3. Research focused on the anxieties of living with continuing uncertainty could yield interventions aimed at reducing and managing the uncertainty and increasing the mother's sense of control. These interventions could be evaluated to see if they reduce the level of anxiety.
4. Mothers' perceptions of nurses and other health care providers should be explored to determine factors contributing to frustrating health care encounters.
5. Further research is necessary to be able to individualize care so mothers are not being asked to take on more responsibility than they feel competent handling. Further studies are needed to validate new and more effective ways to reinforce family strengths and assist family members to cope with the stressors of chronic illness.
6. Research studies need to be done on methods to support families who have children on preventive medication for years. Findings of this study indicated that medication ambivalence was a neglected issue. Effective methods of providing education and developmentally appropriate strategies to encourage children to cooperate, along with positive

reinforcement of parental efforts, need to be developed. Interventions need to be developed so nurses can assist families in their attempts to provide the normal experiences of childhood while taking the necessary precautions.

7. Research is needed to identify the barriers to asthma education in the emergency department, hospital, and primary care setting. Once the barriers are identified, research needs to be pursued using the empowerment model (Funnell et al., 1991) to develop interventions to provide asthma education and resources at every contact with the family with a child with asthma.
8. Further studies focused on nurses' perceptions of their role in relation to mothers of children with asthma might help identify why only school nurses see their role as one of educator and resource provider. Continuing research should have application in nursing curriculum to incorporate the role of patient advocate and asthma educator.

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APPENDIX A
ORAL DESCRIPTION OF STUDY

The Lived Experience of Mothers of Children with Asthma

Oral Description of the Study

You are being asked to participate in a study conducted by Mary Kay Garcia, a graduate student at Texas Woman's University College of Nursing. This study is designed to explore how you manage your life with a child with asthma. This is important so that nurses and other health care personnel will know how and when to make appropriate interventions to support mothers who have children with asthma.

If you agree to participate, you will be asked questions relating to how you deal with life events. This will be done in privacy in a mutually agreed upon location. Your answers to these questions will be audiotaped so that they may be transcribed for analysis. These interviews will take approximately 1 hour.

Your interview will be conducted by me. A possible risk is that you may experience some anxiety, fatigue, or questions during the interview. The following things will be done to decrease anxiety and fatigue: the interview will be conducted in a private location; adequate time will be allowed for you to ask questions or discuss any concerns; you will be free to interrupt the interview at any time, either to rest or to stop the interview; if you wish any rest period, the interview will be stopped until you wish to continue; the researcher will remain after the interview is completed to answer any questions or discuss any concerns. Additionally, if you have any questions, please call me, Mary Kay Garcia, MN, RN at 713/794-2109. I will be happy to answer your questions.

You are free to participate or not to participate. The choice is yours. If you choose to join the study, you may withdraw from the study at any time without penalty. Your child's care will not be affected in any way if you do or do not participate.

Confidentiality will be protected. Only a number will be placed on each form and audiotape. This is necessary to keep your data separate. No names will appear on any data forms or audiotapes. Neither you nor any person caring for your child will be identified anywhere in this research study. All audiotapes will be kept in a locked file cabinet and destroyed no later than two years after the completion of the study.

Efforts will be made to prevent any complication that could result from this research. Medical services and compensation for injuries incurred as a result of your participation in the research are not available. The investigator is prepared to advise you in case of adverse effects, which you should report to her promptly. A telephone number where the investigator may be reached is listed in the beginning of this form.

Thank you for your time and interest.

APPENDIX B
CONSENT FORMS

TEXAS WOMAN'S
UNIVERSITY
DENTON/DALLAS/HOUSTON

COLLEGE OF NURSING
Houston Center
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2100

The Lived Experience of Mothers of Children with Asthma

Consent Form

I hereby authorize Mary Kay Garcia, MN, RN to ask me some questions about myself and my feelings or perceptions of managing my life with a child with asthma. I was informed that my answers to these questions will be audiotaped. It is my understanding that I will be interviewed once for approximately one hour.

I understand that the interview will be conducted in privacy in a mutually agreed upon location. I understand that two possible risks to me are that I may experience some anxiety during the interview or anxiety related to a potential risk of loss of confidentiality. I know that if I experience some anxiety or have questions during the interview, that adequate time will be allowed for me to ask these questions or to discuss any concerns. I am free to interrupt the interview at any time, either to rest or to stop the interview. If I wish any rest period, the interview will be stopped until I wish to continue. I understand that the researcher will remain after the interview is completed to answer questions or to discuss any other concerns. Additionally, if I have any questions, I may call Mary Kay Garcia at 713/794-2109 during business hours.

I was informed that confidentiality will be protected. Only a number will be placed on my data forms and audiotape. I know that this is necessary to keep my data separate. I further understand that my name will not appear on any data forms or identified by others. Therefore, care will be taken to keep all tapes locked in a file cabinet. I understand that no one besides the investigator and transcriber will have access to, or be able to listen to the tapes. Neither myself nor any other person caring for my child will be identified anywhere in this research study. I understand that all audiotapes will be destroyed no later than two years after the conclusion of the study.

There is no direct benefit to me as a participant in this study. I understand that I am free to participate or not to participate. The choice is mine. If I choose to join the study, I may withdraw from the study at any time without penalty. My child's health care will not be affected in any way if I do or do not participate.

An offer to answer all my questions regarding this study has been made. If I have any other questions regarding this research that cannot be answered by Mary Kay Garcia, I can contact the TWU Office of Research and Grants, Denton, TX at 817/898-3377. If alternative procedures are more advantageous to me, they have been explained. A description of possible discomfort or risks reasonably expected has been discussed with me.

Participant's signature _____ Date _____

Witness

Date

**TEXAS WOMAN'S
UNIVERSITY**
DENTON/DALLAS/HOUSTON

COLLEGE OF NURSING
Houston Center
1130 M.D. Anderson Blvd.
Houston, TX 77030-2897
Phone: 713/794-2100

The Lived Experience of Mothers of Children with Asthma

Consent to Audiotape

Consent form

I, the undersigned, do hereby consent to the recording of my voice by _____,
acting under the authority of Texas Woman's University, for the purposes of the research
project, entitled "The Lived Experience of Mothers of Children with Asthma." I understand
that the material recorded is for research purposes, and I hereby consent to such use.

Signature of the Participant Date _____

The above consent form was read, discussed, and signed in my presence. In my opinion,
the person signing said consent form did so freely and with full knowledge and
understanding of its contents.

Authorized representative of the
Texas Woman's University Date _____

APPENDIX C
INSTRUMENT

Code: _____

Date: _____

Participant Interview Guide

- | | |
|-----------------------------------|--|
| 1. Age _____ | 2. Marital status _____ |
| 3. Employment status _____ | 4. # of years of education _____ |
| 5. Age of child with asthma _____ | 6. Age of child with asthma at diagnosis _____ |
| 7. # of children _____ | |

Semi-structured Questions

The interview will begin with a question such as, "please tell me what it is like to be the mother of a child with asthma."

Other questions which will be used to elicit core variables will include:

- *How did you feel when you were told that your child had asthma?
- *What was it like for you before, compared with after diagnosis?
- *How have others, family, friends, health care professionals played a role in your experience of being a mother of a child with asthma?

Questions will then emerge which will attempt to elicit general essences and to gain an understanding of essential relationships among essences.