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A STUDY OF THE RELATIONSHIPS AMONG MATERNAL CAREGIVER FAMILY
MANAGEMENT BEHAVIORS, CHILDHOOD ASTHMA MORBIDITY, AND
ASTHMA CONTROL

by

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A DISSERTATION

Submitted to the graduate faculty of The University of Alabama at Birmingham,
in partial fulfillment of the requirements for the degree of
Doctor of Philosophy

BIRMINGHAM, ALABAMA

2011

A STUDY OF THE RELATIONSHIPS AMONG MATERNAL CAREGIVER
FAMILY MANAGEMENT BEHAVIORS, CHILDHOOD ASTHMA
MORBIDITY, AND ASTHMA CONTROL

ABSTRACT

LINDA GIBSON

NURSING

Childhood asthma, the most common chronic childhood condition, is associated with high rates of asthma morbidity (emergency department visits, hospitalizations, and school days missed due to asthma). Inadequate asthma control accounts for \$1.9 billion annual health expenditures. Numerous studies have identified the relationship of the family caregiver's perception regarding asthma management and the child's asthma outcomes; though few have examined family caregiver asthma management behaviors. Knafl and colleagues (2003) defined family management behaviors as accommodations that family members use to manage the condition on a daily basis. The primary aim of this study was to examine the relationship among family management behaviors, such as condition management ability and condition management effort; asthma morbidity; and asthma control from the perception of maternal caregivers.

A total of 101 maternal caregivers of school-aged children diagnosed with persistent asthma were recruited from a specialty asthma clinic. Data were obtained through maternal caregiver self-report and included demographics, asthma morbidity, asthma control (Asthma Control Questionnaire (ACQ), and family management behaviors (effort and ability subscales, Family Management Measure). Data were analyzed using correlations and regressions.

Data analysis ($N = 101$) indicated 94% of maternal caregivers are mothers, while the majority currently work outside the home (57%). Children were 53% male, had an average age of 8.9 (range 5-12) and 66% were minority. 54% of the children had poor control as determined by the ACQ (using score of >1.5 to indicate poor control) and 62% had greater than one emergency department visit or hospitalization during the past year. Effort positively correlated with asthma control ($r = .426, p = .001$) and school days missed ($r = .259, p = .010$) while ability negatively correlated with hospitalizations ($r = -.206, p = .039$). When controlling for minority, income, and work status, effort is predictive of school days missed ($\beta = .920, p = .020$) and asthma control ($\beta = .253, p = .028$) and ability is predictive of asthma control ($\beta = -.238, p = .037$).

Minority status, income, and work status correlated with emergency department visits, school days missed and asthma control; thus confirming what has been previously published in the literature. When caregivers perceived they were expending a lot of effort on their child's asthma management and were not confident in their ability to perform asthma management activities, the child's asthma outcomes were worse. This indicates the need to focus more interest on perceptions of maternal caregivers.

DEDICATION

I dedicate this dissertation to my husband, Jeff, for all the countless hours spent working in the garage while I completed this project. I appreciate all your support and guidance, as you know just how to say the right words to keep me focused. I also want to dedicate this dissertation to my parents; your endless praise challenged and motivated me to continue my journey towards this finished product. Last but not least, this dissertation is dedicated to my son, Greyson, who taught me how to be a maternal caregiver of a child diagnosed with asthma.

ACKNOWLEDGEMENTS

I want to acknowledge my dissertation committee, composed of Dr. Lynn Gerald, Dr. David Lozano, Dr. Marti Rice, and Dr. David Vance, who generously volunteered their time and expertise for this work; I am forever indebted for your contributions and support. Next, I wish to acknowledge the pulmonary medical team at Children's Health System. This team (Pulmonary MDs, CRNPs, RNs, staff) gave me direction for access and provided valuable expertise for the Interdisciplinary Asthma Clinics. I also wish to acknowledge my UAB colleagues and classmates who have shared this journey with me and continually offered their encouragement and support. Most of all, I want to acknowledge my committee chair and mentor, Dr. Anne Turner-Henson. It was by the recognition of your strength and dedication as a nurse, a professor, a wife, a mother, and various other responsibilities that I continued this endeavor. You saw my struggles and challenges in this endeavor, yet you never stopped encouraging me to complete this process.

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LIST OF ABBREVIATIONS

ACQ	Asthma Control Questionnaire
FaMM	Family Management Measure
FMSF	Family Management Style Framework
GINA	Global Initiative for Asthma
IRB	Institutional Review Board
NAEPP	National Asthma Education and Prevention Program
NHLBI	National Heart, Lung, and Blood Institute
SON	School of Nursing
USHHS	United States Department of Health and Human Services

A Study of the Relationships among Maternal Caregiver Family Management Behaviors, Childhood Asthma Morbidity and Asthma Control

Asthma and asthma-related morbidity are significant health problems in the United States (U.S.). While asthma affects individuals of all ages, children, due to their developing and immature respiratory tracts, can be greatly impacted by asthma. Approximately nine and a half million school-aged children (13% of all U.S. children) have been diagnosed with asthma (Bloom, Cohen, & Freeman, 2009). This makes asthma the most common chronic childhood condition and the largest public health burden for children (Akinbami et al., 2011; Turner-Henson, Holaday, & Swan, 1992). Since the 1990s, childhood asthma prevalence has increased 15% among school-aged children (Centers for Disease Control [CDC], 2008). The rates of asthma are disproportionately high for children living in urban environments. This is emphasized by the wide range of asthma prevalence in various populations, between 1.6% and 36.8%, with highest prevalence rates in urban populations (Akinbami et al., 2011; Akinbami & Schoendorf, 2002; Aligne, Auinger, Byrd, & Weitzman, 2000).

Childhood asthma is associated with high rates of asthma morbidity. Asthma morbidity is defined as outcomes such as emergency department (ED) visits, hospitalizations, and school days missed due to asthma (CDC, 2008; Cloutier, Wakefield, Hall, & Bailit, 2002; Warman, Silver, & Stein, 2001). Over the past ten years, approximately seven percent of all school-aged children have required treatment by healthcare providers for asthma symptoms (Bloom et al., 2009). School-aged children are defined as children between the ages of five and 18 years. Healthcare use for school-aged children with asthma has been reported to cause five million unscheduled healthcare

visits per year. In addition, emergency department utilization is increasing (Bloom et al., 2009; Lara, Duan, Sherbourne, Halfon, Leibowitz, & Brook, 2003). This accounts for more than 727,000 ED visits, with seven percent of school-aged children requiring two or more emergency department visits for asthma per year (Bloom et al., 2009).

When compared to Caucasian children, African American children are more than three times as likely to be hospitalized, have significantly higher emergency department visits (380% higher), and are more than four times as likely to die from asthma (Cloutier et al., 2002; Bloom et al., 2009). Morbidity also affects a child's education; children with asthma miss an average of 7.6 school days annually, compared to healthy peers who miss on average 2.5 days (Horner, 2008). School-aged children (ages 7-17 years) with asthma miss 14.7 million days of school each year, approximately three times more than children without asthma (Bloom et al., 2009). For the purposes of this study, school days missed are defined as missed days from school due to problems with asthma. From the above statistics, it is clear that the escalating trends in childhood asthma prevalence and morbidity tend to excessively affect minority children (Akinbami et al., 2011; Bloom et al., 2009; Butz et al., 2004; Cloutier et al., 2002; Horner, 2008). Asthma morbidity in minority children has been correlated with lower socioeconomic status, home allergen exposure, deficient health insurance coverage, and lack of caregivers' education (Kruse, Deshpande, & Vezina, 2007; Lara et al., 2003; Wallace, Denk, & Kruse, 2004). Furthermore, deficient or lack of health insurance is correlated with reduced healthcare utilization in minority populations (Horner & Fouladi, 2003). For example, 23% of African American and 34% of Hispanic families lack health insurance. With these populations, asthma morbidity outcomes occur as increased emergency department use,

hospitalizations, and school days missed rather than preventative, primary care services (Butz et al., 2004; McQuaid et al., 2006), and increased use of the emergency department tends to correlate with ethnic background, socioeconomic status, and insurance status (Kruse et al., 2007; Lara et al., 2003). Due to these findings, emergency department use has been reported as a primary factor in asthma morbidity for the childhood asthma population.

Child, maternal caregiver, and family characteristics may greatly influence the ability and effort involved in caring for a child with asthma. Studies examining family management of childhood chronic conditions have focused on child, maternal caregiver and family demographic variables and how they impact maternal caregiver home management of childhood asthma (Horner, 2004; Horner & Fouladi, 2003; Ungar et al., 2011). Child demographic characteristics frequently examined include age, gender, ethnicity; maternal caregiver characteristics such as work status, educational status; and family characteristics such as type of insurance information (private, public, or no insurance), family structure (single parent, nuclear, or blended), and residence zip code.

Much research has evaluated demographic characteristics of school-aged children diagnosed with asthma (Horner et al., 2002; Horner, 2004; Horner & Fouladi, 2003; Ungar et al., 2011; Wamboldt et al., 2002) and often these demographic characteristics focus on child age, ethnicity, gender, environmental exposures, and asthma severity. Reported findings have identified associated characteristics between child's age and asthma severity or specific environmental triggers with asthma symptoms. For example, environmental characteristics such as exercise, rain, and dust, strong odors, and cigarette smoke may lead to increased asthma severity (United States Department of Health and

Human Services [USHHS], 2002). Horner et al. (2002) identified child's asthma limitations, such as child school days missed, was often associated with the parent's work of asthma management. Another relationship has associated parents with no college experience exposed children with asthma to environmental cigarette smoke more than those attending college after high school (Ungar et al., 2011). In relation to family characteristics, family structure is often correlated with individual outcomes. For example, a two parent families may share daily responsibilities and care of a child with asthma, while single parent families may have increased responsibilities, including emotional and financial limitations (Horner, 2004). The family may consist of a single parent (one parent with child[ren]), nuclear family (husband and wife with biological child[ren]), or blended family (husband and wife with biological child[ren] and child[ren] from another relationship). Notably, very few studies address single parent households, particularly when maternal caregivers are the primary caregivers of a child with asthma (Horner, 2004; Turner-Henson et al., 1992). Since infrequently evaluated, this dissertation examines the relationship among child, maternal caregiver, and family variables; family management behaviors (ability and effort); and asthma morbidity and asthma control from the perspective of the maternal caregiver.

Asthma control is defined as minimization of symptoms for the chronic condition of asthma during daytime and nighttime hours (Juniper et al., 2004). Inadequate asthma control accounts for annual health expenditures of \$1.9 billion each year and is the main cause of asthma morbidity (Velsor-Friedrich, Pigott, & Louloundes, 2004). Asthma morbidity is defined as outcomes such as emergency department visits, hospitalizations, and school days missed due to asthma (CDC, 2008). Carlton and colleagues reported

56% of the school-aged asthma population has required at least one emergency room visit or hospitalization in the past 12 months, thus signifying a lack of asthma control in the majority of this population (Carlton, Thompson, Wan, Conboy-Ellis, & Coates, 2010). More recently, Dozier and colleagues (2006) found discrepancies in parental report of asthma control and morbidity. This research documented that despite parental perception of the child's asthma as being under control, parents reported high asthma morbidity outcomes, including frequent emergency department visits and hospitalizations (Dozier et al., 2006).

Childhood asthma is a chronic condition that necessitates daily home management. Management of childhood asthma requires family caregivers to monitor daily for symptoms, administer medications, make home environmental modifications, coordinate health care visits and purchase of health supplies, as well as manage children's other needs such as basic care needs, school, and family activities (Butz et al., 2004; Horner, 2004; Horner & Fouladi, 2003; McQuaid et al., 2006). Family caregivers respond in various ways on how they manage a child's asthma condition, and ultimately the family caregiver response can be closely related to the child's outcomes (Morawska, Stelzer, & Burgess, 2008). Also, the family member perception of a chronic condition may inevitably alter a family's response towards management of that condition (Horner, 2004). Knafl and colleagues (1996; 2003) have defined childhood chronic condition family management behaviors as accommodations that family members use to manage the condition on a daily basis.

Two specific types of family management behaviors, known as condition management ability and condition management effort, focus on the family's response

towards managing a chronic condition. The condition management ability focuses on parental perceptions regarding the family's competency in managing the child's condition, while the condition management effort focuses on the work required of the family when managing the chronic condition (Knafl et al., 2009). For this dissertation, ability defines condition management ability and effort defines condition management effort.

In the past two decades, an extensive body of research has been published on families' management of childhood chronic conditions (Deatrick, 2006; Gallo & Knafl, 1998; Horner, 2004; Turner-Henson et al., 1992; Wamboldt & Wamboldt, 1995). In particular, family behaviors such as home management, daily symptom monitoring, and treatment for children with a chronic condition have been addressed in research (Butz et al., 2004, McQuaid et al., 2006; Horner & Fouladi, 2003; Horner, 2004; Wamboldt et al., 2006). In these studies, mothers' and fathers' behaviors in chronic condition management were examined, and in the majority of cases the maternal caregiver was distinguished as the primary family caregiver.

Family caregiver is defined as the caregiver or caregivers accountable for the daily care responsibilities of children on a regular basis (Fisher et al., 1998). Within families, maternal caregivers are by and large the primary family caregiver for children with chronic conditions (Sterling & Peterson, 2003). Though, few studies have focused on maternal caregivers. Children's day to day needs, such as food, drink, personal care, and acute condition care are also generally the responsibility of the maternal caregiver. The management of children with chronic conditions requires additional time and work from the maternal caregivers (Deatrick et al., 2006; Turner-Henson et al., 1992).

Because mothers have been shown to be the primary family caregiver and the number of children affected by chronic conditions is increasing, there is demand for research to focus on the maternal caregiver's perspective. Demographic variables regarding maternal caregivers often include family role of maternal caregiver (mother, grandmother, or guardian), and maternal caregiver work status (employed full-time, part-time, or no employment). Work status also plays a role in management of childhood asthma. While all maternal caregivers must balance illness and family demands, working maternal caregivers must further shift their roles when balancing parental time and medical treatments (Sullivan-Bolyai, Sadler, Knafl, & Gilliss, 2004; Turner-Henson et al., 1992). For example, maternal caregivers who are employed outside the home may be required to miss work due to the child's asthma management and this may increase daily responsibilities for the family affected by asthma (Morawska et al., 2008; Sterling & Peterson, 2003).

Background of Study

Research examining family management behaviors of childhood chronic conditions has been examined from the limited perspectives of family management by the early qualitative work of Davis (1963) to the more advanced perspectives of Knafl and colleagues (2009) conceptualization of family management behaviors. Davis (1963) recognized family management characteristics by observing patterns of daily management in mothers and fathers of children with a chronic condition. This research evaluated the patterns of care by mothers and fathers independently when affected by children with chronic conditions. In this qualitative study, Davis (1963) identified two overarching patterns termed normalization and disassociation, and found the patterns to

be linked to the quality of family life. Fisher and colleagues (2000) expanded the views of family management to include four family typologies identified as balanced, traditional, disconnected, and emotionally-strained. These typologies were based on both individual and family measures, focusing primarily on observed responses when affected by a chronic condition within the family.

Based on the early studies of family management with children's chronic conditions, Knafl and Deatrick, along with a team of researchers (Knafl et al., 1998), begin examining the family's response to childhood chronic conditions. In addition, this team of researchers began to evaluate the family's management of the home treatment regimen and how families incorporated the home treatment regimen into everyday family life. This research began with qualitative work and ultimately led to conceptualization of a framework termed Family Management Style Framework (FMSF) (Knafl & Deatrick, 2003).

Knafl and Deatrick recognized the appropriateness of a framework while studying caregivers of children with chronic conditions, and attempted to identify how such conditions are incorporated into daily life within the family from the perspective of a family caregiver (Knafl & Deatrick, 2006). This framework has been used to study the important balance required between the caregiver's management of the child's daily home treatments, such as in children with cancer and daily family requirements (Deatrick, 2006). Ultimately, this requires balance among daily responsibilities, and the chronic condition requirements may affect family management behaviors and may be evident in parental perceptions of ability and effort when managing a chronic condition.

Individual family members may exhibit various responses when managing chronic conditions, and variations in this management are often attributed to types of chronic conditions in which trajectories or treatment type differs depending on the disease, such as children with brain tumors, diabetes, and cystic fibrosis (Knafl & Deatrick, 2003). Investigators have published research focusing on the unique styles of a family member's perceptions in managing specific chronic childhood conditions (Deatrick, 2006; Deatrick et al., 2009). However, most research on family management has been limited to examining family caregivers of children with particular conditions. For example, perceptions of the family management behaviors particularly from the viewpoints of the mother and father of children with childhood cancer were examined by various researchers (Deatrick et al., 2009; Knafl & Deatrick, 2003; Nelson, Deatrick, Knafl, Alderfer, & Ogle, 2006). When focusing on brain tumor cancer, Deatrick and colleagues (2009) found parents of children who survived brain tumors reported various perceptions of family management behaviors including much difficulty and effort when managing the disease. Knafl and colleagues (2003) identified family caregivers of children with cancer to be at risk for difficulty in managing the condition and often feel less capable of managing the condition. Family management has also been measured with adults. Specifically, caregivers of adults living with life-sustaining therapy were studied to evaluate family management behaviors when influenced by chronic conditions with an adult patient (Wiegand, Deatrick, & Knafl, 2008). With asthma as the most common chronic condition in children, further research is needed to explore how family management behaviors affect the maternal caregiver's perceptions of family management behaviors when managing asthma in children.

Family Management Behaviors and Chronic Childhood Conditions

Family management behaviors have been conceptually defined as accommodations that family members use to manage the condition on a daily basis and balance the demands of childhood chronic condition with family life (Knafl & Deatrick, 2006; Knafl & Deatrick, 1990). By examining ability and effort, healthcare team members may better understand how maternal caregivers manage asthma in the home. Additionally, the relationships among ability and effort with chronic disease outcomes could be used to add to knowledge of maternal caregivers' management of childhood chronic conditions. By evaluating key aspects of family management from the perspective of the maternal caregiver, the Family Management Style Framework (FMSF) may direct researchers to understanding specific behaviors associated with family management of chronic childhood conditions, such as asthma. The FMSF is a comprehensive assessment of maternal caregivers' efforts to manage chronic conditions. This framework will be incorporated in this study by assessing the maternal caregiver perceptions of managing childhood asthma (Knafl et al., 2009).

Furthermore, in families of children with asthma there are many family management responsibilities (Smetana et al., 2004), though the maternal caregiver usually assumes the majority of the daily caregiving management responsibilities. In caring for a child with asthma, maternal caregiving management responsibilities often center on daily medications, monitoring symptoms, and management skills to ensure optimization of the child's health (Riekert, Butz, Eggleston, Huss, Winklestein, & Rand, 2003). These management skills may include integration of chronic condition management tasks into the family's daily life. Other studies have examined outcomes of

family management behaviors in terms of family functioning, communication, decision-making, and coping (Butz et al., 2004; McQuaid, Walders, Kopel, Fritz, & Klinnert, 2005). In contrast, few studies have looked at child-specific outcomes such as asthma morbidity and asthma control (Horner, 2004). The current study will seek to bridge this research gap.

Asthma Control

As the leading cause of childhood hospitalization and emergency department visits, asthma is difficult to manage. Childhood asthma trajectories vary among children, with those who have mild asthma only needing daily symptom monitoring and occasional medication to those with persistent asthma, which may require daily medications and treatment when asthma exacerbations occur. Due to this variation, the National Heart, Lung, and Blood Institute (NHLBI) authored the National Asthma Education and Prevention Program (NAEPP) Expert Panel Report 3 guidelines for healthcare providers managing asthma, and recommend assisting families in controlling asthma so children can sleep at night and be more active during the daytime hours (USHHS, 2007). The guidelines propose that providers should assess asthma control with each visit. For this reason, this study included asthma control and asthma morbidity as child-specific outcomes.

Family caregiver response may fluctuate in actions and management and when limited to maternal caregivers, this variance in management reaction may greatly affect asthma morbidity and asthma control. For example, specific behaviors regarding ability and effort that maternal caregivers utilize with chronic conditions may ultimately affect

the outcome, particularly asthma control with childhood asthma (Amuwo, Fabian, Tolley, Spence, & Hill, 2004; McQuaid et al., 2006; Miller & Drotar, 2006).

Statement of the Problem

Many factors may contribute to asthma morbidity (i.e., lack of adherence to inhaled corticosteroids, allergen exposure, etc.) and may be influenced by family management behaviors. Few studies address family management behaviors reported by maternal caregivers of children with chronic conditions. This limited research describes family management behaviors for conditions such as diabetes and cancer (Deatrick et al., 2009; Knafl & Deatrick, 2006; Nelson et al., 2006). Little to no research involves family management behaviors and childhood asthma management.

In addition, there are limited studies on how family management behaviors impact disease specific outcomes, such as morbidity. Particularly, no studies have evaluated the relationship between family management behaviors and child-specific outcomes for asthma such as asthma morbidity and asthma control. Therefore, focusing on childhood asthma management, this study involved evaluating family management behaviors, including ability and effort, from the maternal caregiver's perspective and sought to determine the relationship of management behaviors with child-specific outcomes, such as asthma morbidity and asthma control.

Statement of the Purpose

This study examined maternal caregivers' perceptions of condition management ability (ability) and condition management effort (effort) in maternal caregivers who have children with asthma; and examined the association of ability and effort with asthma morbidity and asthma control.

Research Questions and Hypotheses

1. What is the relationship between maternal caregiver perceptions of condition management ability and condition management effort with child, maternal caregivers, and family characteristics?

Hypothesis 1. There is a relationship between condition management ability; condition management effort; and child, maternal caregiver and family characteristics.

2. What is the relationship between family management behaviors (ability, effort) and children's emergency department visits, hospitalizations, and school days missed as reported by maternal caregivers?

Hypothesis 2. There is a relationship among family management behaviors (ability, effort) and children's emergency department visits, hospitalizations, and school days missed.

3. What is the relationship between family management behaviors (ability, effort) and children's asthma control as reported by maternal caregivers?

Hypothesis 3. There is a relationship between family management behaviors (ability, effort) and children's asthma control.

4. After controlling for income, maternal work status, minority status, children's gender, and children's grade, are family management behaviors (ability, effort) predictive of children's emergency department visits, hospitalizations, school days missed, and asthma control?

Hypothesis 4. Family management behaviors (ability, effort) are predictive of children's emergency department visits, hospitalizations, school days missed, and asthma control.

Significance of the Problem

There is limited empirical evidence regarding family management behaviors of childhood chronic conditions from the perspective of the maternal caregivers (Knafl et al., 2009). Asthma in childhood is a chronic condition and a major public health problem particularly among inner city and minority populations. This problem is acknowledged by increasing asthma diagnoses and asthma morbidity in children (Bloom et al, 2008). Recently, researchers have studied typologies of family management behaviors compared with chronic childhood condition outcomes (i.e. cancer, diabetes) using diverse measures to evaluate the effects on or within the family unit (Deatrick et al., 2006; Knafl et al., 2009). However, no studies have identified how the family manages asthma from strictly the maternal caregiver's perspective, or the relationship to asthma morbidity and asthma control.

Asthma morbidity and asthma control are often gold standard for measuring the effects of asthma in research (USHHS, 2007). However, no studies have related family management behaviors with such child-specific outcomes. This study assessed the relationship among family management behaviors, selected asthma morbidity outcomes, and asthma control.

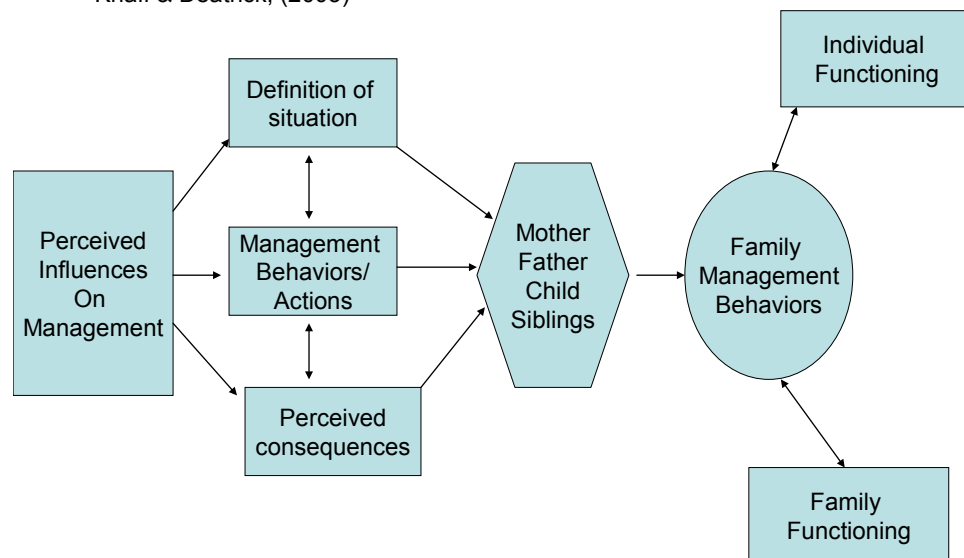
Emerging theory identified as the FMSF identifies how the family management behaviors may ultimately affect the outcome of the chronic condition of the child (Knafl et al., 1996; Knafl & Deatrick, 2003). In this framework, the family (defined as the

mother, father, child, and siblings) must appropriately manage care for the child affected by a chronic condition, such as a child with asthma since the management behaviors ultimately affect individual and family functioning. There must be more research focused on evaluating the perceptions of family management behaviors, particularly the maternal caregiver perceptions, of childhood asthma management with child-specific outcomes including asthma morbidity and asthma control.

Theoretical Framework

The study was guided by the FMSF (Knafl & Deatrick, 2003). The theoretical framework is illustrated in Figure 1.

Figure 1. Family Management Style Framework
Knafl & Deatrick, (2003)



The FMSF model currently includes the following dimensions: a) definition of the situation, b) management behaviors, and c) perceived consequences (Knafl & Deatrick, 2003). Definition of the situation is defined as the importance of daily family life requirements in the perspective of the chronic childhood condition. Management

behaviors are defined as the assessment of underlying principles that guide the family's ability of integrating chronic conditions into the family's normal routine. Whereas, perceived consequences can be described as the family member's perception on experience and how that chronic condition affects the family (Knafl & Deatrick, 2003).

The conceptual development of the FMSF, as well as the interplay of concepts, is well documented within the literature (Knafl & Deatrick, 1990; Knafl et al., 1996; Knafl & Deatrick, 2003; Deatrick et al., 2009). This framework is appropriate for use since chronic conditions with similar trajectories to asthma have integrated the FMSF with significant conclusions. For example, families of children diagnosed with cancer are frequently challenged with management issues, and through qualitative and quantitative descriptive studies, the FMSF relevance has proven beneficial to research (Deatrick et al., 2003; Deatrick et al., 2009).

The FMSF incorporates the perceptions of particular individuals, such as the maternal caregiver (Knafl et al., 2009). This framework focuses on an individual family member's perception of the family's style of management, instead of the perceptions of multiple family members. Knafl and Deatrick (2006) revealed early in the development of the framework that family response was a function of how individual family members define and manage key characteristics with chronic conditions. Research that uses the FMSF often views the family unit from the perception of the mother or father in regards to the family unit (Knafl & Deatrick, 2006).

The framework also tests the response of family management behaviors on individual functioning (Knafl & Deatrick, 2003). This study measured family management behaviors as condition management ability (ability) and condition

management effort (effort) on asthma morbidity and asthma control variables. By assessing ability and effort, this study tested the framework of the family management behaviors (ability, effort) on individual function variables (asthma morbidity, asthma control).

Conceptual Framework

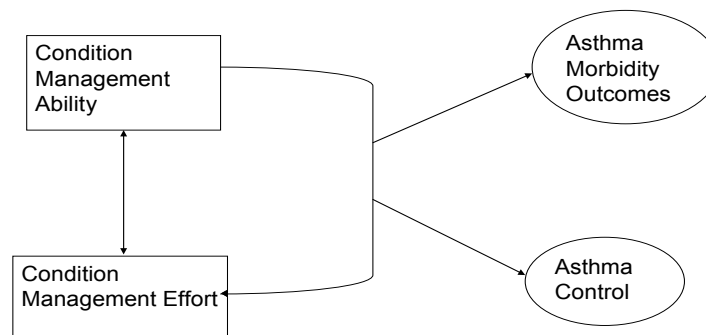
The conceptual framework for this study used an adaptation of Knafl and Deatrick's (2003) framework to provide a foundation for examining family management behaviors on individual child outcomes. This dissertation focused on two management behaviors including ability and effort in relation to the outcome variables of child asthma morbidity and asthma control. These management behaviors are appropriate for families of children with asthma as the focus is on the maternal caregiver perception of a) the ability to manage chronic conditions and b) how much effort is required with chronic conditions.

Family management behaviors are defined as the capacity to which a family as a unit incorporates the demands of childhood condition into family life (Knafl & Deatrick, 1990). Whereas, condition management ability is defined as the parental perceptions regarding the family's competency in managing the child's condition and condition management effort is the work required of the family when managing the chronic condition (Knafl et al., 2009).

Individual child outcomes in this study were asthma morbidity and asthma control. Asthma morbidity is defined as outcomes such as emergency department visits, hospitalizations, and school days missed due to asthma (CDC, 2008). A hospital stay was defined as a required stay overnight due to asthma as self-reported by the maternal

caregiver. Asthma control is defined as minimization of symptoms for the chronic condition of asthma during daytime and nighttime hours (Juniper, 2004). Therefore, the conceptual framework proposes the relationships among the variables identified for this study and is illustrated in Figure 2.

Figure 2.
Adapted from Knafl & Deatrick (2003) and Horner (2004)



The FMSF and conceptual framework for this study is elaborated upon further in the next chapter.

Assumptions

For the purpose of this study, the following assumptions are made:

1. Asthma during childhood has a negative impact on health.
2. Maternal caregivers are the primary caregivers within families affected by childhood asthma (Horner, 2008; Turner-Henson and Johnston, 1992).
3. Maternal caregivers will accurately report perceptions of family management behaviors (effort, ability).

4. Maternal caregivers will accurately report asthma morbidity outcomes for the child with asthma.

These assumptions guided the proposed study.

Summary

This study focuses on the perceptions of ability and effort of maternal caregivers who have children with asthma. Overall, the study examines the relationship among family management behaviors (condition management ability and condition management effort), asthma morbidity outcomes, and asthma control. Since maternal caregivers are the primary family caregiver of children, this investigation focused on perceptions of the maternal caregivers and sought to better understand how families perceive the chronic condition of asthma in children. The research identifies maternal perceptions of managing asthma and quantifies management ability and effort required when affected by the condition on a daily basis. In particular, this study sought to identify how maternal caregivers evaluate condition management ability and condition management effort when their children are affected by asthma.

By examining maternal caregiver perceptions regarding asthma, researchers hope to influence daily management efforts when caring for children with asthma. Since the perceptions of maternal caregivers may influence care, understanding perceived ability and effort of the maternal caregivers is significant when caring for children with chronic conditions. When families are continuously affected by family member requirements as a result of chronic conditions, ability and effort are strongly influenced. The perceived effects of ability and effort may drive families to adjust daily actions and responsibilities.

Asthma morbidity outcomes and asthma control are considered gold standards when measuring the effects of asthma, particularly when measuring how the family manages asthma. Understanding the family management of childhood asthma and assessing asthma control is complex. With asthma as the leading cause of childhood hospitalizations, emergency department visits, and school days missed, it is imperative to evaluate how the family manages asthma on a daily basis. With variations in chronic childhood asthma, healthcare providers are charged with ensuring asthma control and minimizing asthma morbidity so children can sleep at night and be more active during the daytime hours.

Chapter Two

Review of Literature

Contrary to many chronic conditions in children, current estimates illustrate the prevalence of asthma to be increasing in school-aged children (ages five-18 years) (Akinbami et al., 2011; CDC, 2008). From 2003 to 2008, the American Lung Association (ALA) reported that the prevalence of childhood asthma has increased to 11% among school-aged children (ALA, 2010). With higher asthma prevalence, more families of children with asthma may experience difficulties in managing this chronic condition. Predominantly, families are required to maintain an adequate balance of managing the child's chronic condition with daily home management. This chapter identifies concepts and synthesizes literature limited to the areas of family management behaviors with chronic childhood conditions, family management behaviors with asthma, maternal caregivers, asthma morbidity, and asthma control. Lastly, this chapter reviews literature related to an innovative theory identified as the FMSF (Knafl & Deatrick, 2006).

This review of literature was acquired through a systematic review identifying research examining family management of common childhood chronic conditions. Specific criteria included peer-reviewed articles that a) addressed a family perspective with a childhood chronic condition, specific attention was made towards maternal caregiver perspectives; b) measured specific family management behavior variables related directly to childhood asthma, and c) evaluated family management behaviors with chronic childhood conditions. Much of the recent research integrated a new concept termed family management style (Knafl & Deatrick, 2003).

Data sources for the literature review focused on published research articles and doctoral dissertations from 1996-2010. The search was complete using internet search tools such as, OVID, Academic Search Premiere, CINAHL, Medline Plus, PubMed, conference proceedings, and personal communication. Specific keywords included maternal caregiver, family, asthma, chronic condition, and family management and key phrases included family management style and family management behavior. Parameters were limited to childhood chronic conditions with an emphasis on asthma and chronic conditions with similar trajectories (i.e. diabetes, cancer); management by family and, specifically, the maternal caregiver, with a child diagnosed with a chronic condition; and family perceptions of management with chronic childhood conditions. In this review, we seek to improve our understanding of family management behaviors with specific childhood chronic conditions.

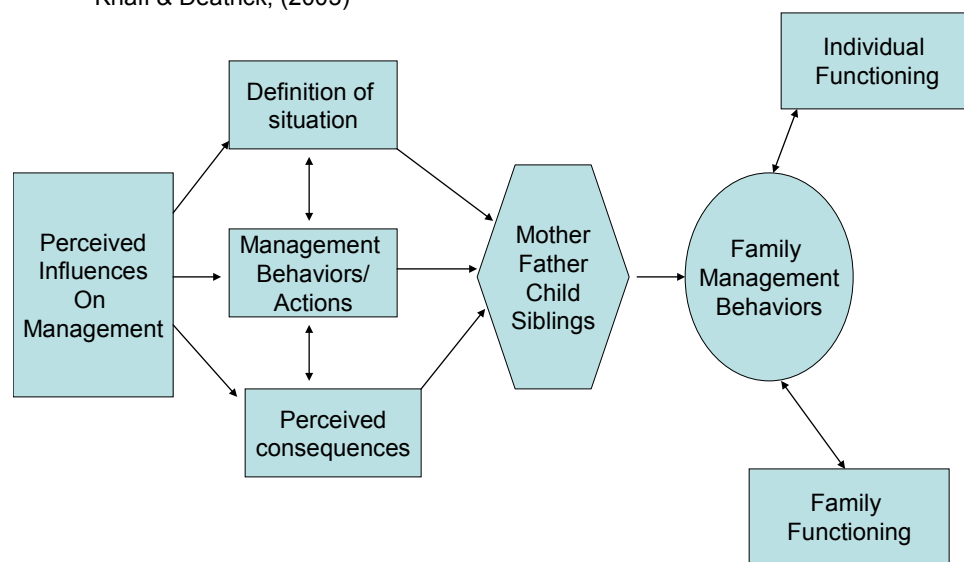
Theoretical Framework

The Family Management Style Framework (FMSF) integrates concepts relating to how families manage chronic conditions and daily management behaviors associated with such conditions. The framework is appropriate for this research study, since the framework focuses on the family management behaviors in children with chronic conditions. With childhood persistent asthma, families must manage this chronic condition on a daily basis with preventative medications in order to lessen the risk of asthma morbidity and mortality. Childhood asthma trajectories may adjust over time for each individual, and the changes are evident in a variety of ways. For example, family caregivers of school-aged children with asthma must recognize early signs of asthma exacerbations. When exacerbations occur, family caregivers must immediately

implement treatment in order to lessen the chance of asthma morbidity outcomes such as emergency visits, hospitalizations, and/or school days missed (Horner, 2004; McQuaid et al., 2006).

Similar to chronic asthma changes, family management behaviors can also change over time. Drs. Deatrick, Knafl and colleagues (2009) developed the FMSF, which describes the family management behaviors with chronic childhood conditions. The FMSF is a conceptual representation of the family response towards a child's chronic condition that incorporates the views of particular individuals within the family (Deatrick et al., 2009). Particularly, this framework focuses on an individual family member's perspective of the family's style of management.

Figure 1. Family Management Style Framework
Knafl & Deatrick, (2003)



The authors of this framework identify the relationship as interplay between three main aspects identified as definition of the situation, management behaviors/actions, and perceived consequences of the chronic condition. The maternal caregiver's definition of

the situation is a subjective meaning or perception attributed to important essentials of family's circumstances. Management behaviors are defined as distinct behavioral accommodations that family members, in this case maternal caregivers, use to manage a child's condition on a daily basis. Perceived consequences are the actual or expected child-specific outcomes that shape the family's management behaviors, ultimately affecting the subsequent definition of the situation. Family management behaviors are observed by maternal caregiver's definition of the situation, management behaviors and/or actions, and perceived consequences of the situation (Knafl & Deatrick, 2003).

The FMSF directs researchers to consider both how individual family members and the family unit as a whole actively manage health-related challenges. The FMSF may center upon an individual family member or the family as a unit, and can focus on a health-related challenge broadly or narrowly. For example, a maternal caregiver's perception of family management behaviors may influence the child's asthma outcomes. In this study, asthma outcomes are defined as asthma morbidity and control.

This emerging body of literature using the FMSF often centers on family perceptions and family management behaviors. Since this study focused on family's response towards managing a chronic condition, this study evaluated two specific family management behaviors termed condition management ability and condition management effort. The condition management ability focuses on parental perceptions regarding the family's competency in managing the child's condition, while the condition management effort focuses on the work required of the family when managing the chronic condition (Deatrick et al., 2009).

In the late 1990s, Knafl and colleagues evaluated how family experience of chronic condition management may vary from the perspective of the mother and the father. The researchers found that perceptions were disconnected from one another and, furthermore, did not influence one other. Maternal and paternal caregiver experiences were examined individually and, though parental approaches differed, caregiver approaches were similar (Knafl & Zoeller, 2000). Furthermore, while assessing family perceptions, the researchers identified a large number of strengths and weaknesses when obtaining information separately from family members. For example, maternal caregivers emphasized increased condition management effort with the chronic condition while the paternal caregiver acknowledged increased condition management ability with less condition management effort for the chronic condition.

Over the past decade, more studies have been published utilizing the FMSF with chronic childhood conditions (Deatrick et al., 2009; Alderfer, 2006; Ogle, 2006). Deatrick and colleagues used the FMSF to assess families with children diagnosed with brain tumors (2009; 2006). These studies found that families who had children with brain tumor diagnoses may function with less desirable family management behaviors than families who had children without a chronic condition (Deatrick et al., 2006). Alderfer (2006) strengthened the FMSF by integrating the family management style theory with other published family intervention theories, including family systems theory. This researcher closely described how family management behaviors and styles may guide healthcare towards better home management when evaluating family managing styles with chronic conditions. This research established the appropriateness of the FMSF with chronic conditions, when conceptual foundations of the framework are

compared with a former substantiated family/systems theory. At the time of this study, no research has evaluated the FMSF incorporating family perceptions in relation to child specific outcomes, such as asthma morbidity and asthma control outcomes.

Deatrick and colleagues (2009) added to family management behavior research with a recent descriptive design to evaluate six family factors associated with family management of chronic childhood conditions. These six factors were identified by a quantitative validation study of family management behaviors and in turn have become identified with the Family Management Measure (FaMM). This study utilizes the FaMM to measure the independent variables.

Family management behaviors.

Family management with chronic childhood conditions.

The term family management behavior has only recently been defined and limited work has been published at this time. Recently studies have evaluated family management behaviors with chronic childhood conditions (Deatrick et al., 2006; Wiegand et al., 2008; Deatrick et al., 2009). A childhood chronic condition is a lifetime condition the family must learn to adapt to and manage. The family management behaviors demonstrate particular adapting and managing approaches towards childhood conditions. By understanding how the family manages a chronic condition, researchers hope to enhance knowledge and expectations for the family when caring for their children with chronic conditions.

The research reviewed all focus on family management behavior concepts associated with family management with a child diagnosed with chronic conditions. Family management behaviors are accommodations that family members use to manage

the child's chronic condition on a daily basis (Knafl & Deatrick, 2003). Gallo and Knafl (1998) evaluated the family management behavior of families ($N = 58$) affected by a variety of chronic conditions, such as cystic fibrosis, cancer, and juvenile rheumatoid arthritis. This qualitative research evaluated how parents managed chronic conditions and found three differing approaches with both mother and father. These three parental approaches included strict, flexible, and selective adherence towards management of a chronic condition (Gallo & Knafl, 1998). By assessing and categorizing various approaches the family may employ, the research provided an improved understanding surrounding daily management of care.

Family research also utilizes the concept of family management behaviors as a predictor of positive functioning within families. Tak and McCubbin (2002) further identified that the challenges created by the chronic condition of congenital heart disease inevitably leads to increased family stress and correlated with poorly perceived social support for the family. These researchers particularly noted an increase stress for families in the early stages of diagnosis and predicted an inability to cope with the chronic condition when increased family stress was involved. In this study, the researchers utilized a resiliency model recognizing the family challenges, and found resilience to be the predictive factor for a hopeful and positive outcome. These findings included the recognition of family caregiver perceptions as a predictor of family management behaviors and recognized challenges families face when managing chronic conditions in children, ultimately leading to difficulty managing the condition within the family. However, a large gap that remains in the literature relates to the discrepancy of

family versus individual management with chronic conditions, particularly associated with behaviors (Tak & McCubbin, 2002).

Frequently, how the family copes with chronic conditions is identified in the literature as a family management behavior. Grant and Whittell (2000) assessed management behavior strategies among families in relation to child's gender, life stage, and family composition. Through their research, the researchers discovered coping differences among the child's genders within the family. Overall, maternal caregivers used more coping strategies than paternal caregivers and ultimately felt more confident in their abilities than paternal caregivers. Grant and Whittell (2000) attributed the parental differences to parental role rather than child's gender specifics. Morrison et al. (2003) reported parental adaptive strategies, such as coping and resiliency, in families managing chronic conditions.

Svavarsdottir & Rayens (2005) evaluated cultural and child's gender differences in parents' well being, sense of coherence, and perception of family hardiness when managing a chronic childhood condition. This research found the family's management behaviors improved with the challenge, yet significantly impacted the morbidity outcomes, whether in entirety or specific elements of the chronic condition. The research findings identified the significance of families' cohesiveness while managing chronic conditions and took into account child's gender and cultural differences within family structure. This was a cross-sectional design with a sample of 137 two-parent families in which family management behaviors were assessed for family behaviors. However, this research primarily assessed an individual family caregiver's behaviors and failed to incorporate a family management perspective (Svavarsdottir & Rayens, 2005).

Family stress can influence the management of the chronic condition on a daily basis. Sullivan-Bolyai et al. (2003) completed a two-part review of literature on published family caregiver literature. In this review, authors described family management behaviors towards stressors associated with management and responsibilities of the child's chronic condition within a caregiver role. These researchers identified four responsibilities including managing the condition, identifying and accessing community resources, maintaining the family unit and maintaining self. This review of family management behavior recognized that a family member's perception of a chronic condition is ultimately linked to management. Yet, this research was the first to communicate that family behavior may affect the outcomes with chronic conditions (Sullivan-Bolyai et al., 2003). Potential outcomes could include morbidity or mortality effects from the chronic condition.

Saloviita, et al. (2003) recognized management behaviors, such as family demands and burden, to be highly correlated with stress. This research examined stress as a family management behavior and evaluated demands and adaptive responses while managing chronic conditions. This research identified the variance with parental stress when managing children with intellectual disabilities using the Double ABCX Model and found negative definition of the situation was associated with behavioral problems in the child.

Gallo and Knafl (1998) examined the impact of childhood chronic conditions on parental and family behaviors. The researchers compared 58 families of school age children with chronic conditions and observed how the family manages specific chronic condition requirements. The researchers identified three stylistic approaches toward

condition management including strict adherence, flexible adherence, and selective adherence. Ultimately, this research was instrumental in recognizing differences between maternal and paternal approaches towards management of chronic conditions. This research was deficient in measuring chronic condition management, in view of the fact that a tool for measuring family management is essential. First, researchers must seek to understand how family management behaviors may affect the outcomes.

Schumacher, Stewart, Archbold, Dodd, and Dibble (2000) identified management behaviors of family caregivers as a multidimensional construct comprised of certain concepts of preparedness, self-efficacy, competency, and mastery. These researchers recognized multiple variables influence the caregiver in home management of a child's chronic condition. For example, preparedness is often identified while a crisis occurs, whereas mastery mainly involves time and focuses on precision. The authors found perceptions of the maternal caregiver regarding her ability can affect potential child-specific outcomes with management (Schumacher et al., 2000).

Sullivan-Bolyai et al. (2004) evaluated literature to review strategies of a family's ability to manage chronic conditions and evaluated family activities associated with the ongoing care of school-aged children diagnosed with a chronic condition. This review presented responsibilities of families when presented with the diagnosis of a chronic condition. In addition, findings by the researchers provided goals for families for ongoing healthcare management, nursing interventions, discharge planning and responsibilities as fundamental focus for nurses and families when children affected by a chronic condition. The study findings indicated the ultimate goals for families included

managing the condition, identifying and accessing community resources, maintaining the family unit and maintaining self (Sullivan-Bolyai et al., 2004).

Furthermore, Smetana and colleagues (2004) examined home management behaviors in a sample of adolescents diagnosed with chronic conditions. These management behaviors were described as family capabilities and were assessed from the perspective of the child and the child's caregiver. This research measured the parent-child dyad, repeatedly a strong point of family research, yet failed to assess any effects a chronic condition has on a relationship or the family involved. It is important to note that the researchers recognized management behaviors as vital achievements in school-aged children attaining the developmental stage of autonomy. Besides this research, few published materials on management behaviors in families of school-aged children were found (Horner, 2004; Yoos, Kitzman, McMullen, & Sidora, 2003), and it would benefit research to evaluate perceptions of family management behaviors.

Trajectories of particular childhood chronic conditions and management may differ (Gallo & Knafl, 1998; Miller & Drotar, 2003; Nelson et al, 2006). Most research regarding family management evaluated included chronic conditions with similar trajectories to asthma, such as diabetes (McQuaid et al., 2006; Deatrick et al., 2009). For some children with chronic conditions, management may simply require daily monitoring of symptoms and medication administration. While for other chronic childhood conditions, long-term therapy management can be difficult and complex. Specific examples include children with chronic conditions such as cystic fibrosis or a child with Type 1 diabetes requiring management associated with glucose monitoring, calorie

counts, and adjusting insulin doses (Nelson et al., 2006; Smetana et al., 2004). Persistent asthma can fall into either category dependent upon asthma control.

Maternal caregivers and chronic conditions.

Maternal caregivers tend to be the primary caregiver of children (Buford, 2004; Gallo & Knafl, 1998). Hanson (1998) found that 92% of maternal caregivers identified themselves as the primary health caregiver within the family. However, few studies address the explicit role of the maternal caregivers in children with chronic conditions (Buford, 2004; Gallo & Knafl, 1998; Horner, 2004; Turner-Henson & Johnston, 1992). Buford (2004) identified the role of maternal caregivers have in assisting children to learn and achieve self-care. This research found the role of the maternal caregiver to be a positive influence. Additionally, nursing research has reported the recognition of a lack of treatment strategies within families of children with asthma (Horner & Fouladi, 2003) and a lack of knowledge related to asthma from maternal caregivers to asthma symptoms and triggers (Horner, 2004). This research has lead to multiple studies assessing the impact of home management factors on asthma and asthma morbidity (Horner et al., 2006; Horner, 2008)

In past years, Sterling & Peterson (2003) found the maternal caregiver approach towards family management is guided by an education focus on skills, preparation, and perceptions of the maternal caregiver. This research recognized the maternal caregiver as primary caregiver of children with asthma. This research focused on African-American women with children diagnosed with asthma and found a need for healthcare providers to recognize maternal caregivers when implementing care for children with chronic conditions. Using qualitative ethnography, the researchers interviewed maternal

caregivers and identified six themes depicting specific characteristics the maternal caregivers had when managing a child's asthma. These themes included knowledge of asthma, gatekeepers of care, religious beliefs, support, roles as teacher, counselor, and advisor, and self-sufficiency (Sterling & Peterson, 2003). Comparatively, Deatrick et al. (2009) found perceptions of maternal caregivers and family management characteristics are similar in nature. Although this research focused on the maternal caregivers of children who survived cancer, it may parallel other chronic conditions.

Maternal caregivers necessitate various responsibilities when caring for children with chronic conditions. This is especially true with the chronic condition of asthma. Maternal caregivers need to possess management skills such as recognition, monitoring and decision making related to childhood asthma in order to adequately manage treatment of childhood asthma (Horner, 2004; Yoos et al., 2003). Recently, Suglia and colleagues (2010) identified poorer outcomes when the maternal caregiver identified stressors in the home of a child diagnosed with asthma. This study acknowledged increased stress within the home often leads to increased risk with asthma morbidity, as well as poorer asthma outcomes.

Maternal caregivers often develop routines within the family. Buford (2004) identified maternal caregiver roles when caring for children with the chronic condition of asthma. This research indicated that mothers take an active role in transfer of responsibility, empowerment, and decision making in children diagnosed with asthma. This research found that the process of the transfer of role from maternal caregiver to child is complex, takes multiple years to complete, and is often completed at various stages and transitions (Buford, 2004).

Family management in childhood asthma.

Family management of chronic conditions may also reveal certain perceptions family members may have regarding a particular condition and diagnosis. Advances in knowledge of family management with childhood conditions have increased over recent years. Such advancements, predominantly with asthma research, over the last decade have focused on theory development, asthma risk factors, environmental situations (i.e. home evaluations, smoking cessation), school-based interventions, and health care disparities. Often identified as the most common childhood condition, asthma prevalence is much higher within the school-aged population than in preschool children. The disparity is often noted with prevalence in preschool children, since asthma is frequently attributable to symptoms recognized as other respiratory ailments versus asthma (Skoner, 2002). In addition, many healthcare providers fail to diagnose asthma until recurrent symptoms occur, due to tendency to misdiagnose asthma symptoms. With such disparity, scientific advances have emerged in assessing specific family behaviors related to asthma or may even focus on the school age child versus preschool age (Riekert et al., 2003; Skoner, 2002).

This review focused on literature relating to family management pertaining to the chronic condition of asthma. Barton, et al. (2002) evaluated management behaviors related to knowledge of asthma in adolescents and parents. This research found that inadequate knowledge leads to inadequate decisions and poor self-management for a chronic condition such as asthma. Whereas, McQuaid et al. (2005) identified family management behaviors related to asthma management on the basis of disease process, pathology, and medication function and use. This research utilized the Family Asthma

Management System Scale (FAMSS) and acknowledged the measure's usefulness when assessing family-based asthma management. The FAMSS uses a clinical interview approach allowing families to explain management behaviors. One asset of this research is the methodology of assessing management from an individual, family and system approach as the clinical interview also accounts for objective evaluation. This research found the FAMSS demonstrated adequate internal consistency ($\alpha = .84$); however it is limited by a small sample size ($n = 53$) and a long collection time (45 minutes). The FAMSS approach also requires time to develop a rapport with participants before beginning the interview (McQuaid et al., 2005).

Family management behaviors, in regards to childhood asthma, often focus on stressors, management, and understanding of daily processes of the family (Horner, 2004; Morawska et al., 2008). Consistently, management of childhood asthma requires family caregivers to monitor daily for symptoms, administer medications, make home environmental modifications, coordinate health care visits and purchase of health supplies, as well as the management of children's other needs such as day to day needs, school and family activities (Butz et al., 2004; Horner, 2004; Horner & Fouladi, 2003; McQuaid et al., 2006). Morawska et al. (2008) examined challenges parents of asthma children perceive when managing the condition on a daily basis. Primarily, parents identified specific tasks associated with entrusting schools and caregivers, identifying symptoms, and avoiding triggers when the child is diagnosed with asthma. McQuaid and colleagues (2006) evaluated 122 children diagnosed with asthma and found the family response towards asthma symptoms mediates the relationship between child symptom perception and asthma morbidity outcomes. This study reported an underestimation of

symptoms from the child regarding asthma, yet found adequate family response mediated the child perception and ultimately the child's outcomes. Consequently, if the family had ineffective responses to the child's symptoms, then the child had increased asthma morbidity outcomes (McQuaid et al., 2006).

Guidelines published by the National Heart, Lung, and Blood Institute (NHLBI) defined how exacerbations in childhood asthma may fluctuate in severity, such that some children may experience asthma exacerbations that are mild and resolve without treatment, while other children may progress to symptomatic instability with ongoing treatment (U.S. Department of Health and Human Services [USHHS], 2007). Childhood asthma is characterized by symptoms that include chest tightness, shortness of breath, coughing, and wheezing. Children with asthma may exhibit one or all of these characteristics; however, due to the young age or developmental maturity level, the family caregiver may not perceive the symptoms as threats of the chronic disease.

High asthma morbidity in children, particularly among children living in urban regions, is often associated with inadequate family management of asthma (Butz et al., 2004). High morbidity may require children and the family to have frequent healthcare visits, emergency department visits, and miss school days. With this morbidity and daily requirements of asthma management, families may struggle financially. To further increase responsibilities, home asthma management may be influenced by family management behaviors (Knafl & Deatrick, 2003; Smetana, Campione-Barr, & Daddis, 2004).

Medical management in childhood asthma conditions has centered on understanding the diagnosis of asthma, participating in medical management of asthma,

and environmental control measure interventions for asthma. Zhao et al. (2002) recognized the significance of family management behaviors in relation to asthma symptom recognition, prevention, medication, and treatment. Research is slowly recognizing how a child's asthma management is integrated with active family management of this chronic condition. National asthma guidelines also direct medical management towards reliance on families by utilizing daily action care plans for the child with asthma (USHHS, 2007). There has been limited focus on integrating management of asthma with maternal caregivers. There is growing recognition that these family management strategies do improve childhood asthma control. However, knowing how families perceive a child's asthma management is important so as to assess whether the perceptions predict a child's asthma morbidity outcomes or asthma control.

Family management behaviors in families of children with asthma have become a great concern to researchers. Daily home management includes symptom monitoring, medication administration, environmental modifications, and scheduling health care visits (Butz et al., 2004; Horner, 2004; Horner & Fouladi, 2003). In a study of caregivers in the inner city caring for 100 children (two to eight years of age) with asthma, Butz and colleagues (2004) examined home asthma management practices, and the relationship to asthma severity. These authors found no significant differences among socioeconomic characteristics of children or family caregivers related to asthma severity. Socioeconomic characteristics included child's gender, minority status, smoking status, family income, and educational level. Yet, the research concluded that, regardless of socioeconomic characteristics, family caregivers of children with asthma often fail to treat early signs of asthma, thus leading to an increase in asthma morbidity outcomes.

Most studies of family management behaviors with asthma focus on the school-aged child. Kitner (2004) found a significant association between the lacking understanding of asthma and accepting the asthma diagnosis within the family of school-aged children. The goal of this research was to identify the relationship among child-specific characteristics, environmental influences, and acceptance of childhood asthma. Findings of this research recognized the need for research to focus on family education with asthma symptoms, specifically how to appropriately manage the symptoms in school-aged children. Researchers called for implementation of psychosocial resources in the early stages of diagnosis to facilitate childhood asthma acceptance in affected families and schools. By introducing these resources, families may demonstrate improved family management behaviors when managing a child with asthma.

Many researchers have evaluated demographic characteristics of school-aged children diagnosed with asthma (Ungar et al., 2011; Horner & Fouladi, 2003; Wamboldt et al., 2002). Several demographic characteristics evaluated focused on age, ethnicity, child's gender, environmental exposures, and child severity with the chronic condition. These demographic characteristics often associate child's age with asthma severity or environmental triggers with asthma symptoms. For example, a child's asthma might be triggered by and respond to exercise, rain, and dust, strong odors, and cigarette smoke. The family caregiver's perception to respond to these triggers and appropriately act will identify the ability to adequately assess the situation and appropriately make the necessary environmental changes to avoid disease progression (USHHS, 2002). For instance, environmental smoke exposure has been found to be associated with increased asthma morbidity in several studies (Ungar et al., 2011; Wamboldt et al., 2002). One

study recognized family members with no college experience exposed children with asthma to environmental cigarette smoke more than those attending college after high school (Ungar et al., 2011). While it is important to assess demographics, this study will also evaluate asthma morbidity and asthma control when assessing particular family management behaviors.

Asthma Morbidity

Childhood asthma morbidity outcomes are defined by Warman, Silver, and Stein (2001) and Cloutier et al. (2002) as emergency department (ED) visits, hospitalizations, and school days missed due to asthma. With childhood asthma prevalence and asthma morbidity escalating in the United States, the family can be significantly affected by a child's asthma morbidity. It is essential to understand that without adequate management, the child may have increased asthma morbidity outcomes.

Asthma is especially problematic for school-age children in low-income and minority populations. In this population, asthma morbidity greatly affects children by emergency department visits, hospitalizations, and school days missed (Akinbami & Schoendorf, 2002; Horner, 2004). Significant absenteeism often required children to miss three times more school days than a child without a chronic condition (Lara et al., 2003). As documented, asthma morbidity often leads to frequent emergency department visits and hospitalizations, thus increasing caregiver work days missed.

A large focus in research centers on the demographic variables of the school-age child with asthma. For example, younger children diagnosed with asthma have a greater number of emergency department visits and hospitalizations. These may all be influenced by family management behaviors thus it is important for us to study this area.

Horner, Surratt, and Smith (2002) identified specific asthma risk factors in a meta-analysis for managing asthma as child's ethnicity, gender, severity of condition, socioeconomic class, and home and neighboring environments. Specifically, research often identified the sociodemographic risk factors that increase childhood morbidity issues as unscheduled office visits, school absenteeism, emergency room visits and hospitalizations (Horner et al., 2002).

Sociodemographic factors are often cited as predictors of poor family management with chronic conditions and increased asthma morbidity. Horner (2004) describes asthma risk factors as minority status, asthma severity, and socioeconomic characteristics. The research described socioeconomic characteristics, such as child's age, maternal work status, or lack of insurance led to high asthma morbidity in school-aged asthma populations living within rural settings. Comparable research findings from inner city areas reported inadequate home management of asthma is correlated with poor asthma control and recurrent asthma morbidity related to failure to adhere to treatment regimes (Butz, et al., 2004).

Healthy People 2020 objectives focus on improving home management and reducing burden of chronic diseases, such as asthma (CDC, 2010). Goals from Healthy People 2020 relate to family management behaviors and asthma morbidity outcomes including school absenteeism, hospitalizations, and acute care visits. These goals identify assessing the impact of climate change and indoor air quality on asthma causation and exacerbations, evaluating causes of asthma, developing effective prevention strategies (i.e. weight control, allergen avoidance), and treatments to alter the progression of disease severity and, ultimately, to prevent asthma onset (CDC, 2010; www.HealthyPeople.gov).

Furthermore, asthma can place a huge burden on the affected children and the family as it may limit a child's activities and requires potentially complex and costly interventions, particularly with school and work days missed (Akanbami et al., 2006). With school-age children, asthma morbidity outcomes can lead to complications within the balance of the family, primarily due to disruption of routine or daily family activities. For example, when the child with uncontrolled asthma is hospitalized, the family must adjust normal daily responsibilities and priorities and many times the family roles must shift. Recent evidence suggests that in daily management of asthma, families have difficulty managing asthma needs such as daily preventative medications, and sometimes even fail to administer the medications (Gerald et al., 2009; Horner, 2008). Gerald et al. (2009) identified a lack of adherence to preventative medications for school-aged children diagnosed with persistent asthma when monitored over a 15 month period. In this study, 78 percent of children were less than 50% adherent with daily prescribed control medications.

Causal relationships between childhood asthma and asthma morbidity outcomes are often described in the literature. Much of this research focuses on environmental stimuli related to exposures for children diagnosed with asthma and how this exposure affects their morbidity. Many factors contribute to asthma morbidity such as lack of adherence to preventative medications or environmental tobacco smoke exposure. Asthma morbidity in minority children is positively correlated with lower socioeconomic status, home allergen exposure, deficient insurance coverage, and lack of education in caregivers (Kruse et al., 2007; Lara et al., 2003; Wallace, Denk, & Kruse, 2004). In this research, all studies presented evidence that children from families with lower availability

of resources frequently require emergency department visits, hospitalizations, and missed school days because of asthma more than families for whom the availability of resources is higher.

Asthma Control

Much research has been published using the terminology of asthma severity when assessing children with asthma (Horner, 2004; Lara et al., 2003; McQuaid et al., 2006). Many measures seek asthma severity using asthma guidelines or severity specific questions assessing the underlying disease process (USHHS, 2007). Yet, national guidelines, Global Initiative for Asthma (GINA) recognize asthma control as the primary goal in asthma management (GINA, 2010). By obtaining optimal control with asthma, children will demonstrate sufficiency in treatment and management of asthma (Juniper et al., 1999).

Over the years, several studies have incorporated asthma control measures into assessing childhood asthma (Gerald et al., 2009; Horner, 2004). Gerald and colleagues (2009) assessed children with persistent asthma and found supervised therapy in a school setting improves childhood asthma control. This research utilized supervised school based monitoring of medication administration and found improved asthma outcomes in children who were monitored by school staff. This research design was instrumental in recognizing the benefit of a school-based monitoring system. Additionally, Horner (2004) found poorer asthma control to cause disruption in the home setting with family routines and resources. This research recognized the effects uncontrolled asthma has on family routines. The findings also reported a limitation with family resources when childhood asthma is not controlled. Juniper et al. (2005) found asthma control may be

achieved spontaneously (without treatment) or with the use of medications. This research also recognized extremely poor-controlled asthma may be life threatening. It is important to note that clinicians often differ from family regarding what constitutes asthma control.

This review of literature supported Juniper and colleagues (2005) finding that with total control of asthma, children demonstrate no symptoms, no physical limitations, no rescue medication usage (bronchodilator), and a normal airway. Published objectives and international asthma goals recommended by NHLBI and GINA focus on asthma control of the individual with asthma with goals for asthma to remain well-controlled (USHHS, 2007; GINA, 2010). In turn, Juniper et al. (2005) recommends utilizing the Asthma Control Questionnaire (ACQ) as a simple measure for assessing asthma control.

Initially when developing the ACQ, Juniper and colleagues (2005) mailed out a list of ten asthma symptoms to 100 asthma clinicians in 18 countries and were asked to score each individually based on significance in estimating asthma control. Of the 100 clinicians, 91, who were also members of various international asthma guideline committees, responded by choosing the top five for assessing asthma control in conjunction with two additional measures (FEV1% predicted prebronchodilator use and rescue bronchodilator use). Additionally, ACQ scoring uses cut off points to assess control. Control is calculated using mean score with individual cut off points of .75 (85% of children are controlled) to 1.5 (66% of children are controlled) (Juniper et al., 2004). This study interpreted a score greater than 1.5 to indicate poor control.

After a review by 20 pediatric asthma colleagues, a validation study was completed to assess the measure for use with children. The findings indicated the ACQ is also suitable for evaluating asthma control in children as the pediatric colleagues

recognized the same top five symptoms (Juniper et al., 1999). In addition, a second validation study assessed whether the measure could be shortened to five questions assessing symptoms only. These findings indicated the shorter version could be utilized in clinical trials without the loss of validity or modification in interpretation (Juniper et al., 2004).

Gaps in Literature

Upon review of the body of literature, there is literature to support the association between certain demographic variables and childhood asthma morbidity outcomes. In addition, there is literature supporting the recognition of family management behaviors with childhood asthma. However, no studies to date have evaluated the relationship among family management behaviors, asthma morbidity, and asthma outcome in school-age children.

The literature has recognized that family management behavior definitions are not consistent within published articles, though various concepts are utilized to identify family management behaviors. Therefore, after evaluating this literature on family management, we may better understand responsibilities and behaviors when families are managing a child with a chronic condition. This study will evaluate demographic characteristics in school-age children with asthma, but will further add specific child-outcomes including asthma morbidity and asthma control measures when assessing particular family management behaviors identified as condition management ability and condition management effort. Additionally, when measuring family management behaviors and asthma control from the perspective of the maternal caregiver we hope to strengthen the Family Management Measure and the Asthma Control Questionnaire.

Ultimately, by understanding the family's perception and family management behaviors with asthma management, health care professionals may reduce asthma morbidities such as emergency department visits, hospitalizations, and school days missed and may improve asthma control for children with asthma. In turn, this understanding may guide researchers in future interventions for improving family management behaviors.

Chapter 3

Methodology

Researchers have long been interested in how families manage children's chronic conditions (McQuaid et al., 2006; Sullivan-Bolyai et al., 2004; Sullivan-Bolyai et al., 2003; Turner-Henson et al., 1992). This study examined ability and effort as family management behaviors, and focused on the maternal caregiver's perception of home management of children's asthma. To reiterate, ability is defined as the parental perceptions of their competency in managing the child's condition, while effort is defined as the work required when managing the chronic condition (Knafl et al., 2009). The study examined the relationships between maternal caregivers' perceptions of ability and effort in children with asthma, asthma morbidity (emergency department visits, hospitalizations, school days missed), and asthma control in a convenience sample of 101 maternal caregivers. The methods used in the study are described in this chapter and include study design, sampling, data collection instruments, procedure for collection of data, and plans for data analysis.

Design

A predictive, cross-sectional design was used to describe the family management behaviors (ability, effort) reported by 101 maternal caregivers of children with asthma, and to examine the relationship between family management behaviors, children's asthma morbidity outcomes, and asthma control. The independent variables of the study were demographic factors (i.e. maternal caregiver work status, child age) and family management behaviors (ability, effort). The dependent variables were maternal report of

the child's asthma morbidity outcomes including emergency department visits, hospitalizations, school days missed, and asthma control.

A predictive, cross-sectional design was appropriate for this study since the researcher examined patterns of relationships among family management behaviors, asthma morbidity, and asthma control outcomes. Quantitative correlational designs are appropriate to recognize associations among variables in the research questions (Polit & Beck, 2008).

Sample and Setting

A nonprobability, convenience sample of maternal caregivers of school-aged children with asthma was recruited from an interdisciplinary pediatric pulmonary clinic. This type of sampling technique was selected to ensure that an adequate number of maternal caregivers of children with asthma were reached. Convenience sampling is useful in correlational studies conducted in new areas of research (Polit & Beck, 2008). Inclusion criteria for the sample included maternal caregivers of a children: 1) diagnosed with asthma for one year or more, 2) on preventative medication for persistent asthma, and 3) enrolled in kindergarten through 5th grade. Maternal caregivers for this study were defined as the female caregiver who acknowledges self as the primary responsible family caregiver for the child with asthma. Medical management of a persistent asthma diagnosis requires prescribed daily preventative medication such as inhaled corticosteroids or leukotriene modifiers (USHHS, 2007). To be eligible for sample selection, the maternal caregiver must have had a child who is prescribed daily preventative medications for asthma. Exclusion criteria included maternal caregivers who identify an inability to read and speak English or had a child with any comorbid

conditions. Comorbid conditions include a medical diagnosis of a chronic condition that may require daily responsibilities potentially affecting daily asthma care. Maternal caregivers with more than one child meeting inclusion criteria were asked to focus the responses on one particular child meeting the inclusion criteria.

The setting for the study was interdisciplinary asthma care clinics in southeastern freestanding pediatric facilities. These interdisciplinary pulmonary clinics are part of a larger children's hospital system and are housed within pulmonary outpatient clinics. The pulmonary clinics include a health care team consisting of physicians, nurse practitioners, social workers, nurses, nutritionists, and respiratory therapists. Approximately 10 to 20 children with asthma are seen in the clinics per day, and an interdisciplinary model of care delivery is used within the clinic. The pulmonary clinic staff members, primarily the nurses, assisted in identifying potential study participants using the set of inclusion and exclusion criteria. By using this procedure, the researchers ensure HIPPA policies are adequately followed.

Power Analysis

Based on a review of family management behavior literature, a medium-effect size was recognized as appropriate for this research (Knafl et al., 2009; Polit & Beck, 2008). The sample size was calculated using the following power analysis formula for regression analysis $n = S^2(t_{\alpha, v} + t_{\beta(1), v})^2 / \delta^2$ (Zar, 1999). A variety of analysis techniques were used including descriptive, correlation, and regression analysis. Regression analysis was used in this study to address the predictive ability of the independent variables (ability, effort) with the four study outcomes: asthma morbidity (emergency department visits, hospitalizations, and school days missed) and asthma control. For a medium effect

size and an alpha of .05, the sample size goal is 91. With a sample size of 101, the observed power is .845173 (<http://www.danielsoper.com/statcalc/calc09.aspx>).

Protection of Human Subjects

To ensure protection of human subjects, the research proposal plan for this dissertation was submitted to the IRB at the University of Alabama at Birmingham and reviewed by the hospital system for the pulmonary clinics. All protocol, informed consent and questionnaires were evaluated and approved by the University of Alabama at Birmingham Institutional Review Board (IRB) prior to the start of data collection. Based on comments from the IRB Committee, one primary change was made from pilot plan to the dissertation. The change as recommended by the IRB was for the maternal caregiver to read the instruments instead of the data collector reading all questions to the maternal caregiver. This suggestion was made by IRB staff to protect the child from hearing the maternal caregiver respond with any type of negative responses. Therefore, all instruments were read and completed by maternal caregiver self-report. Procedures were in place if the mother had a low literacy. If the mother reported or was observed having difficulty completing the instruments, the data collector would read the instrument after the child was removed from the room by the staff nurse until all questions were completed.

Instruments

Study instruments included a demographic measure with a focus on asthma morbidity outcomes, the Juniper Asthma Control Questionnaire (ACQ), and the Family Management Measure. The demographic questionnaire focused on maternal caregiver characteristics and events related to the child's asthma. The Juniper ACQ was used to

estimate adequacy of control of the chronic condition of asthma in children diagnosed with the condition (Juniper et al., 2004). Lastly, the Family Management Measure (FaMM) was used to measure the maternal caregiver's perception of family management behaviors with the chronic childhood condition of asthma (Knafl & Deatrick, 2003). The instruments are collectively found in Appendix B.

Demographic Data Questionnaire

A demographic data questionnaire assessed maternal caregiver self-report of key demographic variables associated with the child diagnosed with asthma, the maternal caregiver, and the family of the child with asthma. The demographic data questionnaire was developed after an extensive review of the literature focusing on family management with chronic childhood conditions and a pilot test of the measure by the principal investigator for this research. The principal investigator has been involved with numerous studies involving childhood asthma populations, in community, inpatient, and outpatient settings, which has led to an understanding of key demographic variables potentially impacting maternal caregiver home management of childhood asthma. Therefore, the principal investigator centered the demographic data questionnaire on child, maternal caregiver and family characteristics, including child diagnosis with asthma, asthma morbidity, maternal work status, and family income.

Thirteen demographic questions were collected through a self-report questionnaire completed by the maternal caregiver. The measure was evaluated for reading level using the Flesch Reading Ease instrument (Microsoft, 2007) and was written at the fourth grade reading level. To strengthen the demographic measure, a pilot

test was completed in fall 2008 with a sample of 12 maternal caregivers of children with asthma. The pilot results are discussed in a later section within this chapter.

Demographic data related to the child with asthma included child's current age and when diagnosed with asthma in years/months, school grade, child's gender (0 = male, 1 = female), and child's minority status (0 = nonminority, 1 = minority). Questions associated to demographics were assessed by self report. For minority status, maternal caregivers were asked to categorize child's ethnicity into Caucasian, African-American, Hispanic, non-Hispanic, or other. Demographic information regarding maternal caregivers included family role of maternal caregiver (mother, grandmother, or guardian) and work status (employed full-time, part-time, or no employment). Additional information obtained on family characteristics included type of insurance information (private, public, or no insurance), family structure (single parent, or nuclear, blended), and residence zip code.

Asthma morbidity was collected using the demographic data questionnaire and all data obtained by maternal caregiver self-report. Based on the questions, maternal caregivers reported the number of emergency department visits, hospitalizations, and school days missed for the child in the previous school-year (2009-2010) due to asthma. Emergency department visit was defined as visit due to asthma symptoms, a hospital stay defined as a required stay overnight due to asthma, and school days missed were defined as missed days of school due to problems with asthma. All asthma morbidity data were collected using continuous data and the questions obtained by maternal caregiver self-report. Validity and reliability of this measure are discussed in the pilot study section.

Asthma Control Questionnaire

Asthma control was assessed within the demographic measure using the Juniper Asthma Control Questionnaire (ACQ) (Juniper et al., 2006). U.S. and international guidelines provide clinical care guidance based on asthma symptoms and directions appropriate preventative or control measures. The guidelines recommend optimal asthma control assessments on a routine done by health providers to insure adequate asthma management (NHLBI, 2007; GINA, 2010). Asthma control must not only be viewed on a daily basis, but there must be measures that incorporate asthma control assessments over time. Therefore, the ACQ was developed to evaluate such asthma control assessing the top five asthma symptoms over the past 7-day period. The ACQ was the first measure to be developed and validated to measure asthma control (Juniper et al., 1999, 2006).

This five-item questionnaire was chosen to evaluate asthma control in children from the perspective of the caregiver. Studies have identified that no single assessment tool appears to be best for assessing the severity of asthma; however, to assess asthma control one should evaluate asthma symptoms over the past week's time (USHHS, 2007; Juniper et al., 1999). For the purposes of this study, asthma symptoms were evaluated using five of the most common symptoms in children with diagnosed asthma. These symptoms include awaking at night with asthma symptoms, limitation of daily activities, symptoms in early morning, shortness of breath and wheezing (Juniper et al., 1999).

The ACQ consists of seven items including the five questions related to symptoms, one question related to rescue bronchodilator use, and one question based on FEV₁ results (Juniper et al., 1999). However, a validation study found that deleting the

rescue bronchodilator use and FEV₁ items do not alter the measure's outcomes, or validity of the measure. Consequently, this study utilized a shortened five-item AQC measure (Juniper et al., 2005).

ACQ content and face validity was assessed by sending the questionnaire to 100 members of asthma guideline committees throughout 18 countries (Juniper et al., 1999). Ninety-one experts responded by scoring the top five asthma symptoms. Next, Juniper and colleagues tested fifty asthma clients with symptomatic asthma and found strong reliability and consistency with the measure over baseline, one, five and nine weeks. The questionnaire was found to be responsive to change with asthma and identified a high reliability of .90 between subjects (Juniper et al., 1999).

Construct validity of the ACQ was measured using Pearson correlation coefficients. Using the entire seven-item measure with a cross-sectional design, the ACQ has a construct validity of .72 and using the five-item measure (symptoms alone) the consistency was .77. Over time, the change in all ACQ has construct validity of .74 while the shortened version (symptoms alone) was reported to be .75. Additionally, reliability of the seven-item ACQ was .83 and the shortened version was .82 (Juniper et al., 2005). Reliability and validity with the shortened version are adequate; therefore, the shortened measure was used to assess asthma control from the perspective of the maternal caregiver in children diagnosed with asthma. Pilot testing was not completed on the ACQ.

Family Management Measure

The Family Management Measure (FaMM) was selected based on the congruence with the study theoretical and conceptual frameworks, a thorough literature review,

psychometric characteristics, and ease of administration. To ensure the appropriateness of this measure, a pilot study ($n = 12$) was conducted with a similar study population to determine the feasibility of the study instruments with the proposed population.

The FaMM was designed to measure the family's perception of management behaviors with chronic childhood conditions (Knafl & Deatrick, 2003). The Family Management Style Framework served as the guiding framework for the FaMM. The FaMM evaluates family caregiver perceptions of family management of the child's chronic condition treatment regimen, and how the family incorporates the regimen into everyday family life (Knafl et al., 2009). This measure, consisting of six subscales (a total of 53 items), is an overall measure of family caregiver self-report of chronic condition management behaviors, including child's daily life, condition management ability, condition management effort, family life difficulty, view of condition impact, and parental mutuality.

After evaluation of the FaMM subscales and discussion with the authors of the measure, two particular subscales were chosen for this study including the condition management ability (ability) and condition management effort (effort) subscales. These subscales were selected because the questions focus on the perception of management ability and how much effort is required with chronic conditions, particularly of interest to maternal caregivers when managing childhood chronic conditions.

The condition management ability subscale focuses primarily on the assessment of the parent's perception of their own ability to manage the child's condition; while the condition management effort subscale focuses more on the work involved with managing a child's asthma. These subscales were deemed appropriate since the questions focus on

the perception of management and how much effort is required with chronic conditions. Additionally, the subscales evaluated the maternal caregiver's perspective specific to childhood asthma management and the relationship of management behaviors with children's asthma morbidity outcomes.

Items within the FaMM subscale measures are scored using a Likert scale, ranging from 1 (strongly disagree) to 5 (strongly agree). Condition management ability is measured using 12 items (possible score range 12-60) with higher responses indicating the chronic condition is viewed as more manageable than those with lower responses by maternal caregivers. Condition management effort is evaluated using 4 items (possible score ranges 4-20) with higher responses indicating greater time and work is involved with managing the chronic condition than those of lower scoring.

Content and face validity of the FaMM was assessed by Knafl and Deatrick (2006) using a panel of experts in family nursing research and practice, and by conducting discussion interviews with more than 500 parents of children with a chronic illness. Separate findings were assessed for mothers and fathers. Data collection procedures used in assessing content validity included telephone interviews with a sample of 579 parents from 417 families of children with a broad selection of chronic conditions (Knafl et al., 2009). Parents responded to the 65-item FaMM as well as to various measures of family functioning, including Family Assessment Device (FAD); child behavior, including Eyberg Child Behavior Inventory (ECBI); and child functional status, including Functional Status II (FSII). The authors of the measures used correlations of the subscales with the identified established measures (Knafl et al., 2009). In addition, construct validity was supported by significant correlations between each of

the scales and validated with family measures of functioning, child functional status, and child behavior. These construct validity correlations were computed from responses for all participating parents accounting for inter-parental correlation within families (Knafl et al., 2009).

Condition management ability subscale.

The condition management ability subscale is a 12-item scale and addresses the maternal caregiver's perception of the overall management of the child's condition. This scale addresses knowledge, ability, and competency to manage the child's condition. This subscale identifies how the family caregiver views the child's chronic condition as manageable now and into the future. Higher scores indicate the maternal caregiver perceives that the chronic condition is viewed as more manageable than those with lower scores. Eight items within this subscale are positively scored and four are negatively coded (Knafl et al., 2009).

Validity of the condition management ability subscale was established by comparison with three established measures including the Family Assessment Device (FAD), Eyberg Child Behavior Inventory (ECBI), and Functional Status II (FSII). In particular, the FAD and ECBI identify higher scores indicative of poorer functioning and behavior was significantly negatively associated with the condition management ability subscale. Additionally, the FSII identifies higher scores indicative of better functioning was significantly positively associated with higher scores on the condition management ability scale.

Recent data analysis of the FaMM included exploratory and confirmatory factor analysis, reliability assessment, and hypothesis testing to evaluate construct validity with

the condition management ability and condition management effort subscales (Knafl et al., 2009). Authors of the FaMM measure (Knafl et al., 2009) published psychometric analyses for the subscale, condition management ability subscale. The ability subscales scores ranging from 24 to 60 (out of a possible range of 12 to 60) for all mothers with mean 49.0 with a standard deviation of 6.2. For a subset of the study population, mothers of children with asthma ($n = 20$), condition management ability subscale scores ranged from 29 to 59 with mean 48.4 and standard deviation 8.3. Mean condition management ability subscale score was not significantly different for these mothers from the others, but the standard deviation was significantly larger ($p = .03$) (Knafl et al., 2009).

Knafl and colleagues reported internal reliability was .72 for mothers for the condition management ability subscale. When retested, the test-retest reliability is .79 for parents (including mothers and fathers) when tested within two to four weeks (Knafl et al., 2009).

Condition management effort subscale.

The condition management effort subscale is a 4-item scale and addresses the maternal caregiver's perception of time and work required to manage the child's condition. Higher responses indicate greater time and work are involved with managing the chronic condition than those of lower scoring. Three items within this subscale are positively scored, while one is negatively coded (Knafl et al., 2009).

Validity of the condition management effort subscale was also established by comparing to the FAD, ECBI, and FSII. In particular, the FAD and ECBI identify higher scores indicative of poorer functioning and behavior was significantly positively associated with associated with the condition management effort subscale. Additionally,

the FSII identifies higher scores indicative of better functioning was significantly negatively associated with higher scores on the condition management effort subscale.

Knafl and colleagues reported psychometric analyses and identified condition management effort subscale scores ranging from 4 to 20 (possible range of 4 to 20) with mean 13.7 and standard deviation of 4.2. For a subset of the study population, mothers of children with asthma ($n = 20$), condition management effort subscale scores ranged from 4 to 20 with mean 13.8 and standard deviation 4.6. Mean condition management effort subscale scores and the standard deviation were not significantly different (Knafl et al., 2009).

Knafl and colleagues reported internal reliability for the condition management ability subscale as .74 for mothers. When retested, the test-retest reliability is .81 for parents (includes both mothers and fathers) when tested within two to four weeks (Knafl et al., 2009).

Definition of Terms

The following terms were a) conceptually and b) operationally defined as follows for the purpose of the study:

Maternal Caregiver a) the primary female caregiver of a child affected by a chronic condition (Deatrick et al., 2009); b) the female caregiver of the child who self identifies as the primary caregiver of the child with the chronic condition.

Family Management Behaviors a) the capacity to which a family as a unit incorporates the demands of childhood condition into family life (Knafl & Deatrick, 1990; Knafl & Deatrick, 2006); b) is measured using two subscales of the Family Management Measure (FaMM), with the family management behaviors described from two subscales of the

measure including condition management ability and condition management effort (16 total items).

Condition management ability. a) the parental perceptions regarding the family's competency in managing the child's condition (Knafl et al., 2009); b) is measured via self report of maternal caregiver with 12 items of an independent subscale titled Condition Management Ability. Higher responses for ability indicate that the chronic condition is viewed as more manageable than those with lower responses by maternal caregivers.

Condition management effort. a) the work required of the family when managing the chronic condition (Knafl et al., 2009); b) is measured via self report of maternal caregiver with 4 items of an independent subscale titled Condition Management Effort. higher responses indicate greater time and work is involved with managing the chronic condition than those of lower scoring.

Asthma Morbidity a) Emergency Department visits, hospitalizations, and school days missed (USHHS, 2007); b) measured in days that a child is affected with asthma symptoms and healthcare is utilized, including maternal caregiver self-report of emergency department visits, hospitalization, and school days missed over the past school year (Bloom et al., 2009; Horner, 2008; Cloutier et al., 2002).

Asthma Control a) defined as minimized symptoms for chronic condition of asthma during daytime and nighttime hours (Juniper et al., 2004); b) is measured by maternal caregiver self-report using the 5-item Asthma Control Questionnaire (ACQ) developed to evaluate the control of the chronic condition of asthma (Juniper et al., 2004).

Pilot Study

A pilot study was initiated in fall 2008 to evaluate the FaMM with the proposed sample population. The purpose of the pilot study was to test the feasibility of the FaMM and demographic questionnaire with the sample. The FaMM has been used in various qualitative studies of maternal caregivers who have children with a variety of chronic conditions (e.g., brain tumors, diabetes) (Knafl & Deatrick, 2006; Deatrick et al., 2009), but no published studies have reported using this measure in maternal caregivers who have children with asthma. After approval by the UAB IRB, the pilot study was conducted in an interdisciplinary childhood pulmonary clinic.

Participant inclusion criteria for the pilot study included maternal caregivers of children with asthma ages 7-12 years, a self-reported child asthma exacerbation by the maternal caregiver in the previous 12 months, and currently prescribed daily preventative medications for asthma. Exclusion criteria included comorbid conditions (e.g., Cancer, Cystic Fibrosis, or Diabetes Mellitus) or if the maternal caregiver did not read or speak English. Pulmonary clinic staff identified eligible maternal caregivers based on inclusion and exclusion criteria. The nursing staff approached the maternal caregivers inquiring whether they would be willing to discuss potential research with a data collector. Once the maternal caregivers agreed, the data collector ensured the maternal caregivers and children met criteria, and then began with the consent process. This information is detailed in the consent form (see Appendix A).

Fourteen maternal caregivers of children (ages 7-12 years) with asthma participated in the pilot study. Data were collected from all 14; however, only 12 were used in the analysis since two participants were unable to finish the measures due to

clinic time restraints. Informed consent was obtained from all study participants in a private exam room within the clinic. After obtaining informed consent from study participants, a 53-item measure was administered to 14 maternal caregivers with children diagnosed with asthma. The maternal caregiver was handed a visual analog scale of response options one to five (Likert scale) with simultaneous faces representing strongly agree to strongly disagree responses. This visual analog is attached in Appendix D. Data collection instruments included the FaMM and demographical information. The researcher administered all data collection instruments in the exam room prior to or following the participant's scheduled visit.

The average time for data collection was 35 minutes per study participant. No participant identified any concerns during the data collection period; however, two participants failed to complete all questions due to time constraints. Time constraints were largely related to clinic activities, such as interpretations for pulmonary function tests and physician encounters with the patients and maternal caregivers. All data were collected prior to visit or immediately following the clinic visit. No maternal caregivers expressed reluctance in answering the questions, and they all openly shared demographic data and responses to given measurement questions.

Data were assessed immediately after collection for any missing data. Pilot data were entered into SPSS 17.0 by the principal investigator for analysis. The subscales, including child's daily life, condition management ability, condition management effort, family life difficulty, view of condition impact, and parental mutuality, were then analyzed. Next, frequency statistics and simple correlations were examined using subscales with asthma morbidity outcomes. The asthma mortality outcomes included

emergency department visits, hospitalizations, school days missed, caregiver work-days missed, and unscheduled acute care visits.

The range of scores identified in the pilot study for the condition management ability subscale were 25 to 48 indicating a difficult time managing the child's asthma from a maternal perspective. In addition, the condition management effort subscale ranged from 15 to 20 indicating a more difficult time managing the asthma from a maternal caregiver perspective.

Significant findings ($p < 0.05$) were identified for asthma morbidity outcomes and certain measurement subscales. The number of emergency department visits correlated with the amount of effort the family extended with asthma ($r = .039, p < .05$). Children's age was negatively correlated with the number of acute care visits ($r = -.615, p = .033$), therefore the younger the child the greater the number of acute care visits. The conditional management ability subscale indirectly correlated with the conditional management effort subscale. Additionally, the child's daily life subscale correlated with the condition management ability subscale. However, these findings are limited based on such a small sample. Refer to Table 1 (correlations).

Additionally, exploratory factor analysis was also completed to evaluate psychometrics for the five subscales within the pilot to identify construct validity. A goal for instrument development is to create a measure with the smallest variance among items (Polit & Beck, 2008) and the pilot sought to identify the results focusing on the maternal caregivers' perceptions of the family to manage the chronic condition of asthma. In this evaluation, all four factors related to the five subscales were distinguished as accumulating 42% of the variance among items. These results were further evaluated

in the larger study. Two factors are of particular interest were recognized as the amount of variance accounted for with the instrument was 34%. An overall thematic description for factor one is likely maternal caregiver views to a treatment regimen and ability to manage effectively. A thematic description for factor two is maternal caregiver views on the extent to which asthma is the focus of family life. Specific examples of questions include a) “our child’s condition rarely interferes with other family activities”; b) “a condition like asthma makes family life difficult”. The results of the pilot study provide the feasibility and psychometric testing of the FaMM for the proposed study.

Procedures for Data Collection

The pilot study results provided information for data collection procedures. Based on the pilot study, the data collection sessions lasted approximately 30 to 60 minutes each. Maternal caregivers received a \$5 gift card from a local general store for participating. Before agreeing to participate, maternal caregivers were provided with relevant information about the project, such as the length of time, number and types of questions. This information is detailed in the consent form (Appendix A). Participants who agreed after verbal discussion were asked to sign the consent form.

Data collection was initiated after approval from the IRB at University of Alabama at Birmingham and after permission obtained from clinic staff. The pulmonary clinic staff members, primarily the nurses, identified potential study participants using a set of predetermined criteria. The inclusion criteria for the sample included maternal caregivers who have a school-aged child with persistent asthma enrolled in kindergarten through 5th grade.

The principal investigator hired research assistants to assist with data collection. All funding was covered from personal funds (principal investigator). The research assistants were all enrolled in healthcare studies. Training for the research assistants focused on childhood asthma, chronic condition management, family communication, how to administer surveys, the informed consent process, and Institutional Review Board (IRB). All training was provided by the principal investigator onsite over a four-hour period. In addition, the principal investigator completed at least four hours with each research assistant in data collection and discussed all protocol with clinic nurses and staff. This research assistant worked in conjunction with the principal investigator to obtain data on 101 maternal caregivers.

All data were collected in the interdisciplinary asthma clinics. Supervision of the research assistants was the sole responsibility of the principal investigator and with every prospective participant the clinic nurse approached the maternal caregiver. This allowed the maternal caregiver to identify interest in the study and to determine if they meet the study sample criteria. Once the participant agreed, the data collector ensured sample criteria were met and completed the consent process prior to data collection.

The maternal caregiver recruitment and informed consent process took place during the child's regularly scheduled clinic visit. Before agreeing to participate in the interview, maternal caregivers were provided with relevant information about the project and the data that were to be collected. This information is detailed in the consent form (see appendix A). Maternal caregivers who agreed to participate after verbal discussion were asked to sign the consent form. Once signed, all maternal caregiver data collections were conducted in a way that insured confidentiality (i.e., no identifying information

appears on observation or interview forms). Children remained in the room for data collection; however, coloring and activity books were distributed to encourage independence for the maternal caregivers. If the maternal caregiver declined to participate, no data were collected and the clinic visit was completed as scheduled.

Data were collected by survey, as the data collector met with the maternal caregivers and completed the consent process. Each maternal caregiver completed a self-report demographic measure on the maternal characteristics, child characteristics, child's asthma, and family characteristics. Next, maternal caregivers completed the FaMM with the assistance of the data collector. For the FaMM, this study collected 45 items of the measure, and analyzed only two of the five subscales (16 items). The entire measure has six subscales, however the parental mutuality subscale was excluded since recommended use is for two parental partners in the home. In this study the parental mutuality subscale was not used, since a large majority of the study population consists of homes with one parent.

The maternal caregivers were given the questionnaires and responded by answering each question using the the corresponding Likert score response. The FaMM items are at the 7th grade reading level using Microsoft's Fleisch reading tool (Microsoft, 2007). Due to potential limited education and low literacy rates in the study population, the researcher prepared two copies of the measure and maternal caregivers were available if the items are not understood. If the caregiver required help with reading, the data collector ensured the child was not able to hear the questions or answers, as requested by the UAB IRB.

Data Management

Prior to the completion of each interview, the data collector reviewed the form to check for missing data. If missing data was identified, the data collector repeated these items for the maternal caregiver. If the maternal caregiver declined to provide a response, the response was recorded as a refusal. The data collector also ensured all responses were understandable and verified with the maternal caregiver prior to completion of the survey. If any data were changed by the mother, the data collector initialed next to the indicated response.

All forms including personal and identifiable information were kept in a locked file by the principal investigator. Additionally, the data were housed on an encrypted computer within the School of Nursing in a password protected file, and the computer access was also password protected. These confidential measures provided security for all documents within this dissertation. In addition, the data collector transported all completed data forms and signed consent forms to the School of Nursing (SON) at the end of each clinic day.

Data Coding and Entering

Data were coded using the predefined codebook from the pilot study. The principal investigator was the single coder for this study. Demographic variable coding was listed in order from the instrument; however some variables were recoded (Ethnicity, age of diagnosis). For example, ethnicity information was obtained by categorical information (Caucasian, African-American, Hispanic, non-Hispanic, or other) and was recoded into minority (African-American, Hispanic, non-Hispanic, or other) and non-minority (Caucasian). For the FaMM, each subscale concept was identified using

acronyms based on the FaMM definitions. For example, condition management ability subscale was documented as ability. All responses were self-marked by the maternal caregivers and were identified by number (i.e., 1 = strongly disagree, 5 = strongly agree). All coding for the demographic instrument and the FaMM located in Appendix C.

Next, data were entered into the Statistical Package for the Social Sciences (SPSS) 18.0 program using meticulous care by the principal investigator. This prevention measure was to avoid any potential problems with multiple entries or data analyses. The principal investigator entered data into SPSS on-campus at the UAB SON. All data coding and entering took place in the School of Nursing over four prearranged visits. Initially, the principal investigator entered data after initial data collection (six sample collections). Secondly, the principal investigator completed a visit at the end of month one for 25 collections. Next, the principal investigator completed midpoint data entry after 3 months to ensure data was accurately collected, closely monitored and adequately entered into SPSS. At this visit, five random charts were pulled to evaluate data entry. Finally, the principal investigator completed data entry at the end of collection period to enter remaining data into SPSS 18.0. At this time, preliminary data were analyzed for findings.

The FaMM scales were scored using independent items from the entire measure. For example, the ability subscale is composed of 12 items for the total the scale score and the effort subscale is composed of 4 items to total the score. Additionally, when scoring data, many items are reverse coded require recoding prior to totaling the score. All subscales were calculated prior to data analysis to include range, mean, standard

deviation, and mode. However, only ability and effort subscales were evaluated in data analyses.

Data Analysis

This research was analyzed using SPSS 18.0 software and procedures. The level of significance was set at alpha to equal .05. Initially, all data were assessed in order to identify missing data. Data were reviewed by a statistician from the principal investigator's PhD committee for accurate data analyses and calculations. The number 999 was noted for any missing information, and the number 888 was noted to indicate any refusals by the maternal caregiver. Next, the investigator ran descriptive statistics on the demographic data to include demographical data such as mean score for age of child, grade, and duration of disease in years. Frequency analysis was used to describe the sample and evaluate demographics. Example of this data analysis included minority status (nonminority, minority), type of insurance (public, private, or no insurance), maternal caregiver work status (full time, part time, and no work outside home), income (<\$10,000, \$10,000-\$50,000, \$50,000-\$100,000, and greater than \$100,000), and asthma control (measured by asthma control questionnaire).

Next, a correlation table was created to evaluate relationships with independent variables (ability and effort) with dependent variables (emergency department visits, hospitalizations, school days missed, and asthma control). Variables appearing to have a correlation ($\alpha \leq .10$) with ability and effort were identified from the correlation table. Step-wise multiple regression methods were then used to identify independent variables that may predict dependent variables of asthma morbidity and control.

Hypothesis Testing

The hypotheses with data analyses are identified below:

1. There is a relationship between condition management ability; condition management effort; and child, maternal caregiver and family characteristics.

This hypothesis was tested using descriptive statistics and presented with central tendencies and frequencies of demographics and subscale scores (ability, effort).

The descriptive statistics reported scores of condition management ability and condition management effort of maternal caregivers of children with asthma. In addition, correlational results were analyzed with self-reported demographic variables, including child, maternal caregiver, and family characteristics.

2. There is a relationship among family management behaviors (ability, effort) and children's emergency department visits, hospitalizations, and school days missed.

This hypothesis was tested using correlational statistics of independent variables and asthma morbidity dependent variables including emergency department visits, hospitalizations, and school days missed.

3. There is a relationship between family management behaviors (ability, effort) and children's asthma control.

This hypothesis was tested using correlational statistics of independent variables with the dependent variable of asthma control.

4. Family management behaviors are predictive of children's emergency department visits, hospitalizations, school days missed, and asthma control.

This hypothesis was tested using predictive statistics to evaluate whether independent variables may predict dependent variables.

For all hypotheses, correlations and simple regression analyses were analyzed to evaluate the data. These hypothesis testing used simple correlations and stepwise regression. Alpha level was set at .1 to include covariates in the regression. Dependent variables include emergency department visits, school days missed, hospitalizations, and asthma control. Level one of the stepwise regression included family management behaviors including ability and effort subscales. Level two included chronic condition variables including age diagnosed with asthma and level three included demographic control variables including family income, maternal caregiver work status, minority status, child's gender, and child's grade. Ultimately, this stepwise regression analysis evaluated whether family management behaviors, including ability and effort, were useful in predicting asthma morbidity and asthma control outcomes.

Based upon the literature, variables such as age of child, maternal caregiver work status, income, and minority status may impact whether ability and effort affect emergency visits, hospitalizations, school days missed, and asthma control. This data analysis aims to identify the relationships among variables and whether the ability and effort subscales can predict emergency department visits, hospitalizations, and school days missed, when controlling for factors that can affect the association between family management behaviors, asthma morbidity outcomes and asthma control.

Summary

In summary, the need to examine management behaviors within families affected by chronic conditions is evident. First, researchers must acknowledge the perceptions of family caregivers with children affected by chronic conditions before interventions are enacted by healthcare. Since maternal caregivers are the primary caregivers for medical

management in children diagnosed with chronic conditions, it is imperative to focus on the perceptions of maternal caregivers. Likewise, the FaMM is a novel tool designed for measuring family measurement behaviors in maternal caregivers of children with chronic conditions. By utilizing the FaMM, researchers can examine the relationships among the perceptions of family management behaviors (ability, effort) with asthma morbidity and asthma control outcomes in maternal caregivers of school-aged children diagnosed with persistent asthma. Furthermore, the researchers hope to have an improved understanding of family management with chronic childhood conditions and subsequently can advance interventions for families affected by a chronic condition.

Chapter 4

Findings

The statistical findings of this dissertation are documented within this chapter. The sample characteristics and demographic information of the children with asthma (including age, grade, minority status, and gender) and their maternal caregivers' work status, family income, and insurance are described by using frequencies and descriptive statistics (mean, median, standard deviation, and range). Next, descriptive information on the study variables and relationships among the variables are included using descriptive statistics and correlations. Additionally, reliability information for the independent and dependent variables for this study will be reported. Lastly, a summary of the findings by each specific aim and hypothesis is presented.

This study was designed to examine the relationship between family management behaviors and child specific outcomes. Family management behaviors included condition management ability (ability) and condition management effort (effort), and were evaluated as predictors for child specific outcomes. The child specific outcomes included asthma control and asthma morbidity, defined as emergency department visits, hospitalizations, and school days missed due to asthma. These child specific outcomes were evaluated from the perspective of the maternal caregiver.

Descriptive Statistics for Demographic Variables

A convenience sample of 101 maternal caregivers of children with asthma was recruited from a pediatric pulmonary clinic in a southeastern hospital system. A total of 115 maternal caregivers were screened (meeting inclusion criteria), and 101 consented to participate in the study (response rate 88%). With alpha level at .05 and medium effect

size, power analysis expectations were exceeded with a sample size of 101; the observed power was .845173.

Demographic variables collected on the sample population included child's date of birth, school grade, gender (0 = male, 1 = female), minority status (0 = nonminority, 1 = minority), and age when diagnosed with asthma in years/months. Asthma morbidity outcomes were obtained by self-report as continuous data. Maternal caregivers responded with the number of times a child went to the emergency department, stayed overnight in a hospital, or missed school because of asthma symptoms over the past school year (2009-2010). Demographic information regarding maternal caregivers included family role of maternal caregiver (mother, grandmother, or guardian), and work status (employed full-time, part-time, or no employment). Additional information of family characteristics includes type of insurance information (private, public, or no insurance), family structure (single parent, nuclear, or blended), and residence zip code.

All maternal caregivers recruited for this study had children diagnosed with moderate to severe persistent asthma based on asthma symptoms and prescribed treatment. In addition, maternal caregivers had a school-aged child enrolled in kindergarten through sixth grade. The children for this sample had an average age of 8.9 years with a range of 5-12 years. The average age at which children were diagnosed with asthma was 36.62 months of age (3 years of age). Children were 53% male. Within the sample, 66% of maternal caregivers identified their child's ethnicity as a minority.

Mothers made up the majority of maternal caregivers (94%), as did caregivers who worked outside the home (57%). Within family structure, the single parent family made up the largest proportion (47%), followed by the nuclear family (37%), and then the

blended family (16%). The average income for the sample participants ranged from \$10,000-\$50,000 per year. No child was identified as lacking insurance, and the majority had public insurance (96%). According to reported residential zip codes, study participants lived 5 miles to 95 miles away from the outpatient pulmonary clinic site.

Table 1. *Demographic Characteristics of the Sample (N = 101)*

VARIABLE	N	%
Age at data collection (years)		
5	17	16.8
6	11	10.9
7	6	5.9
8	15	14.9
9	15	14.9
10	17	16.8
11	14	13.9
12	6	5.9
Child's School Grade		
Kindergarten	16	15.8
1st	10	9.9
2nd	8	7.9
3rd	20	19.8
4th	9	8.9
5th	20	19.8
6 th	18	17.8
Child's Minority status		
Minority	67	66.3
Non-minority	34	33.7
Child's gender		
Male	54	53.5
Female	47	46.5
Maternal Work Status		
Full-time	41	40.6
Part-time	17	16.8
No work outside of home	43	42.6
Family Structure		
Single Parent	47	46.5
Nuclear	37	36.6
Blended	16	15.8

Variable	<i>N</i>	%
Family Income Level		
<\$10K	41	40.6
\$10K-\$50K	39	38.6
\$50K-\$100K	16	15.8
>\$100K	5	5
Child's Insurance		
Public	96	95.6
Private	5	4.4

Note: Because of rounding, some percentages may not total 100 percent.

Descriptive Statistics for Independent Variables

The independent variables for this study were measured using two subscales within the Family Management Measure (FaMM). These were the condition management ability (ability) subscale, which focused primarily on the assessment of the maternal caregiver's perception of her own ability to manage the child's condition, and the condition management effort (effort) subscale, which focused on the time and work involved with managing a child's asthma. Ability was measured using the subscale consisting of 12 items (possible score range 12-60) with higher responses indicating that the chronic condition is viewed as more manageable than those with lower responses. In contrast, effort was evaluated using the subscale consisting of 4 items (possible score ranges 4-20) with higher responses indicating that the chronic condition requires greater time and work than those with lower scoring.

The ability subscale scores ranged from 12-60 with a mean of 32.4 and standard deviation of 5.77. The effort subscale scores ranged from 4-20 with a mean of 13.0 and a standard deviation of 3.69 (See Table 2). Each subscale was scored using appropriate

scoring instructions as documented in on FaMM website (available: <http://nursing.unc.edu/research/famm/>).

The relationship between the two subscales, ability and effort were examined. There was no significant correlation between ability and effort ($r = -.078, p = 0.439$); thus ability and effort were recognized as two different constructs. However, significant findings were found amongst the independent and dependent variables. Effort positively correlated with asthma control ($r = .426, p = .001$) and school days missed ($r = .259, p = .010$) while ability negatively correlated with hospitalizations ($r = -.206, p = .039$) (See Table 3).

Table 2. Descriptive Statistics of Independent Variables

	Condition Management Ability (Ability)	Condition Management Effort (Effort)
Possible Score Range	12-60	4-20
Mean	32.4	13.0
Standard Deviation	5.77	3.69
Range	12-40	4-20

Table 3. Correlations of Independent Variables and Asthma Morbidity Variables

Variable	Ability	Effort
Emergency Department Visits	-0.089 ($p = .38$)	0.171 ($p = 0.088$)
Hospitalizations	-0.206 ($p = .039$) *	0.003 ($p = .979$)
School Days Missed	0.043 ($p = 0.673$)	0.259 ($p = 0.01$) **
Asthma Control	-0.165 ($p = 0.099$)	0.426 ($p < 0.0001$) **

Note: Significant values: * $p \leq 0.05$; ** $p \leq 0.01$

Descriptive Statistics for Outcome Variables

In this study, emergency department visits, hospitalizations, school-days missed, and asthma control were examined using descriptive statistics (see Table 4). More than one emergency department visit during the past year was reported by 61.2% of the

sample. Emergency department visits were defined as visits due to asthma as self-reported by the maternal caregiver. The range for emergency department visits were 0-30 visits in the previous year, with 30% of maternal caregivers reporting children had greater than three emergency department visits.

However, 72.3 % of children did not require a hospitalization for asthma during the previous school year. A hospital stay was defined as a required stay overnight due to asthma as self-reported by the maternal caregiver. The average number of hospitalizations for this sample was 0.52. The range of the sample was 0-14 hospitalizations within the past year.

Maternal caregivers reported children missing an average of 6.5 school days per school year. School days missed were defined as missed days of school due to problems with asthma. Based on literature reports, the average school days missed for all children during a single school year averaged 3.25 days per year, while children with asthma miss an average of 7 days per year (Horner, 2004; Bloom et al., 2009). The range was 0-84 days of school missed within this sample population, and a large percentage (19.8%) missed more than 15 days in the previous year.

Additionally, asthma control was indicated as a determinant of asthma morbidity. The Juniper Asthma Control Questionnaire (ACQ) was utilized to assess asthma control by maternal caregiver self-report. The average score was 1.7 with a range of 0-5.6 on the ACQ ($sd= 1.25$). A score of 1.5 or greater was used to indicate poor asthma control; whereas, a score of less than 1.5 indicated perceived control of asthma from the view of the maternal caregiver (Juniper et al., 2006). Within this sample, 54% of the children had poor control as determined by the ACQ.

Table 4. Asthma Morbidity Variables

Variable	<i>N</i>	%
Emergency Department Visits		
0	39	38.8
1-2	30	29.8
3-5	21	20.8
6-10	8	7.9
>10	3	2.9
(Range 0-30)		
Hospitalizations		
0	73	72.3
1-2	20	19.8
3-5	3	2.9
>5	5	4.9
(Range 0-14)		
School Days Missed		
0	13	12.9
1-5	32	31.7
6-10	19	18.8
11-15	14	13.9
>15	20	19.8
(Range 0-84)		
Asthma Control		
Score <1.5	47	46.5
Score >1.5	54	53.5
(Range 0-5.6)		

Note: Due to rounding, percentages may not total 100 percent.

Descriptive Statistics for Outcome Variables Not Related to Research Questions

Previous studies have reported relationships between child variables including minority status, child's gender, work status, and family income with child-specific outcome variables including emergency department visits, hospitalizations, and school-days missed (Butz et al., 2004; Horner, 2004; Horner et al., 2002; Suglia et al., 2010; Unger et al., 2011). The findings of this study confirm what has been documented in previous research, as is explained in the following sections.

Minority Status

The child minority status (0 = nonminority, 1 = minority), positively correlated with effort ($r = .302, p = .002$), emergency department visits ($r = .332, p = .001$), hospitalizations ($r = .248, p = .012$), and asthma control ($r = .443, p < .0001$); indicating if child was of minority status, then maternal caregivers reported greater perceived effort, more emergency department visits, and more hospitalizations. Furthermore, when the child was minority status then we noted poorer asthma control (using score >1.5). The child's minority status negatively correlated with ability ($r = -.357, p < .0001$). This indicated less perceived ability from the perception of the maternal caregiver with minority status.

Child's Gender

The child's gender (0 = male, 1 = female), negatively correlated with emergency department use ($r = -.25, p = .03$). in this sample. Therefore, maternal caregivers of male children were more likely to report increased emergency department for asthma than female children.

Maternal Caregiver Work Status

The maternal caregiver work status (employed full-time, part-time, or no employment) positively correlated with emergency department visits ($r = .237, p = .017$) and asthma control ($r = .207, p = .037$). This indicates when the maternal caregiver is employed (full-time or part-time), more emergency department visits and poor asthma control were self-reported.

Family Income

Family income was positively correlated with ability ($r = .323, p = .0001$), indicating a greater perception of the ability to manage asthma when the family income was higher. Whereas, family income is negatively correlated with effort ($r = -.200, p = .044$), school-days missed ($r = -.236, p = .019$), hospitalizations ($r = -.229, p = .021$), and poor asthma control ($r = -.371, p < .0001$). This indicates the lower the family income the more perceived time and work, school-days missed, and hospitalizations. Additionally, the lower the income the poorer asthma control in the sample of children diagnosed with persistent asthma.

Table 5. Correlation Matrix of the Study Variables

Variable	Grade	Minority status	Child's gender	Work	Income	ED [^]	Hosp	SDM+	Control	Effort
Grade	-									
Minority status	.31**	-								
Child's gender	.07	.04	-							
Work	.03	.36**	-.15	-						
Income	-.11	-.44**	.18	-.50**	-					
ED[^]	.01	.33**	-.25*	.24*	-.18	-				
Hosp	-.07	.25*	-.09	.19	-.30*	.15	-			
SDM +	-.10	.20	-.11	.17	-.24*	.58**	.07	-		
Control	.15	.44**	0.15	.21*	-.37**	.37**	.08	.37**	-	
Effort	.05	.30**	.04	.19	-.20*	.17	.00	.26**	.43**	-
Ability	-.14	-.36**	-.01	-.16	.32**	-.09	-.21*	.04	-.17	-.08

Note: $N = 101$ for all correlations. * $p \leq .05$ ** $p \leq .01$

+ SDM – School days missed, ^ED= emergency department visits

Research Questions

Research Question One

Research Question One examined the relationship between maternal caregiver perceptions of condition management ability and condition management effort with child, maternal caregiver, and family characteristics. To answer this question, correlational statistics were utilized and correlations for all study variables are listed in Table 5.

The independent variables (ability, effort) were correlated with specific demographic variables. These relationships are presented in the correlation matrix in Table 5. Ability positively correlated with family income ($r = .323, p = .001$), indicating the higher the family income the greater the perceived ability to manage the child's asthma. Whereas, ability negatively correlated with child's minority status ($r = -.357, p = < .0001$), identifying a relationship between minority status and poorer perceived ability to manage a child's asthma. Additionally, effort positively correlated with the child's minority status ($r = .302, p = .002$), indicating a relationship between minority status and the perceived time and work involved in managing a child's asthma. Whereas, family income was negatively correlated with effort ($r = -.200, p = .044$), identifying a relationship between lower family income and greater perceived time and work involved in managing a child's asthma.

Research Question Two

Research Question Two evaluated the relationship between family management behaviors (ability, effort) and children's emergency department visits, hospitalizations, and school days missed as self-reported by maternal caregivers. To answer this question, correlational statistics were utilized and correlations for all variables are listed in Table 5.

Effort positively correlated with school days missed ($r = .259, p = .010$), identifying a positive relationship between greater school days missed and greater perceived time and work involved in managing a child's asthma. Ability negatively correlated with hospitalizations ($r = -.206, p = .039$), identifying greater numbers of hospitalizations correlated with lower perceived ability to manage the child's asthma. It is important to note the relationship indicating a lower perceived ability to manage the child's asthma and an increased number of hospitalizations in school-aged children diagnosed with asthma.

Research Question Three

Research Question Three evaluated the relationship between family management behaviors (ability, effort) and children's asthma control as reported by maternal caregivers. Question three was evaluated through correlation statistics. Significant findings identified that effort positively correlated with asthma control ($r = .426, p = .001$). Maternal caregivers of children with asthma who perceived better asthma control also perceived greater time and work involved in managing the child's asthma. The results of this analysis are presented in Table 3.

Research Question Four

To answer this research question, relationships among family management behaviors (ability, effort), children's emergency department visits, hospitalizations, school days missed, and asthma control were examined using step-wise regression analyses (see Table 6). The step-wise regression used forward selection, which involves starting with no variables in the model, then including the variables one by one if they are statistically significant. Statistically significance was set at .10 for this study. Four

independent regression analyses were performed using the entire sample ($N = 101$) including:

1. Family Management Behaviors and Emergency department visits
2. Family Management Behaviors and Hospitalizations
3. Family Management Behaviors and School-days missed
4. Family Management Behaviors and Asthma control

The series of analyses examined results of each variable separately. In each analysis, condition management ability and condition management effort were entered in the first step, child's age at diagnosis in second step, and demographic control variables in third step. In order to minimize degrees of freedom and maximize power with predictive statistics, only predictor variables with significant correlations between variables ($p \leq .10$) on the initial correlation chart were included in the regression analyses. Demographic control variables were defined by using the correlation chart to recognize p values less than .10; all variables with p greater than or equal to .10 were removed from the model. The control variables for the regression analyses included minority status, family income, maternal work status, child's grade, and child's gender.

Family management behaviors and emergency department visits.

The results of the regression analysis predicting emergency department visits are shown in Table 6. As seen in the table, ability and effort were not predictors of emergency department visits. Yet, when ability, effort, and child's age at diagnosis were controlled, minority status and child's gender were predictive of emergency department visits.

Table 6. Step-wise Regression Analysis Predicting Emergency Department Visits from Family Management Behavior Perceptions: Ability and Effort

Variable	Model 1	Model 2	p value
Constant	-2.217	.79	.668
Minority Status	2.806	2.898	.000
Child's gender	-.263	-2.108	.005
Work Status	.137	.092	.360
Age Dx	-.133	-.109	.241
Effort	.079	.088	.365
Ability	.032	.029	.767

Note: * $p < .10$, ** $p < .05$, *** $p < .001$

Family management behaviors and hospitalizations.

The results of the regression analysis predicting hospitalizations are shown in Table 7. As seen in the table, ability was a significant predictor of hospitalizations. Additionally, when controlling for ability, effort, child's age at diagnosis, family income and minority status were also predictive of hospitalizations.

Table 7. Step-wise Regression Analysis Predicting Hospitalizations from Family Management Behavior Perceptions: Ability and Effort

Variable	Model 1	p value
Constant	- .974	.191
Minority Status	1.091	.012
Family Income	- .149	.171
Age Dx	.039	.688
Effort	- .080	.438
Ability	- .134	.199

Note: * $p < .10$, ** $p < .05$, *** $p < .001$

Family management behaviors and school days missed.

The results of the regression analysis predicting school days missed are shown in

Table 8. In this analysis, effort was a significant predictor of school days missed.

Table 8. Step-wise Regression Analysis Predicting School-Days Missed from Family Management Behavior Perceptions: Ability and Effort

Variable	Model 1	Model 2	p value
Constant	17.668	5.883	.334
Minority Status	.115	.063	.573
Family income	- 3.618	- 2.979	.053
Work status	.069	.048	.673
Age Dx	- .155	- .125	.205
Effort	.223	.819	.026
Ability	.135	.140	.174

Note: * $p < .10$, ** $p < .05$, *** $p < .001$

Family management behaviors and asthma control.

The results of the regression analysis predicting asthma control are shown in

Table 9. As seen in the table, effort was a predictor of asthma control. When ability, effort, and child's age at diagnosis were controlled, minority status and child's gender were predictive of asthma control.

Table 9. Step-wise Regression Analysis Predicting Asthma Control from Family Management Behavior Perceptions: Ability and Effort

<i>Variable</i>	<i>Model 1</i>	<i>Model 2</i>	<i>Model 3</i>	<i>p value</i>
Constant	- .272	.736	- .330	.614
Minority Status	1.172	.918	.703	.007
Family income	- .218	- .317	- .279	.042
Work status	.055	- .037	- .058	.558
Age calculated	.025	.039	.042	.642
Age Dx	- .017	- .016	.034	.691
Effort	.321	.307	.104	.001
Ability	- .008	.035	.019	.836

Note: * $p < .10$, ** $p < .05$, *** $p < .001$

Hypotheses

Hypothesis One

There is a relationship between condition management ability; condition management effort; and child, maternal caregiver and family characteristics.

This hypothesis was partially supported in the data. To test this hypothesis, correlational statistics were utilized and correlations for all study variables are listed in Table 5. There were relationships between ability and child's minority status, ability and family income, effort and child's minority status, and effort and family income. There was no significant relationship between effort and ability. Therefore, the constructs are independent of one another.

Hypothesis Two

There is a relationship among family management behaviors (ability, effort) and children's emergency department visits, hospitalizations, and school days missed.

This hypothesis was partially supported in the data. To test this hypothesis, correlational statistics were utilized and correlations for all study variables are listed in Table 5. Results indicate that effort is positively correlated with school days missed; while, ability is negatively correlated with hospitalizations.

Hypothesis Three

There is a relationship between family management behaviors (ability, effort) and children's asthma control.

This hypothesis was partially supported in the data. To test this hypothesis, correlational statistics were utilized and correlations for all study variables are listed in Table 5. Results indicate that effort is positively correlated to asthma control. Additionally, there was no statistical significant relationship between ability and asthma control.

Hypothesis Four

Family management behaviors are predictive of children's emergency department visits, hospitalizations, school days missed, and asthma control.

This hypothesis was partially supported in the data. Results of predictive data are presented in Tables 6-9. Overall, the regression analyses indicated ability is predictive of hospitalizations, while effort is predictive of asthma control and school days missed.

Instrument Reliability

Reliability coefficients using Cronbach's alpha were calculated to assess the internal consistency of the study instruments used in the collection of data. The Cronbach's alpha reliability coefficients for instruments used in this study ranged between .73 and .94 (Knafl et al., 2009). According to Polit and Beck (2008), the FaMM coefficients of .84-.94 were adequate (Cronbach's alpha >0.80), while the demographic coefficients of .73 were lower than recommended (Cronbach's alpha >0.80).

Summary

The results of this study confirm what was previously examined in the literature and further extends the findings when examining family management behaviors from the perspective of maternal caregivers with children diagnosed with asthma. The findings reported relationships of family management behaviors, specifically ability and effort, with child-specific outcomes, including asthma morbidity and control outcomes. By examining ability and effort, we have innovative findings for research involving family management behaviors and asthma morbidity and control.

Primary findings of this study indicated family management behaviors of ability and effort are significant variables with child-specific outcome variables, including asthma morbidity and control. To reiterate, the higher responses for ability indicate that the chronic condition is viewed as more manageable than those with lower responses by maternal caregivers; whereas, the higher responses indicate greater time and work is involved with managing the chronic condition than those of lower scoring responses. Specifically, maternal caregivers of children with asthma who perceived poorer asthma control also perceived greater time and work involved in managing the child's asthma.

There was a positive relationship identified between greater school days missed and greater perceived time and work involved in managing a child's asthma. While, greater numbers of hospitalizations correlated with lower perceived ability to manage the child's asthma. Lastly, findings recognized that ability is predictive of hospitalizations, while effort is predictive of asthma control and school days missed.

Chapter 5

Discussion

Over the past 20 years, there has been a 15% increase in childhood asthma prevalence among school-aged children (CDC, 2008). The impact of asthma on children's lives is often measured by prevalence and outcome variables, such as asthma mortality and morbidity. Asthma morbidity results in significant impacts on children and family's lives, as well as financial and public health burdens. While previous research has reported on the psychosocial consequences of asthma management on children's and family's lives (Butz et al., 2006; Horner & Fouladi, 2003), few studies have examined the maternal caregivers perceptions of chronic disease management and the relation to child specific outcomes (Horner, 2004; McQuaid et al., 2006). By studying the relationships between maternal caregiver perceptions of these family management behaviors (ability and effort) and variables related to child-specific outcomes (childhood asthma morbidity and control), the researchers hope to gain insight to explain caregiver perceptions, asthma disparity, as well as potentially target interventions to high-risk groups.

In this study, perceptions of family management behaviors were examined in a sample of maternal caregivers with school-aged children diagnosed with asthma. The main findings of this cross-sectional correlational and predictive study indicated a relationship of family management behaviors (ability and effort) with asthma morbidity and asthma control. Furthermore, maternal perceptions of management behaviors (ability, effort) were predictive of emergency department visits, hospitalizations, school days missed, and asthma control with children diagnosed with asthma. Overall, the regression analyses indicated ability was predictive of hospitalizations, while effort was

predictive of asthma control and school days missed.

In this chapter, the following sections will be discussed: procedures, purpose and objectives, summary of findings, recommendations for research, limitations, and conclusions. The results of this study support published family management literature with demographic variables, such as the positive correlation of child minority status and maternal work status, with increased emergency department visits; as well as new findings of relationships between maternal caregiver perceptions of increased effort with increased asthma morbidity and poorer asthma control and increased ability with decreased hospitalizations in asthma children.

Procedures

The target population for this study included maternal caregivers of school-aged children with asthma in the southeastern United States. The accessible population consisted of maternal caregivers visiting the pediatric asthma specialty clinic with their child diagnosed with asthma between June 2010 and October 2010. The sample selected reflected maternal caregivers, including mothers, aunts, and grandmothers with school-aged children diagnosed for one year or more with moderate to severe persistent asthma based on prescribed treatment and current asthma symptoms. Maternal caregivers completed all study questionnaires, to self-report child diagnosis, maternal caregiver and family characteristics, family management behaviors, asthma morbidity, and asthma control.

Study design, sample recruitment and data collection were completed as set out in chapter three. The primary investigator and research assistant(s) collected data over a five month period (June –October 2010). The primary investigator entered all data into

Excel documents at prearranged intervals (initial collection, one month, three months, and five months, which were the end collection point). Coded data from the Excel® spreadsheets were imported into the Statistical Package for the Social Sciences (SPSS) version 18.0 for data analysis. No problems occurred with data entry.

For data analysis, the level of significance was set at .05. The FaMM subscales were scored using independent items from the entire measure. For example, the ability subscale calculates 12 items to total the scale score, and the effort subscale calculates 4 items to total its scale score. All FaMM subscales were calculated prior to data analysis to include range, mean, standard deviation, and mode. However, only ability and effort subscales were evaluated in data analyses.

Descriptive statistics were calculated to summarize the demographic and diagnosis characteristics of the sample. Frequencies and percentages were evaluated on demographic variables and asthma morbidity outcomes. Family management behaviors (ability, effort) and asthma control were scored and evaluated with measures of central tendency. Additionally, correlations were assessed between all variables and with a large correlational table created. Variables appearing to have a correlation with ability and effort were identified from the correlation table. Step-wise multiple regression methods were then used to identify independent variables that may predict dependent variables of asthma morbidity and control outcomes.

Purpose and Research Questions

The purpose of this study was to examine maternal caregiver by perceptions of condition management ability and condition management effort and child specific

outcomes such as asthma morbidity and asthma control. The research questions and hypotheses of the study included:

1. What is the relationship between maternal caregiver perceptions of condition management ability and condition management effort with child, maternal caregivers, and family characteristics?

Hypothesis 1. There is a relationship between condition management ability; condition management effort; and child, maternal caregiver and family characteristics.

2. What is the relationship between family management behaviors (ability, effort) and children's emergency department visits, hospitalizations, and school days missed as reported by maternal caregivers?

Hypothesis 2. There is a relationship among family management behaviors (ability, effort) and children's emergency department visits, hospitalizations, and school days missed.

3. What is the relationship between family management behaviors (ability, effort) and children's asthma control as reported by maternal caregivers?

Hypothesis 3. There is a relationship between family management behaviors (ability, effort) and children's asthma control.

4. After controlling for income, maternal work status, minority status, children's gender, and children's grade, are family management behaviors (ability, effort) predictive of children's emergency department visits, hospitalizations, school days missed, and asthma control?

Hypothesis 4. Family management behaviors (ability, effort) are predictive of children's emergency department visits, hospitalizations, school days missed, and asthma control.

Summary of Findings

Demographics and Asthma Morbidity

The findings of this study confirm and extend results from other studies of maternal caregivers who have school-aged children diagnosed with asthma. Comparable to other studies assessing demographic variables with asthma morbidity (Cloutier et al., 2002; Bloom et al., 2009; Lara et al., 2003), this study found children of minority status (African American) were more likely to be hospitalized and had significantly higher emergency department visits. Additionally, this study found male gender to be associated with increased emergency department visits for asthma, comparable to other studies in which child's gender was correlated with emergency department visits (Bloom et al., 2009; Lara et al., 2003).

In this study, a negative relationship was identified between family income and asthma morbidity outcomes. Lower family income was found to be associated with increased hospitalizations and school days missed, consistent with other published studies (Bloom et al., 2009; Horner, 2004; Kruse et al., 2007). Lower income families often struggle with balancing resource needs, such as purchasing daily preventative medications or transportation to scheduled acute care visits, thus potentially leading to poorer asthma outcomes. Additionally, a quantity of research has described risk factors for families in managing asthma and found poorer families have a greater need for education regarding asthma management (Horner, 2004; Horner & Fouladi, 2003;

Velsor-Fredrich et al., 2004).

Maternal caregivers who worked outside the home (part-time or full-time) were more likely to have children with increased emergency room visits and poor asthma control, findings not previously reported in the literature. One possible reason for elevated emergency department visits might be due to care utilization and maternal caregivers working during daytime hours with the emergency department as the only source of healthcare after hours (Lara et al., 2003). On a daily basis, maternal caregivers must balance chronic conditions and family demands; however working maternal caregivers must further shift their roles when balancing parental time and medical treatments, (Sullivan-Bolyai, Sadler, Knafl, & Gilliss, 2004; Turner-Henson et al., 1992). Working maternal caregivers may have a difficult time balancing these roles as maternal caregivers must recognize, monitor and make decisions related to childhood asthma in order to adequately manage treatment of childhood asthma (Horner, 2004; Yoos et al., 2003). Additionally, maternal caregivers who are employed outside the home may be required to miss work due to asthma and this may augment family responsibilities when the family is affected by asthma.

While maternal work status may be a significant risk factor in poor asthma outcomes, other factors that may alter the maternal caregiver relationship (such as social support) were not examined in this study (Butz et al., 2004; Horner, 2004; Horner & Fouladi, 2003). While not surprising, it is important to note that maternal caregivers who work outside the home may benefit from increased support and frequent healthcare encounters when managing a child with asthma. With increased support, the family may ultimately improve asthma control and potentially decrease emergency room visits for the

child with asthma.

Asthma Morbidity

Overall, high rates of asthma morbidity were reported for the study sample, and thus reflect the patient population that is generally found in pediatric pulmonary clinics (Butz et al., 2004; Gerald et al., 2009). The maternal caregivers in the sample reported a mean of 1.2 emergency department visits, .60 hospitalizations, and 6.5 days of school missed for asthma for the 2009-2010 school year. These numbers are similar to previous studies of school-aged children with asthma, most often studied in general pediatric clinics (Bloom et al., 2009; Butz et al., 2004; Gerald et al., 2009). In addition, it is often cited that families of children with asthma frequently utilize the emergency room for various minor symptoms of asthma (cough, wheeze) (Lara et al., 2003). Many health care providers would state these children could be easily treated with home management for such asthma symptoms, yet repeatedly maternal caregivers bring children to emergency department on the basis of minor symptoms alone. For example, caregivers may see frequent cough not as an asthma symptom and treat with cough suppressant, often leading to worsening asthma symptoms and emergency room visits; rather than administering bronchodilator for the acute asthma symptom of cough. In such example, the emergency department is overused. Similarly, the numbers are high for emergency department visits in this study; high rates of emergency department use are frequently cited in literature and continue to demonstrate the critical health disparities in asthma and need for further research (Lara et al., 2003; McQuaid et al., 2006).

Family Management Behaviors and Asthma Morbidity

No relationship was found between family management behavior concepts of

ability and effort. Since the concepts are unique to one another, the lack of association between ability and effort is interesting as there is no statistical connection. Knafl et al. (2006) found an association between ability and effort; however, this was in a population of children with many different types of chronic disease. Ability, as defined by the FMSF, is a competency in managing a child's chronic condition by knowing what needs to be done, and carrying out those tasks in chronic disease management. Often, we recognize that knowing and doing are two different concepts, and ability holds true to this distinction. Effort, on the other hand, is time and work involved in caring for a child with a chronic condition (Knafl et al., 2006). It is important to point out that this study was measuring family management behaviors, and was not measuring self-efficacy or self-management, as frequently cited in the literature.

A key finding in this study was the significant relationships among ability and effort with asthma morbidity outcomes. Interestingly, ability negatively correlated with hospitalizations; that is, the lower the maternal perception of ability to manage the child's asthma, the greater the number of hospitalizations. Whereas, effort positively correlated with school days missed, that is, the greater the maternal caregiver perception of effort (time and work) the greater the number of school days missed by the child. Recently, Deatrick et al. (2009) identified family management behaviors, including ability and effort, as a means to assess family functioning in the care of childhood brain tumors. Deatrick and colleagues recognized the significance of assessing how families function and manage a chronic condition such as childhood cancer. Overall, goals of this study sought to adapt interventions particular to the family needs. Morawska et al. (2008) recognized that family home asthma management is the key towards reducing asthma

morbidity. This research associated dysfunctional parenting management styles with poorer child asthma outcomes. By this greater understanding of family management of ability and effort, this study explores relationships with outcome variables.

Butz and colleagues (2004) examined home asthma management practices, and the relationship to asthma severity. This research concluded that, regardless of socioeconomic characteristics, family caregivers of children with asthma often fail to treat early signs of asthma, thus leading to an increase in asthma morbidity outcomes. Parallel with published literature (Butz et al., 2004; Horner, 2004; Horner & Fouladi, 2003), findings of this study strengthen the findings of the family management behavior literature and the use of the measure, FaMM. Ability was a significant predictor of hospitalizations. When controlling for child's gender, maternal caregiver work status, and family income, ability was also predictive of hospitalizations. On the contrary, ability and effort were not predictors of emergency department visits. Yet, when ability, effort, and child's age at diagnosis were controlled, minority status and child's gender were predictive of emergency department visits.

As compared to other studies in school-age populations, asthma morbidity greatly affects children by emergency department visits, hospitalizations, and school days missed (Akinbami & Schoendorf, 2002; Horner, 2004). Another regression analysis indicated effort was a significant predictor of school days missed. Significant absenteeism often requires a child with a chronic condition to miss three times more school days than a child without a chronic condition (Lara et al., 2003). Child's age was also correlated to hospitalizations. Similar to numerous other findings (CDC, 2008; Horner, 2004; Bloom et al., 2009), younger children were more likely to be hospitalized. For this reason, the

FaMM is appropriate for use in further studies related to family management behaviors with child outcomes.

Family Management Behaviors and Demographic Variables

In this study, there were significant relationships between family income and minority status with effort and ability. A negative association was identified with reported family income and effort, thus indicating that lower family income was associated with maternal caregivers reporting higher perceived effort (greater time and work) involved with childhood asthma management. Lower family income is often associated with fewer material resources, and for many of these caregivers there may be less support. In this study, 40% of maternal caregivers reported a family income of less than \$10,000. Working maternal caregivers and those who are low income may lack the appropriate resources, and this in turn may lead to less perceived time and work towards adequately managing their children's asthma (Horner, 2004).

A positive relationship was found between perceived ability and family income. In this relationship, when family income is lower, maternal caregivers perceived lower ability in managing the child's asthma. This is significant since ability involves the maternal caregivers understanding how to take care of the condition and the maternal caregiver's ability to competently manage the child's condition (Knafl et al., 2009). When the income is lower, the maternal caregivers may have less confidence in adequately managing the children's asthma. Effective asthma management not only requires that the parent have knowledge and skill with management but they also have to have confidence in their ability (Moraska et al., 2008).

It is well documented that children of minority status have increased prevalence of asthma (Lara et al., 2003; Velsor-Friedrich et al., 2004). Additional research has reported that maternal caregivers of minority children often perceive asthma as requiring increased time and work (Butz et al., 2004; Horner, 2008; Lara et al., 2003; Sterling & Peterson, 2003). In this study, there was a positive association between minority status and effort indicating that if the child is minority status, maternal caregivers reported more time and work required in the daily management of the child's asthma.

A negative correlation was found between children's minority status and maternal caregiver report of ability, that is, if the child was of minority status the maternal caregiver reported lower perceived ability to manage the child's asthma condition. Ability focuses on the confidence in managing a child's asthma. If minority caregivers report low confidence health care providers should investigate ways to increase caregiver confidence in management, such as examining how the treatment plans can be adjusted to meet the needs of the family. Standard health education (knowledge, skill demonstrations) may not address caregiver ability (confidence) in disease management. Other caregiver interventions, such as problem solving or ways to improve caregiver confidence should be examined in order to adequately prepare maternal caregivers for asthma management.

In the current study, family management behaviors from the perspective of the maternal caregiver were measured by use of the condition management ability and condition management effort subscales. The sample mean for the condition management ability subscale was 40.2 out of a total score of 60 and the sample mean of the condition management effort subscale was 10.4 out of a total score of 20. Since the psychometric

establishment of the FaMM in this study, we have further enhanced and supported the use of the FaMM in children diagnosed with asthma. Overall, the results were quite similar when compared to Drs. Knafl, Deatrick, and colleagues' preceding research (Knafl et al., 2009); however, that research examined family management behaviors in non-minority and higher income populations.

Asthma Control and Asthma Morbidity

This study also demonstrated that asthma control was a strong outcome variable for family management behaviors. Specifically, this study identified significant relationships between lower ability and more reported hospitalizations, increased effort and more reported school days missed, and increased effort and poorer asthma control. This study identified significant relationships among asthma control and child's minority status, maternal caregiver work status, and family income. Minority status has a strong positive relationship with asthma control; therefore, when the child is of minority status there is poorer asthma control (ACQ score greater than 1.5). In addition, maternal caregiver work status has a positive relationship with asthma control. When the maternal caregiver works outside of the home there is a correlation with poorer asthma control from the perspective of the maternal caregiver. Lastly, there is a negative relationship between family income and asthma control. In this relationship, when the family income is lower there is a relationship with poorer asthma control from the maternal caregiver perspective when managing childhood asthma.

This study identified significant relationships among asthma control and asthma morbidity. It has been documented that poorer asthma control leads to increased asthma morbidity (Gerald et al., 2009; Unger et al., 2011). Specifically, some studies have

documented relationships among poorer asthma control and increased number of reported emergency department visits, as well as poorer asthma control and increased number of reported school days missed due to asthma.

Maternal caregiver management of childhood asthma varies from individual to individual, and this management may have an influence asthma morbidity and control. For example, specific behaviors regarding ability and effort that maternal caregivers utilize with chronic conditions may ultimately affect the outcome, particularly asthma control with asthma (Amuwo et al., 2004; McQuaid et al., 2006; Miller & Drotar, 2006). In this study, asthma control inversely correlated with number of reported emergency department visits for children with asthma. This indicated that poorer asthma control is associated with an increased number of reported emergency department visits. Asthma control was also positively associated with a child's school days missed due to asthma. With a inverse correlation between poorer asthma control and increased number of reported school days missed due to asthma, asthma control is a meaningful tool in assessing a child's asthma control. These results are encouraging since the asthma control questionnaire is a prompt measure providing a quick and easy administration with maternal caregivers at the time of a visit. Additionally, 54 percent of maternal caregivers perceived the child's asthma control as uncontrolled.

Family Management Behaviors and Asthma Control

Additionally, this study assessed family management behaviors of ability and effort with the outcome variable of asthma control. There was a strong relationship between effort and asthma control. This indicated that there is a relationship between more perceived time and work involved in managing a child's asthma from the perspective of

the maternal caregiver and poorer asthma control. Furthermore, effort was a predictor of asthma control. When ability, effort, and child's age at diagnosis were controlled, minority status and child's gender were predictive of asthma control. While not statistically significant, ability could have some clinical significance with asthma control.

Family Management Style Framework (FMSF) Theory

The Family Management Style Framework (FMSF), an emerging theory, identifies how family management behaviors may ultimately affect the outcome of the chronic condition of the child (Knafl et al., 1996; Knafl & Deatrick, 2003). The FMSF model currently includes the following dimensions: a) definition of the situation, b) management behaviors, and c) perceived consequences (Knafl & Deatrick, 2003). This study looked only at the right side of the model. By assessing the family member perception of the family management behaviors (specifically ability, effort) with the individual outcomes (asthma morbidity, asthma control), this study was able to test part of the model. Through further studies are needed to examine disease outcomes in order to strengthen the model.

Chronic condition management has been assessed from the perspective of home management by researchers examining home management, daily symptom monitoring and treatment (Butz et al., 2004, McQuaid et al., 2006; Horner & Fouladi, 2003; Horner, 2004; Wamboldt et al., 2006); however, no published studies have evaluated the relationship between family management behaviors and child-specific disease outcomes. This is the first study that used the examined family management behaviors along with disease outcomes. This addition seemed vital in research assessing family management behaviors from the perspective of the maternal caregiver self-report in children with

asthma. Family caregiver response may fluctuate in actions and management and when limited to maternal caregivers, this variance in management reaction may greatly affect asthma morbidity and asthma control.

The Family Management Measure (FaMM) was developed to examine the family's perspective of management behaviors with chronic childhood conditions, while representing the perceptions of individual family members. Additionally, the FaMM measure has had limited use in research (Knafl & Deatrick, 2003). The FaMM is a valuable tool when assessing maternal caregivers of childhood asthma (Deatrick, 2009). This study provides psychometric data for the FaMM and further use is encouraged. Others have looked at family management behaviors, yet none had assessed family management behaviors in maternal caregivers of childhood asthma. And, many of the studies that have used the FaMM measure have had study populations from nonminority and higher income families. As seen in this study, the study population consisted of primarily minority and lower family income population.

With recent findings identifying asthma control as gold standard when measuring childhood asthma, the ACQ was used in this study to evaluate asthma control from the perspective of the maternal caregiver. Using the ACQ in conjunction with the FaMM measure provides a broader perspective of asthma control and family management from the maternal caregiver perspective. As demonstrated in the review of literature, the rationale for assessing the maternal caregiver was appropriate given that maternal caregivers are the primary caregivers of childhood chronic conditions (Buford, 2004; Gallo & Knafl, 1998).

Implications for Practice

The diagnosis of a child's asthma greatly affects the family, particularly the maternal caregivers. In this study, when condition management ability is perceived to be lower in maternal caregivers, healthcare providers may promote educational interventions to improve this ability for maternal caregivers when managing asthma (Morawska et al., 2008). Encouraging maternal caregivers to communicate goals for asthma management and identifying how management occurs in the home setting must be included. Furthermore, healthcare providers must commonly provide asthma education and resources for families of children with asthma at every visit (Lara et al., 2004). This study has identified a need for healthcare providers to tailor the approach when educating families of children with asthma, as not every family will learn the same way (Horner, 2004).

This is the first study to look at family management behaviors with maternal caregivers of school-aged children with asthma. Findings from this study recognized that healthcare providers must utilize each opportunity with families to identify asthma management behaviors in order to improve asthma control (Horner, 2003; Lara et al., 2003). Healthcare providers should consider recognizing family responses and praise families and encourage the learning effort. Additionally, when effort is higher in maternal caregivers, healthcare providers must begin to assess causes of increased time and work in the home setting.

Recommendations for Further Research

While the research examining family management of children with chronic conditions is expanding, few studies have included child specific disease outcomes

(McQuaid et al., 2006; Horner, 2004). While other studies have examined factors such as family functioning, parental self-efficacy, family disease management knowledge, and child's psychosocial variables, no studies have examined parental caregiver management behaviors along with child disease outcomes. In management of childhood asthma, it is often challenging to accurately assess maternal caregiver home management of childhood asthma (Horner, 2004; Horner & Fouladi, 2003). Childhood asthma trajectories vary among children, particularly based on asthma severity. Some children have mild asthma requiring some children require daily symptom monitoring with occasional medication to those with symptomatic asthma, which may require daily medications and treatment when asthma exacerbations occur. Future research would clearly benefit by using the FaMM to assess family management of chronic conditions with similar trajectories to asthma, such as diabetes or sickle cell anemia. In examining maternal caregiver perceptions of family management with chronic conditions and the relationship to child-specific outcomes, researchers will have a better awareness of the significance of family perceptions towards chronic childhood conditions.

Maternal caregiver perception of ability and effort were identified as important constructs in family caregiver chronic disease management. Deatrick et al. (2009) found perceptions of maternal caregivers and family management characteristics are similar in nature. Based on the findings of this study, maternal caregiver perceptions of ability and effort were significantly related to asthma control and morbidity. While few studies have linked poor asthma control and increased asthma morbidity to inadequate asthma management knowledge (Gerald et al., 2009; Horner, 2004), this study found that maternal ability, may not always indicate a need for more education. This study

recognizes maternal caregivers may lack ability or confidence in managing childhood asthma, and would likely benefit from further assessment of family management behaviors.

Maternal caregiver perception of increased effort (time and work) was found to be associated with children's poor asthma outcomes. Maternal caregivers viewed childhood asthma as requiring much time and work, and further research might incorporate specific interventions to improve time and work efficiency for maternal caregivers of children with asthma. Further research is needed to examine children's asthma management plans, to determine if management complexity, time, or work to implement plans places increased burdens or stress on maternal caregivers. As with ability, effort may also be related to maternal caregiver knowledge. The FaMM concepts of effort and ability, along with other components of the FAMSF may be helpful in designing interventions to improve asthma outcomes. Future studies are needed to examine if maternal caregiver perception of ability is related to asthma management knowledge. Further, researchers should examine how perception of ability may be related to actual knowledge or stressors in families with children diagnosed with asthma.

Research would also benefit by use of additional measures to assess maternal caregivers in families managing asthma. We must recognize that how we respond to families helps families build confidence when managing asthma. As healthcare providers, we could begin training families how to self-manage asthma from home (Koenig & Chesla, 2004). By doing so we grant families the ability to manage asthma and create a management plan for caregivers to follow when monitoring their child's asthma. By assessing maternal caregivers, we begin to focus on daily requirements in

family management behaviors that may ultimately affect childhood asthma management. Maternal caregivers need to possess management skills such as recognition, monitoring and decision making related to childhood asthma in order to adequately manage treatment of childhood asthma (Horner, 2004; Yoos et al., 2003). Healthcare providers must begin to acknowledge that families may manage asthma from home, and the healthcare providers are not the only one making decisions. This will allow maternal caregivers to build confidence in managing asthma.

Based on the findings, we cannot say maternal caregivers need more education, yet this evidence inquires if current practice of education is truly the best practice. Standard health education, that is providing standard classes on disease processes, symptoms, risk factors, environmental modifications, and technical skills in medication administration alone may not be effective. As seen in this study, ability and effort were significantly related to asthma control and outcomes, thus more studies are needed to examine what other types of asthma management interventions for families would be effective. Further study might assess whether ability is consistent with measuring confidence in management or whether effort accurately measures time and work involved in chronic condition management. Additionally, we must recognize how perception of ability may be related to actual knowledge or competence in families with children diagnosed with asthma, or whether knowledge and actions are measured in a different way.

Future research also includes furthering the FMSF and FaMM measure. Further refinement of the conceptualization of the variables is required. Maternal caregiver perception with ability and effort are important constructs and greatly enhance our

knowledge of families with children diagnosed with asthma. The FaMM measure has had limited use in studies and will be strengthened with more involvement in research. Over the past twenty years, this measure has undergone extensive development (Knafl et al., 1996; Knafl et al., 2003; Deatrick et al., 2006) and psychometric testing (Knafl et al., 2009). In time, we need to understand more about typologies of family management behaviors. Particularly, the FaMM subscales will eventually define family management style typologies in children with chronic conditions. Ultimately, by assessing specific typologies we hope to eventually decrease perceived demands of a chronic condition for caregivers of children affected by long-term disease processes (Deatrick et al., 2006).

Limitations

Several limitations should be noted for this study. The sampling method was a convenience sample of maternal caregivers of children diagnosed with asthma, consisting of 101 maternal caregivers. The sample was recruited from maternal caregivers with children diagnosed with asthma and were attending interdisciplinary pulmonary clinics for asthma. The interdisciplinary asthma clinics often serve high-risk children with moderate to severe persistent asthma, who are referred to the clinic due to difficulties in managing the asthma in the primary care system. These high-risk children often require detailed asthma management plans, including more than one daily preventative medication for asthma, multiple environmental changes, or frequent visits to the healthcare provider.

Generally, primary care providers usually will manage child's asthma, and refer to pulmonary clinics only if asthma control and/or management becomes troublesome. Thus, the sample may have represented children with higher asthma morbidity as

compared to the general population of children with asthma. By this type sampling, convenience samples with nonprobability methods typically limit generalizability of the findings to the study population only (Polit & Beck, 2008).

Another limitation for this study included testing only a portion of the Family Management Style Framework, focusing only on the individual family member perceptive, family management behaviors, and individual functioning. This study did not examine maternal caregivers definition of the situation or the perceived consequences in association with childhood asthma. Therefore, future studies are needed to examine how other components of the FMSF is associated with child specific disease outcomes.

Asthma control is a time sensitive measure as it may change from day to day (Juniper et al., 2004). The Asthma Control Questionnaire (ACQ) was used to examine asthma control; however, the ACQ is used to assess the individual with asthma. Until this point, the ACQ has been tested in children 7-17 years of age and adults (Juniper et al., 1999; Juniper et al., 2005); yet the measure was not designed to be tested from the perspective of a family member. Hence, this study used the ACQ in a non-standardized manner to assess maternal caregivers of children with asthma.

Self-report measures are also a source of bias in studies. Self-reports are frequently used in research to assess perceptions of a participant, such as maternal caregivers perceptions of family management behaviors. However, self-report measures are limited by concerns over validity and reliability of self-reports (Polit & Beck, 2008). The child's asthma morbidity is based solely on the maternal caregivers self report of emergency department visits, hospitalizations, school days missed, and asthma control symptoms. It should be noted that assessing maternal caregiver self-report as a measure

for asthma morbidity outcomes may not accurately portray the numbers of emergency department visits, hospitalizations, and school days missed over the past school year in school-aged children with asthma. The findings may be influenced as self-report measures are very subjective and require the maternal caregiver to remember an accurate number of days for specific events.

A limitation with this methodology of data collection is that data may be inaccurately reported by parents due to lapses in recollection, desires to hide utilization, or inability to manage chronic conditions. Whereas, school-days missed are often reported inaccurately since parents have a difficulty deciphering which days of school were missed for asthma and which days were missed due to another reason (McQuaid et al., 2006). Often self-report literature is utilized with instruments assessing chronic condition outcomes. There is far less research available on self-report related to family management behaviors in children with a chronic condition.

Conclusions

Family management behaviors were shown to have significant relationships with demographic variables, asthma morbidity outcomes, and asthma control. Maternal caregivers of children with asthma identified family management behaviors similar to parents of a child with other chronic conditions. Low-income families with children diagnosed with chronic conditions often lack financial and support resources to manage childhood asthma, and would benefit by improved understanding of family perceptions when it comes to managing childhood asthma. Healthcare providers can utilize this data when managing childhood asthma, as the provider may recognize the significance of the perceptions of the maternal caregivers on family management behaviors. This is

particularly effective when looking at the relationship of these family management behaviors with child-specific outcomes such as asthma morbidity and control.

Additionally, children of minority status, low income, and maternal caregivers working outside the home had greater numbers of school days missed and emergency department visits, and poor asthma control. Until this time, no single study had compared demographic factors (child age at diagnosis, maternal work status), asthma morbidity, asthma control and family management behaviors (ability, effort). For health care providers, these findings highlight the significant findings as this study has also provided new evidence on the relationship of ability and effort with demographics, asthma morbidity, and asthma control. The FaMM and ACQ prove to be valuable measures when assessing maternal caregivers of children with asthma. In all, we have gained significant knowledge and recognize the importance of assessing maternal caregivers perceptions on family management behaviors and the relationship with child disease specific outcomes.

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Appendix A

UAB THE UNIVERSITY OF
ALABAMA AT BIRMINGHAM
Institutional Review Board for Human Use

Form 4: IRB Approval Form
Identification and Certification of Research
Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on October 26, 2010. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56 and ICH GCP Guidelines.

Principal Investigator: GIBSON, LINDA M

Co-Investigator(s):

Protocol Number: X100427027

Protocol Title: *A Correctional Study of Maternal Caregiver Family Management Behaviors and Childhood Asthma Morbidity*

The IRB reviewed and approved the above named project on 5-12-10. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.

IRB Approval Date: 5-12-10

Date IRB Approval Issued: 5-12-10

Marilyn Doss

Marilyn Doss, M.A.
Vice Chair of the Institutional Review
Board for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.

TITLE OF RESEARCH: A Correlational Study of Maternal Caregiver Family Management Behaviors and Childhood Asthma Morbidity

IRB PROTOCOL NUMBER: X100427027

INV

Linda Gibson, Doctoral Student, University of Alabama Birmingham School of Nursing

Shaina Parker, nursing student, University of Alabama

Dr Arne Turner-Henson (Faculty Mentor)

SPONSOR:

University of Alabama Birmingham School of Nursing

Explanation of Procedures

We are asking you to take part in a research study. This research study will ask you questions about how you manage your child's asthma condition. This study is being conducted as part of my doctoral nursing studies at University of Alabama at Birmingham. If you enter the study, we will ask you questions about how you manage your child's asthma condition. This study will enroll 125 participants from this type setting. It will take about 40 minutes to complete the two questionnaires. You do not have to answer all the questions.

Risks and Discomforts

The risks and discomforts associated with participating in this study are no greater than the risks and discomforts of day-to-day living. You do not have to answer all of the questions.

Benefits

You may not benefit directly from taking part in this study. However, this study may help us better understand how families manage a child's asthma.

Alternatives

This study does not provide treatment. The alternative is to not participate in this study.

Confidentiality

All personal information gathered in this study will be kept confidential. Forms including personal and identifiable information will be kept in a password protected file by Linda Gibson, the project investigator. The results of the questionnaires will be published for scientific purposes, though your identity will not be disclosed. Information obtained about you for this study will be kept private to the extent allowed by law. However, research information that identifies you may be shared with the UAB Institutional Review Board (IRB) and others who are responsible for ensuring compliance with laws and regulations related to research, and the Office for Human Research Protections (OHRP). The results of the study may be published for scientific purposes. However, your identity will not be given out.

Participant's initials _____

Page 1 of 3

Version Date: 05/11/2010

UAB-IRB

Consent Form Approval 5-12-10

Expiration Date 5-12-11

Refusal or Withdrawal without Penalty

Your taking part in this study is your choice. There will be no penalty if you decide not to be in the study. If you decide not to be in the study, you will not lose any benefits you are otherwise owed. You are free to withdraw from this research study at any time. Your choice to leave the study will not affect your relationship with this institution.

Cost of Participation

There are no costs to you participating in this project.

Payment for Participation in Research

You will receive a gift card worth \$5 for your participation in this study.

Questions

If you have any questions, concerns, or complaints about the research, please contact Ms Linda Gibson. She will be glad to answer any of your questions. Ms Gibson's number is 205-515-6491. Or, you may contact Ms Gibson's faculty mentor, Dr Turner-Henson at 205-934-7533 or 1-800-822-8816. If calling the toll-free number, press the option for "all other calls" or for an operator/attendant and ask for extension 4-7533.

If you have questions about your rights as a research participant, or concerns or complaints about the research, you may contact Ms. Sheila Moore. Ms. Moore is the Director of the Office of the Institutional Review Board for Human Use (OIRB). Ms. Moore may be reached at (205) 934-3789 or 1-800-822-8816. If calling the toll-free number, press the option for "all other calls" or for an operator/attendant and ask for extension 4-3789. Regular hours for the Office of the IRB are 8:00 a.m. to 5:00 p.m. CT, Monday through Friday. You may also call this number in the event the research staff cannot be reached or you wish to talk to someone else.

Legal Rights

You are not waiving any of your legal rights by signing this informed consent document.

Signatures

Your signature below indicates that you agree to participate in this study. You will receive a copy of this signed document.

Signature of Participant

Date

Signature of Investigator

Date

University of Alabama at Birmingham
**AUTHORIZATION FOR USE/DISCLOSURE OF HEALTH INFORMATION
FOR RESEARCH**

What is the purpose of this form? You are being asked to sign this form so that UAB may use and release your health information for research. Participation in research is voluntary. If you choose to participate in the research, you must sign this form so that your health information may be used for the research.

Participant Name: _____
Research Protocol **A correlational study of
maternal caregiver family management
behaviors and childhood asthma morbidity**

UAB IRB Protocol Number: _____
Principal Investigator: Linda Gibson _____

Sponsor: University of Alabama Birmingham
School of Nursing _____

What health information do the researchers want to use? All medical information and personal identifiers including past, present, and future history, examinations, laboratory results, imaging studies and reports and treatments of whatever kind related to or collected for use in the research protocol.

Why do the researchers want my health information? The researchers want to use your health information as part of the research protocol listed above and described to you in the Informed Consent document.

Who will disclose, use and/or receive my health information? The physicians, nurses and staff working on the research protocol (whether at UAB or elsewhere); other operating units of UAB, HSF, UAB Highlands, The Children's Hospital of Alabama, Callahan Eye Foundation Hospital and the Jefferson County Department of Public Health, as necessary for their operations; the IRB and its staff; the sponsor of the research and its employees; and outside regulatory agencies, such as the Food and Drug Administration.

How will my health information be protected once it is given to others? Your health information that is given to the study sponsor will remain private to the extent possible, even though the study sponsor is not required to follow the federal privacy laws. However, once your information is given to other organizations that are not required to follow federal privacy laws, we cannot assure that the information will remain protected.

How long will this Authorization last? Your authorization for the uses and disclosures described in this Authorization does not have an expiration date.

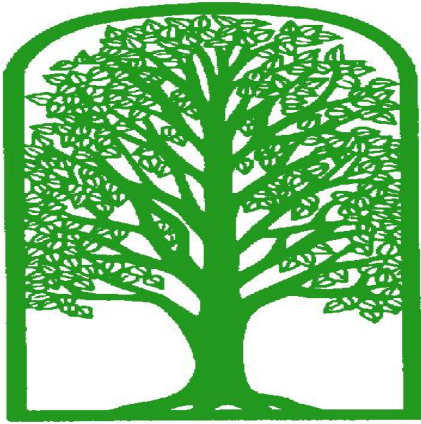
Can I cancel the Authorization? You may cancel this Authorization at any time by notifying the Director of the IRB, in writing, referencing the Research Protocol and IRB Protocol Number. If you cancel this Authorization, the study doctor and staff will not use any new health information for research. However, researchers may continue to use the health information that was provided before you cancelled your authorization.

Can I see my health information? You have a right to request to see your health information. However, to ensure the scientific integrity of the research, you will not be able to review the research information until after the research protocol has been completed.

Signature of participant: _____
or participant's legally authorized representative: _____
Printed Name of participant's representative: _____
Relationship to the participant: _____

Date: _____
Date: _____

Appendix B



FAMILY MANAGEMENT MEASURE

**Kathleen Knafl, PhD
Janet Deatrck, RN, PhD
Agatha Gallo, RN, PhD
Jane Dixon, PhD
Margaret Grey, RN, PhD**

E-mail: Knaflk@ohsu.edu



FAMILY MANAGEMENT MEASURE

This questionnaire is about how your family manages caring for a child with a chronic condition.

INSTRUCTIONS

For each statement in this questionnaire, you are asked to rate your response to the statement on a scale of 1 to 5, with 1 indicating “Strongly disagree” and 5 indicating “Strongly agree”. Please respond to each statement in this questionnaire based on what you think, not on how you think others might respond. If your child has more than one chronic condition the word “condition” refers to all of their diagnoses together. Also, many of these questions use the word “family”. This refers to those people living in your household who you think of as family.

Section 1: to be completed by everyone
Please check the boxes with your answers.

	Strongly Disagree				Strongly Agree
	1	2	3	4	5
1. Our child’s everyday life is similar to that of other children his/her age.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Our child’s condition gets in the way of family relationships.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Our child’s condition requires frequent visits to the clinic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. In the future we expect our child to take care of the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Our child enjoys life less because of the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Taking care of our child’s condition is often overwhelming.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Our child’s condition is like a roller coaster with lots of ups and downs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly Disagree 1	2	3	4	Strongly Agree 5
8. Our child's condition is the most important thing in our family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. It is very hard for us to take care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Our child takes part in activities he/she wishes to despite the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Because of the condition, we worry about our child's future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Our child's condition doesn't take a great deal of time to manage.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. We have some definite ideas about how to help our child live with the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Despite the condition, we expect our child to live away from home in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. We have enough money to manage our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Our child is different from other children his/her age because of the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. It is difficult to know when our child's condition must come first in the family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. We are looking forward to a happy future with our child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. When something unexpected happens with our child's condition, we usually know how to handle it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Our child's friendships are different because of the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly Disagree 1	2	3	4	Strongly Agree 5
21. We expect to be devoting less time to our child's condition in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. A condition like the one our child has makes family life very difficult.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Our child's condition rarely interferes with other family activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Our child's condition requires frequent hospital stays.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. We feel we are doing a good job taking care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. People with our child's condition have a normal length of life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. It's often difficult to know if we need to be more protective of our child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. We often feel unsure about what to do to take care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Our child's condition will be harder to take care of in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. We think about our child's condition all the time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. It seems as if our child's condition controls our family life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Many conditions are more serious than our child's.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. It is hard to get anyone else to help us with our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. We have not been able to develop a routine for taking care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly Disagree 1	2	3	4	Strongly Agree 5
35. It takes a lot of organization to manage our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. We are sometimes undecided about how to balance the condition and family life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. It is hard to know what to expect of our child's condition in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Even though our child has the condition, we have a normal family life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Our child would do better in school if he/she didn't have the condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. We are confident that we can take care of our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. We have goals in mind to help us manage our child's condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. It is difficult to fit care of our child's condition into our usual family routine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Dealing with our child's condition makes family life more difficult.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. We know when our child needs to be a child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. A condition like the one our child has makes it very difficult to live a normal life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

This ends Section 1.

Section 2 covers aspects of family management when there are adult partners in a household.

The term "partner" refers to a spouse or partner living in the same household.

Do you have a spouse or adult partner living in your home?

Yes ☐ No ☐

If you currently have a partner living in the same household, please proceed to the next page. If you do not have a partner, please stop here.

Section 2

The questions in the next section relate to you and your partner. For each statement in this section, rate your response to the statement on a scale of 1 to 5, with 1 indicating “Strongly disagree” and 5 indicating “Strongly agree”. Again, please respond to each statement in this questionnaire based on how YOU feel, not on how you think your partner or others might respond.

	Strongly Disagree 1	2	3	4	Strongly Agree 5
46. We are a closer family because of how we deal with our child’s condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. My partner and I have different ideas about how serious our child’s condition is.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. I am pleased with how my partner and I work together to manage our child’s condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. My partner and I argue about how to manage our child’s condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. My partner and I consult with each other before we make a decision about our child’s care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. My partner and I have similar ideas about how we should be raising our child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. I am unhappy about the way my partner and I share the management of our child’s condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. My partner and I support each other in taking care of our child’s condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2/16/07

**A Correlational Study of Maternal Caregiver Family Management Behaviors and
Childhood Asthma Morbidity**

Interview Form

**Maternal Caregiver
Name:** _____

Child DOB: ____ / ____ / ____

Checklist for participating:

☐ child dx with asthma

☐ currently prescribed
daily preventative meds

Date of Interview ____ / ____ / ____

**Child's Asthma
ID:** _____

Interviewer: _____

Introduction

Hello. My name is Linda Gibson and I am a PhD student at the University Alabama in Birmingham. I am conducting a study for my doctoral studies at UAB and I would like to talk with you.

My study focuses on assessing maternal caregivers of children ages 7-12 with asthma. I will evaluate the family management behaviors that used by the family when caring for a child with a chronic condition. What that means is how the family functions on a day to day basis with the chronic condition of asthma.

I would you like to read and respond to questions about the background of your child's asthma and 45 questions about your family in relation to your child's asthma. This will take 30-40 minutes. I have a copy of the questions and request that you mark a number between 1 and 5. If you have difficulty with reading, please let me know.

Your assistance would be greatly appreciated. Would you be willing to participate in this study?

Maternal Caregiver Information

Your relationship to child: _____

Residence Zip Code: _____

Work Status: ☐ Full Time ☐ Part Time ☐ No work outside home

Income status: ☐ <\$10,000 ☐ \$10,000-\$50,000 ☐ \$50,000-\$100,000 ☐ >\$100,000

Family Structure: ☐ single parent ☐ nuclear ☐ blended ☐ other

Child Information

Age diagnosed with Asthma: ____ years ____ months

Gender: ☐ Male ☐ Female

Ethnicity:

☐ Caucasian ☐ African-American ☐ Hispanic ☐ non-Hispanic ☐ Other

Which grade will your child attend in the fall? _____

Healthcare Information

Since this school year began (2009-2010), how many times did you have to take your child to the emergency department (E.D.) because of their asthma?

____ times

☐ Don't know, do not recall

☐ Child did not need to go to the E.D.

Since this school year began (2009-2010), how many times did your child have to stay overnight in the hospital because of their asthma?

~~1~~ ____ times

☐ Don't know, do not recall

☐ Child did not need to be hospitalized

Since this school year began (2009-2010), how many times did your child miss school because they were having problems with asthma symptoms?

____ times

☐ Don't know, do not recall

☐ Child did not miss school

Is your child currently enrolled in a health insurance plan, such as Blue Cross Blue Shield, Medicaid?

☐ Not sure / don't know

☐ No

☐ Yes (if yes, please answer the following question)



Which insurance plan does your child belong to?

1. ☐ All Kids

5. ☐ Liberty National

9. ☐ United

2. ☐ Aetna

6. ☐ Medicare

10. ☐ Viva

3. ☐ Blue Cross Blue Shield

7. ☐ Medicaid

11. ☐ Other:

4. ☐ Caremark

8. ☐ Cigna

1. On average, during the past week, how often were you **woken by your asthma** during the night?

- 0 Never
- 1 Hardly ever
- 2 A few times
- 3 Several times
- 4 Many times
- 5 A great many times
- 6 Unable to sleep because of asthma

2. On average, during the past week, how **bad were your asthma symptoms when you woke** up in the morning?

- 0 No symptoms
- 1 Very mild symptoms
- 2 Mild symptoms
- 3 Moderate symptoms
- 4 Quite severe symptoms
- 5 Severe symptoms
- 6 Very severe symptoms

3. In general, during the past week, how **limited were you in your activities** because of your asthma?

- 0 Not limited at all
- 1 Very slightly limited
- 2 Slightly limited
- 3 Moderately limited
- 4 Very limited
- 5 Extremely limited
- 6 Totally limited

4. In general, during the past week, how much **shortness of breath** did you experience because of your asthma?

- 0 None
- 1 A very little
- 2 A little
- 3 A moderate amount
- 4 Quite a lot
- 5 A great deal
- 6 A very great deal

5. In general, during the past week, how much of the time did you **wheeze**?

- 0 Not at all
- 1 Hardly any of the time
- 2 A little of the time
- 3 A moderate amount of the time
- 4 A lot of the time
- 5 Most of the time
- 6 All the time

The Asthma Control Questionnaire is copyrighted. It may not be changed, translated, or sold (paper or software) without the permission of Elizabeth Juniper.

APPENDIX C

CODEBOOK

Child Information

Age diagnosed with Asthma: ____ years ____ months

Variable listed in months

Gender:

- 1 Male
- 2 Female

Ethnicity:

- 1 Caucasian
- 2 African-American
- 3 Hispanic
- 4 non-Hispanic

Which grade will your child attend in the fall? _____

- 0 Kindergarten
- 1 1st grade
- 2 2nd grade
- 3 3rd grade
- 4 4th grade
- 5 5th grade
- 6 6th grade

Child Insurance:

- 1 All Kids
- 2 Aetna
- 3 Blue Cross Blue Shield
- 4 Caremark
- 5 Liberty National
- 6 Medicare
- 7 Medicaid
- 8 Cigna
- 9 United
- 10 Viva
- 11 Other

Maternal Caregiver Information

Work Status:

- 1 Full Time
- 2 Part Time
- 3 No work outside home

Family Information

Income status:

- 1 <\$10,000
- 2 \$10,000-\$50,000
- 3 \$50,000-\$100,000
- 4 >\$100,000

Family Structure:

- 1 single parent
- 2 nuclear
- 3 blended
- 4 other

Family Management Measure (45 items)

Family Management Measure (FaMM) Subscales:

^^Condition Management Ability

^^Condition Management Effort

Child's Daily Life

View of Condition Subscale

Family Life Difficulty Subscale

##Parental Mutuality Subscale

Key:

^^Primary independent variables used in this study

Did not use in this study

Follow these steps to compute the FaMM scales.

1. Determine the number of items in a scale with valid responses (i.e., values of 1-5).
2. Compute a scale score from the valid responses as instructed in steps 3-7, **but only if at least seventy percent of the items for that scale have valid responses** (minimum numbers for the scales are provided below). If less than 70% of the items are answered, the scale cannot be computed.
3. Reverse code the negative item responses (indicated by asterisks) by subtracting those item responses from the value 6.

4. Sum the positive item responses and the reverse coded negative item responses.
5. Divide by the number of valid responses.
6. Multiply by the total number of items for the scale.
7. Round to the nearest integer.

Condition Management Ability Subscale

4. In the future we expect our child to take care of the condition.
13. We have some definite ideas about how to help our child live with the condition.
14. Despite the condition, we expect our child to live away from home in the future.
15. We have enough money to manage our child's condition.
18. We are looking forward to a happy future for our child.
19. When something unexpected happens with our child's condition, we usually know how to handle it.
25. We feel we are doing a good job taking care of our child's condition.
41. We have goals in mind to help us manage our child's condition.
17. *It is difficult to know when our child's condition must come first in our family.
27. *It's often difficult to know if we need to be more protective of our child.
28. *We often feel unsure about what to do to take care of our child's condition.
34. *We have not been able to develop a routine for taking care of our child's condition.

Total number of items = 12

Condition Management Effort

3. Our child's condition requires frequent visits to the clinic.
7. Our child's condition is like a roller coaster with lots of ups and downs.
35. It takes a lot of organization to manage our child's condition.
12. *Our child's condition doesn't take a great deal of time to manage.

Total number of items = 4

Child's Daily Life Subscale

1. Our child's everyday life is similar to that of other children his/her age.
10. Our child takes part in activities he/she wishes to despite the condition.
5. *Our child enjoys life less because of the condition.
16. *Our child is different from other children his/her age because of the condition.
20. *Our child's friendships are different because of the condition.

Total number of items = 5

View of Condition Subscale

8. Our child's condition is the most important thing in our family.
11. Because of the condition, we worry about our child's future.
24. Our child's condition requires frequent hospital stays.
29. Our child's condition will be harder to take care of in the future.
30. We think about our child's condition all the time.

- 37. It is hard to know what to expect of our child's condition in the future.
 - 21.*We expect to be devoting less time to our child's condition in the future.
 - 26. *People with our child's condition have a normal length of life.
 - 32. *Many conditions are more serious than our child's.
 - 40. *We are confident that we can take care of our child's condition.
- Total number of items = 10.

Family Life Difficulty Subscale

- 2. Our child's condition gets in the way of family relationships.
 - 6. Taking care of our child's condition is often overwhelming.
 - 9. It is very hard for us to take care of our child's condition.
 - 22. A condition like the one our child has makes family life very difficult.
 - 31. It seems as if our child's condition controls our family life.
 - 33. It is hard to get anyone else to help us with our child's condition.
 - 36. We are sometimes undecided about how to balance the condition and family life.
 - 39. Our child would do better in school if he/she didn't have the condition.
 - 42. It is difficult to fit care of our child's condition into our usual family routine.
 - 43. Dealing with our child's condition makes family life more difficult.
 - 45. A condition like the one our child has makes it very difficult to lead a normal family life.
 - 23. *Our child's condition rarely interferes with other family activities.
 - 38. *Even though our child has the condition, we have a normal family life.
 - 44. *We know when our child needs to be a child.
- Total number of items = 14

APPENDIX D
VISUAL ANALOG SCALE



STONGLY AGREE



AGREE



NEUTRAL



DISAGREE



STRONGLY DISAGREE



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March 2, 2011

Appendix E

Mrs. Linda Gibson
PhD Student
University of Alabama Birmingham
31337 Prestwick Avenue
Birmingham,
Alabama 32776
USA

Dear Mrs. Gibson,

REFERENCE: ACQ

I am delighted that you have decided to use the Asthma Control Questionnaire (Symptoms only) for your PhD and I confirm my permission for you to use this questionnaire in your studies.

You will be aware that all my questionnaires are protected by copyright and must not be altered or changed in any way.

With good wishes

Elizabeth Juniper MCSP, MSc

Professor

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