ILLNESS REPRESENTATIONS AND SELF-MANAGEMENT BEHAVIORS OF AFRICAN AMERICAN ADOLESCENTS WITH ASTHMA

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DEDICATION

This dissertation is dedicated to my parents Acie and Frances Johnson.

You were destined for greatness. Your impact was because of a commitment established long ago to each other, to our family, to your roles as educators and leaders.

You created a family environment of prayer and love, always supporting our dreams and aspirations. You shared your journey so we had role models in each of you.

Your dedication to improving the lives of students and communities created a legacy that propelled you to greatness. That greatness was acquired because you followed your divine purpose and plan. As a team, you mentored students as they achieved goals, you served in order to enrich lives, you led in order to enhance education, and you cared—and it inspired others. You created a dynamic legacy.

It has been a journey, divinely inspired by God, and along the journey our lives were forever transformed.

Now it is up to me and to others touched by your lives to carry forth your torch, displaying the same dedication, leadership, and commitment to our roles as change agents.

It is with this sense of purpose that we, too, will create our legacy.

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ABSTRACT

Sharron Johnson Crowder

ILLNESS REPRESENTATIONS AND SELF-MANAGEMENT BEHAVIORS OF AFRICAN AMERICAN ADOLESCENTS WITH ASTHMA

African American adolescents have inadequate self-management behaviors, particularly during middle adolescence (14–16 years of age). Inaccurate beliefs, degree of asthma impairment (well controlled or not well controlled), and gender could influence asthma self-management (symptom management, medication management, and environmental control). The researcher used the illness representations concept from the common sense self-regulation model as the framework for this study.

The descriptive correlational study explored (1) differences in illness representations (cognitive and emotional) and self-management behaviors by gender, asthma impairment, and gender by asthma impairment of African American adolescents with asthma; and (2) relationships between illness representations and asthma self-management behaviors, gender, and asthma impairment in 133 African American adolescents with asthma. Data were collected using the Asthma Control Test, the Illness Perceptions Questionnaire-Revised, and the Asthma Self-Care Practice Instrument. Data were analyzed using ANOVA, MANOVA, Pearson correlations, and multiple regressions.

Findings indicated that females whose asthma was not well controlled had more beliefs about the chronicity of their asthma than those who were well controlled. However, there were no differences in such beliefs among males whose asthma was not

well controlled from those who were well controlled. Well controlled adolescents differed from not well controlled adolescents for cognitive representations of cyclic timeline, treatment control, psychological attributes, and consequences as well as for emotional representations. There were no significant differences in the means of the self-management behaviors by gender, by asthma impairment, or by gender by asthma impairment. A significant bivariate relationship was found between representations of identity, consequences, treatment control, and symptom management. In the multiple regression model, representations of treatment control and consequences contributed to variances in symptom management; however, no other representations, gender, or asthma impairment variables were statistically significant. The representations, gender, and asthma impairment variables did not contribute to variances in medication management or environmental control. Limited studies have been conducted with African American adolescents with asthma; therefore, the findings will contribute information to the literature on their illness representations and self-management behaviors. The findings also contribute to the literature information based on adolescents' genders and levels of asthma impairment.

Kathleen M. Hanna, PhD, RN, Chair

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ABBREVIATIONS

Abbreviation	Term
ACT	Asthma Control Test
ACTION	Adolescent Care Team in Our Neighborhood
ASCPI	Asthma Self-Care Practice Instrument
CDC	Centers for Disease Control and Prevention
ED	Emergency Department
FEV	Forced expiratory volume
FVC	Forced vital capacity
IDOE	Indiana Department of Education
IPQ-R	Illness Perceptions Questionnaire-Revised
IRB	Institutional Review Board
MHC	Minority Health Coalition
NHLBI	National Heart, Lung, and Blood Institute of the National Institutes of Health, United States Department of Health & Human Services
PI	Primary investigator
PFT	Pulmonary function test
VIF	Variance inflation factor

CHAPTER I INTRODUCTION

Asthma is a chronic respiratory condition that affects approximately 25 million Americans including about 2.5 million adolescents (Akimbami, Moorman, Garbe, & Sondik, 2009; Centers for Disease Control and Prevention [CDC], FastStats, 2007). Asthma requires vigilant patient self-management; however, poor self-management is a significant problem for adolescents with asthma (Bruzzese, Unikel, Gallagher, Evans, & Colland, 2008; Joseph, Havstad, Johnson, Vinuya, & Ownby, 2006; Rhee, Belyea, Ciurzynski, & Brasch, 2009). Adolescents' inadequate management behaviors include such activities as non-adherence to medication, delaying treatment during an exacerbation, and subjection to known triggers such as smoking.

Adolescents' poor self-management behaviors impact not only the adolescent but also his/her parents, the adolescent's school attendance, and the economy. More than 10.5 million school days are missed annually because of asthma (Akimbami, Moorman, & Liu, 2011). According to recent estimates, the economic burden of asthma is approximately 30 billion dollars per year in total costs (Kamble & Bharmal, 2009). For adolescents with asthma, the costs of medication, office and emergency department (ED) visits, and their parents' loss-of-work days contribute substantially to this economic burden (Barnett & Nurmagambetov, 2011; Wang, Zhong, & Wheeler, 2005). Thus, asthma is a public health problem.

Prevalence, morbidity, and mortality rates differ according to ethnic/racial groups. Relative to all racial and ethnic groups, African American adolescents have the highest prevalence of asthma and asthma-related deaths (Akimbami et al., 2009; CDC, 2002). From 2007 to 2009, the rate of deaths for African American children and adolescents with asthma (aged 0–14 years) was almost eight times that for Whites in that age group (Gorina, 2012). When compared to all other racial/ethnic groups, African American adolescents with asthma also differ in their healthcare utilization. They have higher rates of ED visits, hospitalizations, and lower ambulatory care (i.e., physician's office and hospital outpatient department) visits (Akimbami et al., 2009; CDC, 2002). The high prevalence, poor asthma control, healthcare utilization patterns, and mortality rates support the need for studies of African American adolescents with asthma.

The problem of self-management among adolescents is compounded further by the potential influences of level of asthma control (asthma impairment), gender, and developmental status (adolescence). The following sections address each of those potential contributors to inadequate management of asthma.

Asthma Impairment (Control)

Clinical manifestations of asthma are characterized by varying levels of asthma classified as well controlled, not well controlled, or very poorly controlled, and this level of asthma impairment potentially influences the self-management behaviors of adolescents with asthma (National Heart, Lung, and Blood Institute [NHLBI], 2007). Adolescents have a lower number of office visits, ED visits, and hospitalizations than children (Merkle, Jones, Wheeler, & Mannino, 2005; Moorman et al., 2007). It could be implied that fewer office visits mean they are not warranted. In many cases, however, this can mean adolescents are not seeking health care until their asthma is poorly controlled. The effects of adolescents' asthma impairment and poor control could lead to additional pharmacological interventions, ED visits, hospitalizations, functional limitations, long-term complications, and increased mortality (NHLBI, 2007; Sadof & Kaslovsky, 2011; Schmier et al., 2007).

Gender

Epidemiology data on asthma prevalence, mortality, and asthma impairment point to gender differences that compound the problem of asthma management. Asthma is more prevalent among boys during childhood, and males under 15 years of age experience more hospitalizations due to asthma than do females (Debley, Redding, & Critchlow, 2004). During adolescence, poor asthma control begins to increase in females, but mortality rates are higher in adolescent males with asthma (MacKay & Duran, 2008; Murray, Stang, & Tierney, 1997). This could be related to the documented variation in medication use between males and females (Debley et al., 2004). It also has been suggested that the gender differences in various epidemiological measures may reflect differences in the ways males and females respond to and manage their asthma (Osborne, Vollmer, Linton, & Bruist, 1998; Rhee et al., 2009).

The influences of gender differences in asthma have been differentiated not only by variances in age but also by race. African American males 11–17 years of age have higher asthma mortality rates than males of other races and all females (Akimbami et al., 2009; CDC, 2002). In addition, African American adolescent males are more likely to delay treatment than females (Murray et al., 1997; Pawar & Smith, 2006). Furthermore, the increased risk of asthma-related death during adolescence specifically has been related to low levels of asthma self-management among African American males (Joseph et al., 2006).

Asthma Self-management Behaviors

The self-management of asthma can be complex, and this complexity contributes to the inadequate self-management behaviors exhibited by adolescents. An adolescent's asthma self-management involves establishing individual routines for symptom management, medication management, and environmental control. Symptom management includes tasks such as ongoing monitoring of asthma signs and symptoms and assessing peak flow levels. Asthma symptoms can be highly variable; therefore, the need for symptom management may intensify depending on the time of day, environmental exposure, and/or the level of exertion. Medication management also is complex and includes such activities as deciding which medication to use based on symptoms, using written action plans to assist with management, self-monitoring for appropriate technique in administration of medication, and administering multiple medications. Adolescents with asthma have the added burden of trying to avoid or reduce exposure to asthma triggers. Increased exposure to allergens can result in increased asthma symptoms, ED visits, hospitalizations, and medication use (Bryant-Stephens & Li, 2008; Gotzsche, Hamarquist, & Burr, 1998; Huss et al., 2001; Morgan et al., 2004). Adding to the complexity of self-management, adolescents must employ self-management behaviors (symptom management, medication management, and environmental control) in a variety of settings such as at home, in school, during sports activities, and with friends (NHLBI, 2007).

Self-management and Adolescence

The complexities of self-management for adolescents are integrated into their lives and influenced by development. Adolescence is a time of tremendous social, biological, psychological, and intellectual change (Steinberg, 2008). It is characterized by a desire for autonomy, a struggle with self-identity, and increased susceptibility to peer influence (Brunner, Lindgren, Langner, Williams, & Yawn, 2005; Bruzzese et al., 2004; Steinberg, 2008; Zebracki & Drotar, 2004). An adolescent's desire for more autonomy could equate to lower adherence to a prescribed treatment regimen (Steinberg, 2008). Adolescents' struggle with self-identity and attempts to "fit in" with peers could result in poor medication compliance (Bruzzese et al., 2004; Sawyer & Aroni, 2003; Steinberg, 2008; Velsor-Friedrich, Vlasses, Moberley, & Coover, 2004).

A specific area of development that could influence self-management is an adolescent's level of cognitive development. Piaget's theory of cognitive development and recent studies in brain maturation validate the decision-making and abstract thinking that occur during middle adolescence to adulthood (Steinberg, 2008). The adolescent's gain in cognitive ability also can lead to a form of what David Elkind describes as "adolescent egocentrism" (Elkind, 1967, p. 1030). As a result, the adolescent imagines his or her behavior is the focus of everyone's attention (Elkind, 1967). Such thinking could be an explanation for some adolescents who do not use their inhalers prior to sports or physical education class because "everybody will notice." Studies also have shown that adolescents' cognitive maturity contribute to more accurate perceptions of health and illness (Eiser & Kopel, 1997). However, differences in perceptions of symptoms or situations occur among adolescents in varying stages of cognitive transitions (Rhee, Belyea, & Elward, 2008; Sawyer, 2007). Therefore, adolescents' self-management behaviors can be influenced by how accurately they perceive symptoms or situations.

Research that focuses on the asthma self-management behaviors of individuals who are in the developmental stage of adolescence is needed.

The complexities associated with the self-management behaviors of adolescents support the necessity for studies of adolescents with asthma and particularly those in the stage of middle adolescence. The researcher identified the age group of 14–16 years of age (i.e., middle adolescence) as the target sample for implementation of this study for several reasons. First, this age group is in the middle of adolescence and exhibits increasing cognitive maturity, abstract thinking, and decision-making skills than do younger adolescents. All of these attributes are needed in order to self-manage a chronic illness such as asthma, and because of these capabilities, many now are managing their asthma independently rather than the parents' management of adolescents' asthma. Second, this age group of middle adolescence is encountering the challenges of wanting to be "normal" and like their peers, while facing the complex treatment regimens of asthma. It is important to address inadequate self-management behaviors of this age group before they become young adults and even more independent. Finally, adolescents of 14–16 years of age have been included in age groups documented with increased prevalence of asthma, poor asthma control, inadequate self-management behaviors, and increased mortality. Despite inadequate self-management behaviors and increased mortality among adolescents with asthma, few studies have been conducted solely on adolescents with asthma (Buston & Wood, 2000; Joseph et al., 2007; Knight, 2005; Velsor-Friedrich, Pigott, & Louloudes, 2004).

Illness Representations (Beliefs and Perceptions)

It has been demonstrated that acquisition of knowledge alone does not improve asthma management for adolescents (Bernard-Bonnin, Stachenko, Bonin, Charette, & Rousseau, 1995). Self-management behaviors might be influenced by the adolescent's subjective perspective, including beliefs, perceptions, and illness representations. For example, adolescents' beliefs about side effects of medication were found to impact adherence to their medication, and perceptions about the severity of asthma symptoms influence how adolescents choose to manage their symptoms (Ayala et al., 2006; Knight, 2005). Some perceptions and beliefs have been studied as the concept illness representations and have been noted to influence self-management behaviors (Cameron & Leventhal, 2003). Illness representations are described as mental representations of knowledge and experience or beliefs about illness (Cameron & Leventhal, 2003). Leventhal, Leventhal, and Schaefer (1992) classified illness representations as cognitive illness representations (identity, cause, timeline, consequences, and control) and emotional illness representations. There is some evidence in research with adults that cognitive illness representations may be associated with adherence behaviors. For example, asthma research has highlighted the influence timeline representations (whether asthma is acute versus chronic) and identity have on treatment adherence (Byer & Meyers, 2000; Halm, Mora, & Leventhal, 2006).

Adolescents' thinking is more advanced, efficient, and effective than that of children; yet, they are still in a stage of cognitive development and in many aspects still different from adults, including their parents and healthcare providers (Peterson-Sweeney et al., 2007; Steinberg, 2008). Therefore, adolescents' level of cognitive maturity could influence their illness representations, beliefs, perceptions, and, subsequently, asthma self-management. For example, the complexity of cognitive transitions during middle adolescence is compounded further when adolescents underestimate their potential for harm (Steinberg, 2008). Interestingly, some adolescents underestimate the harm in "holding out" on taking asthma medication during acute exacerbations or in thinking asthma can be controlled strictly through their mindset. These inaccurate behaviors and beliefs of holding out, or control through mindset, could be influenced by the adolescent's cognitive illness representation (control) and level of cognitive development. Identifying adolescents' beliefs, perceptions, and illness representations associated with asthma will increase our understanding of their asthma self-management behaviors (Knight, 2005; Logan, Zelikovsky, Labay, & Speigel, 2003). However, there are limited studies of adolescents' beliefs, perceptions, and illness representations of asthma (Hagger & Orbell, 2003; Knight 2005).

Beliefs, perceptions, illness representations, and self-management behaviors potentially are influenced by asthma impairment and gender. For example, one explanation for the relatively higher rates of asthma morbidity in males is that they differ from females in illness representations and/or self-management behaviors (CDC, 2002; Joseph et al., 2006). Understanding asthma illness representations will be very important if inaccurate representations are shown to be associated with poor self-management behaviors; these inaccurate beliefs would be excellent targets for nursing interventions.

Summary of the Problem

Asthma is a chronic disorder that affects adolescents and requires their involvement in the management of the illness (American Lung Association, 2006).

Adolescents are developing self-management behaviors that will be used to manage their asthma during adulthood, and it is important to identify variables that influence inadequate self-management behaviors early so they can be corrected before adulthood (Institute of Medicine of the National Academies, 2007). The study investigator identified adolescents in middle adolescence (14–16 years of age) as the target sample for implementation of this study because of their developmental changes and inadequate self-management behaviors and the potential for inaccurate beliefs, perceptions, and illness representations. Adolescents' illness representations and self-management behaviors may be influenced by their asthma impairment and gender; therefore, the investigator also included those variables in this study. The illness representations and self-management of African American adolescents are of concern because of their varying levels of asthma impairment (especially their poor control of asthma), inadequate self-management behaviors, and mortality rates. The investigator identified no studies in the literature that focused on the illness representations and self-management behaviors of African American adolescents with asthma.

Purpose of the Study

The goals of this study of African American adolescents (aged 14–16 years) with asthma were two-fold: (1) to explore differences in illness representations and self-management behaviors by gender and level of asthma impairment and (2) to explore relationships between cognitive and emotional illness representations and asthma self-management.

Aims and Research Questions

The specific aims and research questions of the study were:

Specific Aim 1: To explore differences in illness representations (cognitive and emotional) and self-management behaviors (symptom management, medication management, and environmental control) by gender, asthma impairment (well controlled and not well controlled), and gender by asthma impairment among African American adolescents (aged 14–16 years) with asthma.

Study questions for Specific Aim 1 included:

1. What are the differences in the means of cognitive representations of identity, timeline, consequences, cause, and control by gender, asthma impairment (well controlled and not well controlled), and gender by asthma impairment for African American adolescents (aged 14–16 years) with asthma?
2. What are the differences in the means of emotional representations by gender, asthma impairment (well controlled and not well controlled) and gender by asthma impairment for African American adolescents (aged 14–16 years) with asthma?
3. What are the differences in the means of self-management behaviors of symptom management, medication management, and environmental control by gender, asthma impairment (well controlled and not well controlled), and gender by asthma impairment for African American adolescents (aged 14–16 years) with asthma?

Specific Aim 2: To explore relationships between illness representations (cognitive and emotional), asthma self-management behaviors (symptom management, medication management, and environmental control), gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma.

Study questions for Specific Aim 2 included:

1. What are the bivariate relationships between cognitive (identity, timeline, consequences, cause, and control) and emotional representations and asthma self-management behaviors (symptom management, medication management, and environmental control) in African American adolescents (aged 14–16 years) with asthma?
2. What are the associations between symptom management and the set of cognitive representations (identity, timeline, consequences, cause, and control), emotional representations, gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma?
3. What are the associations between medication management and the set of cognitive representations (identity, timeline, consequences, cause, and control), emotional representations, gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma?
4. What are the associations between environmental control and the set of cognitive representations (identity, timeline, consequences, cause, and control), emotional representations, gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma?

Conceptual Framework

Illness Representations–Asthma Self-management Model

The illness representations–asthma self-management framework (see Figure 1) guided this study. Because those with poorly controlled or not well controlled asthma would experience more frequent symptoms, their illness representations and self-management behaviors should differ from those with well controlled asthma. In addition, because of gender differences in the prevalence, morbidity, and mortality rates as well as self-management behaviors and beliefs, perceptions, and representations of illness, gender was included as a variable (Osborne et al., 1998; Rhee et al., 2009).

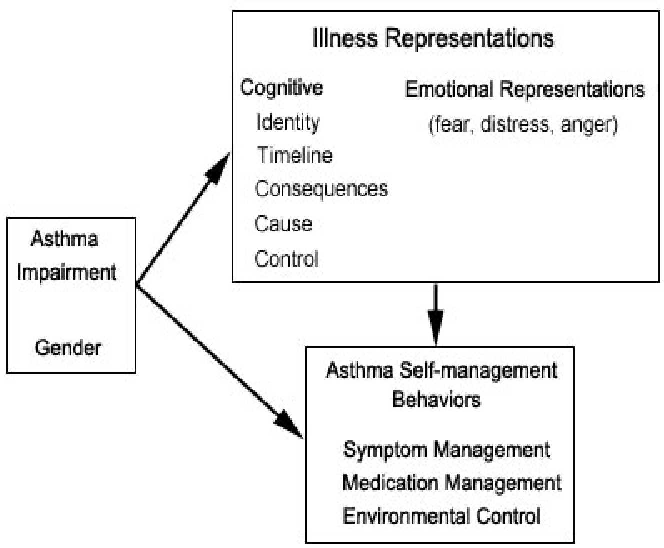

Figure 1. Illness representations–asthma self-management framework. Copyright 2012 by Sharron Johnson Crowder. Adapted with permission (Figure A1) from Commonsense Model of Illness by Leventhal, Leventhal, & Schaefer, in *Aging, Health and Behavior*, p. 112, Ory, Abeles, & Lipman (Eds.), 1992, Newbury Park, CA: Sage Publications.

The study investigator adapted components of Leventhal's common sense self-regulation model (Leventhal, Leventhal, & Cameron, 2001) for the conceptual framework for this study. This study focused on illness representations and the concepts of cognitive and emotional representations, based on the common sense self-regulation model. The cognitive representations include illness beliefs of identity, timeline, consequences, cause, and control. The researcher defined the emotional representations as emotional responses such as distress, fear, and anger. There is a considerable amount of research supporting the role of illness representations in adults with chronic illness on self-management (Cameron & Leventhal, 2003; Hagger & Orbell, 2003; Johnson, 1999; Scisney-Matlock, Collings, & Wakins, 2001). The study investigator included the concept of illness representations in the model to determine if there are illness representations (beliefs and perceptions) that influence the self-management behaviors of African American adolescents with asthma and, if so, which ones.

The health outcome of focus for this study was self-management and, specifically, these three behaviors: symptom management, medication management, and environmental control. It was important to study these subcategories of self-management behaviors because of their crucial role in the overall management of asthma.

In this study, the conceptual framework proposed that asthma impairment and gender influence illness representations and asthma self-management. The framework also proposed that illness representations influenced asthma self-management. Therefore, the influence of asthma impairments, gender, and illness representations formed the basis for the analysis of asthma self-management behaviors. The study investigator controlled the influence of race and adolescent development by limiting the sample to African American middle-aged (14–16 years old) adolescents.

The components of the illness representations–asthma self-management model are discussed further in this section. The section includes discussions on the common sense model and the concepts selected for the study, followed by the topics of illness representations, self-management, gender socialization, race socialization, and asthma impairment.

Asthma Impairment

Asthma, and more specifically asthma impairment, potentially influences illness representations and self-management behaviors. Asthma is a complex disease of the airways that is characterized by variable and recurring symptoms, airflow obstruction, bronchial hyperresponsiveness, and underlying inflammation (NHLBI, 2007). The interrelationships among these various characteristics determine the clinical manifestations, influence the severity of the disease, and serve as a target for asthma management (Gruchalla et al., 2009). The "Practical Guide for the Diagnosis and Management of Asthma: Expert Panel 3 Report" (NHLBI, 2007) recommended assessing asthma severity and control as key components of effective asthma care. One of the important new domains of assessment is asthma impairment. Asthma impairment is characterized by the frequency and intensity of symptoms and functional limitations. It is classified as well controlled, not well controlled, or very poorly controlled (NHLBI, 2007). Assessment of asthma impairment is a recent recommendation and descriptions in the literature mainly pertain to the guidelines. Therefore, identification of the influences of asthma impairment (how well controlled, not well controlled, or poorly controlled) on illness representations and self-management (see Figure 1) will contribute to the literature.

Gender

Illness representations and asthma self-management behaviors may be influenced by gender. Gender differences in asthma have been attributed to several factors including biology and socialization (Naleway et al., 2006; Rhodes, Moorman, & Redd, 2005). However, socialization will be focused upon here. Researchers have identified other factors that reflect a socialization process where male or female identities contribute to gender differences in asthma. In one of his classic articles, Holstein (1987) emphasized that gender effects not only are associated with the behaviors exhibited by men and women but also those gender beliefs imposed by society. Reflective of how males and females are socialized, a repeating theme found in the literature was that men and women have different behaviors towards symptom management and healthcare utilization. Women's patterns include using more physician services, seeking more preventive care, and taking more medicine. Conversely, men use fewer preventative services, visit the ED more frequently, and delay seeking healthcare services (Tudiver & Talbot, 1999; Weiss & Lonnquist, 2006). Tudiver and Talbot (1999) specifically looked at illness behaviors in men and found that men were more susceptible to particular illnesses because they delay seeking care. Men demonstrated this behavior to delay based on a choice to "tough it out," which is a reflection of a belief or perception (Tudiver & Talbot, 1999, p. 47). Although most gender research has been conducted with adults, some common themes of adult illness behaviors (e.g., medication use, delays in seeking health care, and ED use) also have been identified in adolescents (Rhodes et al., 2005; Rydstrom, Hartmen, & Segesten, 2005).

Gender differences according to race also have been described in the literature. African American male adolescents had relatively greater reliance on emergency services and demonstrated less understanding of their asthma disorder, less environmental control, and less adherence to medication regimens. Despite access to health care through

Medicaid, African American males often delayed seeking health care until they were on the verge of severe exacerbations (Murray et al., 1997).

Common Sense Self-Regulation Model

Howard Leventhal and his colleagues (Leventhal et al., 2001) initiated the foundational studies and developed the common sense self-regulation model. Two basic assumptions underlie the self-regulation model: (1) people construct representations of illness threats; and (2) these representations generate goals for self-management, suggest procedures for goal attainment, and inform criteria for evaluating outcomes (Leventhal, Brissette, & Leventhal, 2003). Leventhal et al.'s (2001) model assumes that individuals process somatic stimuli and information about health threats as perceived cognitive representations and emotional representations of the experience. The illness representations (cognitive and emotional) then inform the coping procedures of individuals. Appraisals of the outcomes of the coping behaviors then modify the representations through a feedback loop (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009; Leventhal et al., 2003).

The common sense self-regulation model is a comprehensive model that progresses from the initial stimuli or threat through coping procedures to influence illness outcomes. Use of the full model may be possible in the future when the study investigator conducts more extensive studies of adolescents with asthma. However, the current study focused upon illness representations' association with self-management behaviors of adolescents with asthma. This study focused on the concept of illness representations because it may be an important explanatory factor in the context of asthma. When faced with an illness threat, individuals form both cognitive and emotional illness representations. Cognitive representations refer to beliefs about the illness, and emotional representations reflect one's emotional responses to illness (Hagger & Orbell, 2003). Cognitive and emotional representations act in parallel to influence illness-associated health behaviors and illness outcomes (Hagger & Orbell, 2003; Jessop & Rutter, 2003). Faced with a situation such as the experience of an unusual symptom or the provision of a diagnosis from a doctor, individuals construct their own representation, which in turn determines their behavior (Weinman & Petrie, 1997). Thus, the concept of illness representations can be used to increase understanding of self-management behaviors to maintain health and control illness (Leventhal, et al., 2001).

Illness Representations, Beliefs, and Perceptions

Sociology literature, specifically David Mechanic's theory of help-seeking behavior, supports the importance of the influence of illness beliefs, perceptions, and illness representations to illness behaviors (Mechanic, 1968). Although the theory is related to another health behavior, health-seeking behavior, the influence of beliefs and perceptions support the use of illness representations in this study. For example, help-seeking behavior is influenced by perceptions and beliefs related to: (1) the visibility, recognizability, or perceptual salience of symptoms; (2) the perceived seriousness of symptoms; (3) available information, knowledge, and cultural assumptions and understandings of the evaluator; and (4) competing possible interpretations that can be assigned to the symptoms once they are recognized (Mechanic, 1968). Although Mechanic's studies (1968) were conducted with adults, some of the factors could help to explain some of the beliefs, perceptions, illness representations, and self-management behaviors of adolescents.

The use of the common sense self-regulation model in research is relatively recent and thus there is limited empirical support for illness representations' influence on behavior, specifically for adolescents with asthma. Illness representations (cognitive and emotional) have been used to gain insight into self-management behaviors and illness outcomes. For example, Halm et al. (2006) used illness representations to characterize asthma beliefs on the acute, chronic, or cyclical nature of the asthma (illness representation of timeline) among adults. Researchers viewed asthma as an acute episodic illness by elderly males who had been diagnosed for years, had high rates of oral steroid use, and made frequent ED visits despite frequent contact with healthcare providers (Halm et al., 2006). Studies of adults with asthma also have shown that illness perceptions and treatment beliefs are substantial predictors of adherence to medication and self-management (Hagger & Orbell, 2003; Horne & Weinman, 2002; Jessop & Rutter, 2003). It is important to determine whether representations influence management in samples of adolescents with asthma as it did in samples of adults with asthma.

Although the support for illness representations is limited with adults and specifically for adolescents with asthma, similar constructs of perceptions and beliefs have been used for some time. Thus, it is important to expand the discussion of the influence of beliefs and perceptions on behavior. Beliefs have been viewed as powerful influences on self-management behaviors (Horn, 1992; Knight, 2005). Beliefs consist of knowledge, opinions, and faith that dispose persons toward certain kinds of behavior (Horn, 1992). As with illness representations, the strength of a belief does not depend necessarily upon its degree of correspondence with reality or with its lack of contradiction to other beliefs (Horn, 1992). Like beliefs, adolescents' illness perceptions are important contributors to their self-management behaviors. Perceptions of illness guide performance of self-management behaviors. Effective self-management is more likely when individuals perceive they can perform self-management behaviors that will consequently improve their health (Holman & Lorig, 1992; Zebracki & Drotar, 2004). Perception is a cognitive process; therefore, it is also important to be aware that adolescents are in a stage of cognitive change as they advance in their thought process. Because adolescents are in a stage of cognitive change, some adolescents might have misperceptions of their asthma. These misperceptions also can influence adolescents' self-management behaviors. The conduction of research with adolescents with asthma could aid in determining the relationship between self-management behaviors and the adolescents' illness representations (beliefs and perceptions).

Asthma Self-management

Thomas Creer and his colleagues were pioneers in the 1960s in the use of the term *self-management* in association with pediatric asthma. They acknowledged basing their work on the theoretic and empiric framework of social and cognitive learning theorists, particularly Bandura, Mischel, and Thoresen (Creer, 1987). Creer (1987) emphasized that self-management requires the active participation of the patient. The self-management of asthma can be complex and involve such core skills as solving problems, making decisions, implementing action plans, using resources, and forming patient/healthcare provider partnerships (Creer, 1987; Lorig & Holman, 2003). Patients with asthma use self-management for the prevention of attacks, for detection and management of asthma episodes, and for the reduction of other factors influencing asthma morbidity (Creer, 1987; Lorig & Holman, 2003). Certain categories of behaviors generally are required for the management of asthma including symptom management, medication management, and environmental control (NHLBI, 2007).

Although the terms self-management, compliance, and adherence are used interchangeably (Bauman et al, 2002; Buelow & Johnson, 2000; Sawyer & Aroni, 2003), the investigator considers self-management the better conceptual term. Compliance and adherence are concepts that have been used longer than self-management and have been researched more extensively. Trostle defined compliance as “the extent to which the patient’s behavior (in terms of taking medication, following diets, or executing other lifestyle changes) coincides with medical or health advice” (2000, p. 38). Huss, Travis, and Huss (1997) defined adherence as an active, voluntary, and mutual relationship in which the patient and provider collaborate to produce a desired or therapeutic outcome. Bauman et al. (2002) emphasized that the expected result of both concepts is for the patient to comply with medical advice but adherence involves joint decision-making and increases the patient’s willingness to comply. Subtle distinctions in the terms have been highlighted in the literature; however, for the purpose of this study, examination of asthma management behaviors considers the complexity of the active process.

Race

The study investigator controlled the influence of race by limiting the sample to African American adolescents. The underlying factors of how a race of people is socialized and the influence of its representations and management behavior are complex and are not understood fully. However, Mechanic (1968, 1977), a sociologist, emphasized the cultural and sociological influences on people’s responses to illness. In his theory, Mechanic described the way people are socialized in families and communities to respond to illness—partially by looking at how people within their group respond to illness and the reactions their behaviors elicit (Mechanic, 1977). Such explanations move illness behaviors outside of the considerations of the individual's sole response to symptoms that include considerations of cultural and sociological influences on illness behaviors (Mechanic, 1977).

Supportive of Mechanic's (1977) assumptions, beliefs and perceptions that influence illness or self-management behaviors have been identified in the literature. Neighbors and Jackson (1984) discussed the beliefs that some African American adults have regarding the use of informal and professional assistance to manage chronic illness. There is a tendency for some African Americans to use informal help in combination with professional help. Limited studies have been conducted with African American adolescents with asthma, and the researcher found none in the literature on the illness representations of African American adolescents (14–16 years old) with asthma. Therefore, this study will contribute to the research on African American adolescents with asthma.

Conceptual Definitions

The investigator based the conceptual definitions for use in this study on the common sense self-regulation model (Leventhal et al., 1992), writings on self-management and gender and the "Practical Guide for the Diagnosis and Management of Asthma: Expert Panel 3 Report" (NHLBI, 2007).

Asthma Impairment

Asthma impairment is the frequency and intensity of symptoms and functional limitations that a patient is experiencing or has experienced recently (NHLBI, 2007). The degree of asthma impairment is determined by the level of asthma control: well controlled, not well controlled, or very poorly controlled. The sections that follow discuss the three levels of control.

Well controlled. Well controlled asthma is indicated by infrequent symptoms, nighttime awakenings, use of $beta_2$ agonist medications, no interference with normal activities, and near normal maintenance of pulmonary function (NHLBI, 2007).

Not well controlled. Not well controlled asthma is indicated by periodic symptoms and nighttime awakenings, sporadic use of $beta_2$ agonist medications, near normal to moderate pulmonary functioning, and some limitation in activity (NHLBI, 2007).

Poorly controlled. Poorly controlled asthma is indicated by frequent symptoms, nighttime awakenings, use of $beta_2$ agonist medications, extremely limited activity level, and poor lung function (NHLBI, 2007).

Asthma Self-management

Self-management is a multidimensional concept that includes activities which the youth perform to manage the disease as well as management decisions that flexible regimens demand (Schilling et al., 2009). The study investigator adapted the conceptual definition identified for the concept of self-management described in this study from Schilling et al. (2002). Schilling and colleagues (2002) defined self-management as "an active, daily, and flexible process in which youth and their parents share responsibility and decision making for achieving disease control, health, and well-being through a wide range of illness-related activities" (p. 797). For the purpose of this study, the researcher adapted Schilling et al.'s (2002) definition, deleted the parental description, and defined self-management of asthma in adolescents as an active, daily, and flexible process in which youth are aware and make decisions for achieving disease control, health, and well-being through a wide range of illness-related activities (including symptom management, medication management, and environmental control).

Symptom management. Symptom self-management involves daily assessments and on-going monitoring of asthma signs and symptoms, recognition and handling of worsening asthma, and monitoring limitations in normal activities because of asthma symptoms (NHLBI, 2007).

Medication management. Medication self-management includes self-adjustment of medication in response to acute symptoms and changes in peak expiratory force; management of dose, number of medications, and frequency of administration according to prescriptions, and written asthma plans (if applicable); proper administration of medication; and monitoring for the effects of the medication (NHLBI, 2007).

Environmental control. Environmental control involves the reduction of exposure, as much as possible, to allergens to which the patient is sensitive (NHLBI, 2007).

Gender

Gender is a person's self-identification as a male or a female.

Illness Representation

Leventhal et al. (2003) defined illness representations as illness beliefs and perceptions that individuals construct in response to health threats or situational stimuli. Two categories comprise illness representations: cognitive and emotional representations.

Cognitive representations refer to beliefs about the illness. The common sense self-regulation model includes five sets of cognitive illness representations (Leventhal et al., 2001).

- *Identity* involves beliefs about symptoms and labels that define the threat.
- *Timeline* involves beliefs about timeframes for the development and duration of the disease.
- *Consequences* involve physical, emotional, social, and economic outcomes of illness.
- *Cause* reflects the external, internal, and behavioral causes of the disease or threat.
- *Control* is the individual's perception of the responsiveness of the condition to self-treatment and expert intervention.

Emotional representations, the second category of illness representations, are emotions generated by the illness (Moss-Morris et al., 2002).

Summary and Contributions of this Study

Asthma in African American adolescents is a significant health problem. Asthma self-management is complex and involves an array of behaviors such as symptom management, medication management, and environmental control. Added to the complexity of self-management is the need to vary management regimens based on levels of asthma impairment (well controlled, not well controlled, or very poorly controlled).

Self-management of asthma among African American adolescents often is inadequate, which can lead to poor asthma control and increased mortality. Inadequate asthma self-management among African American adolescents is compounded further by gender differences.

A potential way of more fully understanding adolescents' self-management is by application of the common sense self-regulation model (Leventhal et al., 2001) which assumes that illness representations (cognitive and emotional) influence health behaviors and subsequently illness outcomes. Little is known about the relationship between illness representations and asthma self-management in African American adolescents. Further, no research has examined how adolescents' illness representations and self-management behaviors might be influenced by gender and asthma impairment. The author developed the illness representations–asthma self-management model (see Figure 1) to reflect these potential influencing factors and relationships. This study contributes to the literature by examining differences between illness representations and self-management behaviors by gender, asthma impairment, and gender by asthma impairment interaction. Furthermore, the study explored the relationships between illness representations and self-management behaviors, gender, and asthma impairment in African American adolescents with asthma. These findings will guide the development of patient-centered interventions focusing on salient representations with African American adolescents with asthma. Furthermore, the findings will guide development of interventions that differ according to gender or specific levels of impairment.

CHAPTER II REVIEW OF THE LITERATURE

Chapter II provides a detailed discussion of empirical literature that relates to the theoretical framework of the study. First, the author presents literature pertaining to asthma self-management. Subtopics for that section include medication management, symptom management, environmental control, self-management and gender, self-management and race, and self-management and asthma impairment. The second major topic reviewed is illness representations (beliefs and perceptions) related to asthma. Subtopics focus on illness representations and gender, illness representations and race, and illness representations and asthma impairment. Third, the study investigator presents literature pertaining to the relationship of illness representations and asthma self-management. The subtopics highlight gender, race, and asthma impairment. A summary of the empirical support for the study concludes the chapter.

The author conducted a review of the literature using CINAHL, EBSCOhost, ERIC, Family and Society Studies Worldwide, Humanities International, MEDLINE, Mental Measurements Yearbook, Sociology Journals, and PsycARTICLES databases from 1975 to 2012. The years searched permitted the review of adherence, compliance, and early self-management studies. The study investigator also manually searched relevant papers for additional citations. The author grouped keywords used in searching the databases as follows: asthma adherence, compliance, and self-management; adolescence and adolescents; African Americans; asthma, asthma impairment, and asthma severity (intermittent or persistent); and illness representations, beliefs, and perceptions. For the purpose of the review of the literature, the study investigator defined adolescence as aged 13–18 years. However, due to the scarcity of research specifically on adolescents, the investigator reviewed additional studies when they included adolescents among a larger sample of children. Additionally, the investigator reviewed studies on adults if they were pertinent to the study but limited or no research had been published in that area relating to adolescents.

Asthma Self-management

This section includes a review of the literature on children, adolescents, parents, and adults as well as literature on self-management, adherence, and compliance. The majority of studies reviewed focused on one of four groups: adults with asthma, younger children with asthma, children and younger adolescents with asthma, or parents of children and adolescents with asthma. However, the findings from those four groups and those studies specifically designed for adolescents contribute to an overall view of asthma self-management as it relates to adolescents. Because the three terms (self-management, adherence, and compliance) have been used interchangeably in the medical and social scientific literature (Buelow & Johnson, 2000; Conrad, 2005; Drotar, 2000; Sawyer & Aroni, 2003), the study investigator reviewed all terms to provide a more comprehensive review of self-management. Subtopics presented in this section of the literature review include medication management, symptom management, environmental control, self-management and gender, self-management and race, and self-management and asthma impairment (severity). The section concludes with a summary of asthma self-management literature.

Medication Management

Literature reviewed. A major component of self-management behaviors of adolescents with asthma is medication management. Such management includes self-adjustment of medication in response to acute symptoms and changes in peak expiratory force; management of dose, number of medications, and frequency of administration according to prescriptions and written asthma plans (if applicable); proper administration of medication; and monitoring for the effects of the medication (NHLBI, 2007).

A study by Buston and Wood (2000) documented poor daily medication management among 49 adolescents who were attending hospital asthma clinics in Greater Glasgow in the United Kingdom. The study identified the adolescents' gender (29 females, 20 males), but race and ethnicity were not reported for the study. The study generally described the participants' levels of asthma impairment; healthcare providers prescribed oral steroids for 28 respondents at their last visit (reflective of not being well controlled), and 20 had been hospitalized in the previous year (also reflective of not being well controlled). During interviews conducted with the adolescents, aged 14–20 years, investigators encouraged the participants to discuss their views and experiences regarding asthma as it related to various topics including medication and day-to-day limitations. Of the 49 adolescents interviewed, only 4 reported that they had always and continued to take their medication as prescribed. Of the 45 who admitted to being non-compliant, most reported compliance with one aspect of their regimen the majority of the time. Investigators described compliance for the total sample and not for subsamples that reflected various levels of impairment, gender, stages of adolescence, or race/ethnicity; all of these factors could contribute to their compliance.

A study of 75 children and adolescents, 8–16 years old, with asthma also documented poor daily medication management (Walders, Kopel, Koinis-Mitchell, &

McQuaid, 2005). The ethnic composition of the participants included 68% White, 27% Black, 4% Biracial, and 1% Latino. The study did not report the gender of the participants. Instead of asthma impairment, study investigators used the term asthma severity to describe the sample. The participants ranged in severity from mild persistent (64%) to moderate persistent (33%) to severe persistent (3%). This study measured daily medication management as adherence to daily use of the participants' long-term controller. The participants had poor adherence to daily controllers, with children and adolescents self-reporting that the daily controller medication was administered 46% of the time. In addition to adherence to daily controller medication, the investigators measured the use of quick relief medication via an electronic monitoring device. The greater use of quick relief medication reflected participants' inadequate daily self-management; 85% of the participants used their quick relief medication at least once per month. The findings of such a high level of non-adherence to daily medication for those with predominately mild to persistent asthma severity confirm the need to study the self-management behaviors of adolescents. Again, this study described adherence for the total sample and not for subsamples that reflected various levels of impairment, gender, stages of adolescence, or race/ethnicity—all of which could contribute to their compliance.

McQuaid, Kopel, Klein, and Fritz (2003) also documented poor daily medication management. McQuaid et al. studied the management of 106 children and adolescents (aged 8–16 years) who were predominately Caucasian (68%), followed by African American (23%), Hispanic (5%), and Biracial (5%). Males comprised 58% of the sample. The study measured adherence by the MDILog™ electronic asthma medication monitor.

The mean level of adherence to prescribed medication was 46% for both males and females no matter what level of asthma impairment. Older (12–16 years of age) children and adolescents had lower levels of adherence (r = -.21, p < .05) than younger (8–11 years of age) children and adolescents. This result indicated that poor medication management is more of an issue with adolescents. The study grouped African American, Hispanic, and Biracial participants into a general minority category for comparison of adherence with Caucasian participants. Significant differences in adherence between Caucasian (M = .53, SD = .29, Mdn = .57) and non-Caucasian participants (M = .37, SD = .26, Mdn = .38) were found, $F(1, 98) = 7.55$, p < .01). Similar to the other studies with self-report measures of management, this study with a more objective measure documented poor medication management.

Another study documented poor daily medication management of adolescents with asthma (Forero, Bauman, Young, & Larkin, 1992). The investigators conducted the epidemiologic study of 1,313 adolescents (12–21 years old) with asthma with participants recruited from high schools and general practitioners' offices in Australia. The study did not identify the racial/ethnicity of the participants. Participants reported asthma impairment in the presence of wheeze symptoms in the previous 12 months. Public school students (18%–20%) reported symptoms, while 40% of the general practitioner patients reported symptoms within the previous 12 months. The study did not report the number of males and females in the sample. The participants completed surveys, and their responses were considered self-reports of their daily medication regimens. Although 90% of both male and female adolescents with asthma reported using short-acting bronchodilators as regular medications, only 44% used inhaled corticosteroids and cromolyn as regular asthma control medication. Healthcare practitioners prescribe these asthma control medications as daily medication for patients with moderate to severe asthma as an anti-inflammatory medication. Additional asthma control medication such as cromolyn may be added to the regimen to decrease lung sensitivity to allergens. Only 44% of the study participants used asthma control medication, suggesting that the medication self-management of the adolescents was suboptimal according to global asthma guidelines. Ten percent of the adolescents used Theophylline®. Seven percent of the participants used non-asthma medications such as antibiotics, nasal sprays, and decongestants. Study investigators described management for the total sample and not for subsamples that reflected various levels of impairment, gender, stages of adolescence, or race/ethnicity; all of these could contribute to the adolescents' self-management.

Kyngas' (1999) study of a sample of 266 adolescents (13–17 years of age) made similar findings. The purpose of that study was to describe the health regimen compliance of adolescents with asthma. The investigator recruited participants through the Finnish Social Insurance Institution's register, but the study identified no specific racial/ethnicity information. The number of males and females were equal, 133 each. Thirty-four percent of the adolescents had mild asthma, 60% moderate asthma, and 6% severe asthma. The adolescents completed questionnaires and self-reported their compliance with health regimens, particularly with medication compliance and avoidance of factors contributing to their asthma. Nearly half (42%) of all the participants, both males and females, reported they complied fully with the asthma regimens, 42% placed themselves in the category of satisfactory compliance, and the remaining 18% cited poor compliance. The participants, aged 13–14 years, assessed their compliance to be better than the older adolescents. All of those who had mild asthma showed good compliance, whereas 61% of those who had severe asthma identified as having good compliance with health regimens. This study was one of the few identified in the literature review that differentiated results by gender and age.

Butz et al.’s (2010) randomized control trial focused on poor medication management among inner-city children. The study followed 231 predominately African American children (93%) with asthma in a longitudinal study to evaluate the effectiveness of asthma education on symptom days and the use of controller medication. The sample included children with a mean age of 8 ± 1.9 years, primarily males (61%), categorized as mild to severe persistent asthma, and a mean of two ED visits in the previous six months. Children in the control group had three home visits for standard education delivered by nurse/health educators over eight weeks. Children randomized to the intervention group received the home-based asthma education, had a nurse/health educator to accompany them to primary care clinics, and participated in clinician-caregiver-child communication skills classes. An added benefit for the intervention group was receiving positive reinforcement of medication administration techniques during clinic visits. Pharmacy dispensation records determined the children’s controller medication (inhaled steroid) and short-acting beta blocker use. The results of the study indicated that the asthma education, communication, and support intervention had no impact on symptom days and only a modest impact on controller medication use. The study’s authors reported that despite their efforts to increase caregiver-clinician communication, the caregivers remained reluctant to discuss asthma management concerns with healthcare providers (Butz et al., 2010).

The baseline data of Guendelman, Meade, Benson, Chen, and Samuel's 2002 randomized, controlled trial study documented poor medication management. Investigators conducted interviews with participants and the primary caregiver. Questionnaires measured self-management behaviors of compliance with medication at baseline for inner-city children and adolescents with asthma, aged 8–16 years. The study characterized the intervention group as males (61%); African American (79%), White (8%), Other (14%); with mild (23%), moderate (66%), or severe asthma (11%). The control group included males (54%); African American (74%), White (12%), Other (15%); with mild (29%), moderate (59%), or severe asthma (12%). At baseline, 46% to 47% of the two groups seldom or never took asthma medication without a reminder. These baseline reports support two considerations. First, the large number of participants who seldom or never took medication without a reminder reflected inadequate medication management. Second, a need exists for research documenting the self-management behaviors of adolescents versus children. The participants' ages ranged from 8 to 16 years. Differences would be expected in the medication compliance of 8-year-olds than for 16-year-olds because they are at different developmental stages.

Summary of medication management literature. The study investigator reviewed seven studies that focused on daily medication management and quick relief medication use and one study on medication for exacerbations. The literature indicated inadequate asthma management no matter if it was for daily, quick relief, or exacerbation medication and did not matter if the conceptualization was management, adherence, or compliance. The investigator identified several limitations in this review of seven studies: only two studies, McQuaid et al. (2003) and Butz et al. (2010) used objective measures to collect data. In many cases, adolescents' self-reports of adherence to medication are less reliable than objective measures (Bender, Milgrom, & Apter, 2003). The researcher identified another limitation as the broad age range of participants in the studies, ranging from 6–21 years of age. The wide range of ages among participants makes it more difficult to determine the specific behaviors of adolescents when they are mixed with young children in a single study. However, in this review of the literature, three (Buston & Wood, 2000; Forero et al., 1992; Kyngas, 1999) of the seven studies targeted adolescent participants and one (McQuaid et al., 2003) analyzed the data from adolescents separately from children. One study (Kyngas, 1999) documented that management was worse for older adolescents than children. The studies reviewed for this section reflected diversity in the race or ethnicity of the participants. The studies predominately identified the participants as Caucasian (McQuaid et al., 2003; Walders et al., 2005), African American (Butz et al., 2010; Guendelman et al., 2002), Australian (Forero et al., 1992), and Finnish (Kyngas, 1999). One study (Buston & Wood, 2000) did not describe the participants but identified the recruitment site as the United Kingdom. In one study (McQuaid et al., 2003), there was a significant difference in the medication adherence between Caucasian and non-Caucasian participants, with non-Caucasian participants having worse adherence. That study supports the need to determine factors influencing differences in medication adherence among races/ethnicities. Furthermore, of the five studies (Buston & Wood, 2000; Butz et al., 2010; Guendelman et al., 2002; Kyngas, 1999; McQuaid et al., 2003) reporting percentages of males and females, three of the studies (Butz et al., 2010; Guendelman et al., 2002; McQuaid et al., 2003) reported a greater percentage of males. Gender differences in medication management were not reported in any of the studies reviewed. Reporting of asthma impairment varied from the broad descriptions based on the number of symptoms within the previous 12 months to specific identification of the percentages of participants with mild persistent, moderate persistent, and severe persistent asthma. None of the studies reviewed used the newer terminology asthma impairment or described the level of asthma impairment as well controlled, not well controlled, or poorly controlled. The studies reviewed in this section focused on medication management. More specifically, the studies reviewed reported findings related to adherence and compliance with medication. These combined studies reflected the problem of non-adherence or noncompliance that exists among children and adolescents.

Symptom Management

Literature reviewed. The management of asthma symptoms requires daily assessments, on-going monitoring of asthma signs and symptoms, use of asthma action plans (if applicable) to recognize and handle worsening asthma, and monitoring limitations in normal activities because of asthma symptoms (NHLBI, 2007). The symptom management of some adolescents also includes peak flow meter assessments. All of these components add to the complexity of asthma self-management required of adolescents. Monitoring asthma symptoms and recognition of signs of an exacerbation allows the patient to make appropriate changes in activity level and physical environment and to initiate the medication regimen (Fritz, Klein, & Overholser, 1990).

The literature also documents symptom management to be inadequate among adolescents with asthma. Yoos and McMullen (1996) compared subjective symptom monitoring with objective (peak flow meter) symptom monitoring. The sample of 28 grouped the participants as school age (16 children) and adolescents (12 adolescents). The participants' ages ranged from 6–18 years of age, but the study did not report specific ages for each group. The study did not identify the numbers of males and females. Thirty-six percent of the children and adolescents were Caucasian, 46% were African American, and 18% were from diverse groups including Hispanic and Biracial. Eighteen children and adolescents had moderate asthma, and 10 had severe asthma. Researchers did not examine gender differences. Results compared by age groups of children and adolescents; participants in both groups missed identification of early symptoms and waited too long prior to intervening in an exacerbation. Although the rates did not achieve significance, adolescents had a greater percentage of accurate recognition of subjective symptoms than did children. Therefore, the potential for better symptom management among adolescents is suggested.

Fritz et al. (1990) also documented inadequate symptom management. The sample consisted of 37 children and adolescents, aged 7–15 years old. The recruitment criteria reflected asthma impairment in that participants had moderate to severe asthma. The authors did not identify the participants' race or ethnicity. More boys (n = 27) participated in the study than girls (n = 10). No statistically significant differences [$t(35) = -0.09$, *ns*] were noted in the subjective assessment of symptoms of males (M = 13.50, SD = 10.91) and females (M = 13.16, SD = 7.88). The participants' subjective ratings of asthma symptoms were compared with standardized peak flow meter rates. The investigators used a cutoff of 0.60 and above for high accuracy, 0.30–0.59 for moderate accuracy, and below 0.30 for low accuracy. Investigators found seven participants to be highly accurate when their subjective ratings of symptoms were compared with the objective peak flow readings. The authors described 17 of the participants as moderately accurate and 13 as inaccurate in their subjective ratings of their asthma symptoms. The inaccurate rating would place those 13 children and adolescents at greater risk because of their inability to recognize their asthma symptoms and make the appropriate symptom management changes.

Summary of symptom management literature. The author reviewed two studies that measured symptom monitoring. One study compared symptom management between children and adolescents and found adolescents to be more accurate (Yoos & McMullen, 1996). One explanation for the differences in accuracy of symptom monitoring could be the cognitive development of adolescents versus children. However, Fritz et al. (1990) described 17 children and adolescents to be moderately accurate in symptom monitoring and 13 of them to be inaccurate in their ratings of asthma symptoms. It is important to note that Yoos and McMullen (1996) measured adolescents separate from children and Fritz et al. (1990) combined the results of their 7- to 15-year-old participants. Further analysis of both studies' findings revealed more about inadequate symptom monitoring among adolescents. Yoos and McMullen (1996) found that the children and adolescents missed identification of early symptoms and waited too long prior to intervening in an exacerbation. The 13 participants in Fritz et al.'s (1990) study were inaccurate in their symptom management thus putting those adolescents at greater risk for asthma exacerbations. Yoos and McMullen (1996) had a larger number of African American participants than of other races. However, there was no examination of racial/ethnic influences in either study. The authors of neither study discussed gender differences in symptom monitoring.

Environmental Control

Literature reviewed. The final self-management behavior addressed in this study is environmental control. Many adolescents are exposed to more indoor allergens because of increased indoor activity choices such as watching television, using the computer, and playing video games. For some adolescents this means increased bedroom exposure to cockroach and dust mite allergens (Platts-Mills, Vervloet, Thomas, Aalberse, & Chapman, 1997). Assisting to manage allergens in their homes could include washing linen or encasing pillows in cases to decrease dust mites or not eating in rooms to decrease prevalence of cockroaches (Sharma et al., 2007). Adolescents have to be aware of indoor allergens not only in their homes but also in the homes of peers and at school. Adolescence is a greater time of peer interactions and influence; therefore, the adolescent with asthma has to determine how to manage allergens when with peers. Environmental control behaviors also must occur at school. Cat and dog allergens can be carried to school on the clothing of those who have pets at home, and the highest airborne allergen levels occur around the desks of students with home pets (Sharma et al., 2007). Allergens in older school buildings also can trigger asthma symptoms and require management by the adolescent as well as school nurses, teachers, and coaches. Finally, outdoor allergens such as trees and grass can impact adolescents during sports activities (Rastogi, Reddy, & Neugebauer, 2006).

A study by Morgan et al. (2004) suggested inadequate environmental control management in the high rate of triggers in homes, reactive symptoms, and the reactive use of medications needed to address the exposure to allergens. Although this study was an intervention study, the investigators documented the environmental triggers in the homes of 937 children (5–11 years old) prior to the intervention. The authors described the intervention and control groups as having a small predominance of boys (60%) and a majority (70%) of African American or Hispanic participants. Study investigators described asthma impairment in terms of the maximal number of days with symptoms (6.0 ± 0.23 days for intervention group and 6.0 ± 0.24 days for control group), baseline lung functions (88% in the intervention, 87% in the control), and unscheduled ED visits in the two months before baseline (intervention 49%, control 53%). Baseline characteristics for the intervention and control groups depicted a high prevalence of allergic sensitization to cockroach and dust mite allergens. They found detectable levels of cockroach allergen in 68.4% and dust mites in 84.1% of the participants' bedrooms. Participants' homes had smokers (16%–18%), dogs (22%), and cats (16%–18%). Presumably due to this lack of environmental control, the study found a high rate of symptoms and medication for control within two weeks of baseline indicated by 84% using a beta_2 agonist but only 45%–46% used an anti-inflammatory medication. Within two months of baseline, 49%–53% of the sample had greater than or equal to one ED visit, and 13%–14% had greater than or equal to one hospitalization (Morgan et al., 2004). Morgan and colleagues (2004) identified several factors that reflected the impact of self-management behaviors on asthma. First, the high presence of cockroaches and dust mites in bedrooms and smokers in the homes demonstrated the types of allergens that are associated with environmental control. Second, the presumed exposure to allergens contributed to the symptoms that required ED visits and hospitalizations. Third, these participants did not use their medication in the proper manner. Eighty-four percent of them used a beta agonist but only 45%–46% used an anti-inflammatory. According to asthma guidelines, the anti-inflammatory medication should be used in a higher percentage than the results in this study showed. In spite of adult assistance with asthma self-management, the participants in this study had inadequate medication management, poor environmental control, and increased ED visits and hospitalizations.

The study of adverse environmental exposure described in the baseline data of a randomized controlled trial for 61 children and adolescents, 3–13 years of age (Turyk et al., 2006) indicated lack of environmental control. Sixty-three percent of the participants were males, and 55% were African American or Puerto Rican. Investigators reported asthma impairment through the number of asthma symptoms and frequency of asthma symptoms in the month before sampling. Thirty-six percent of the participants had 0–1 symptoms while 16% had 6–7 symptoms. Forty-two percent had no asthma symptoms while 27% had symptoms during the day and at night. Forty-two percent of the participants had smokers in their homes, and 54% of the participants used anti-inflammatory asthma control medication. Thirty-eight of 61 homes had high presence of cockroaches, and the cockroaches were found to be significantly related to the participants' asthma symptoms.

Bryant-Stephens and Li (2008) documented lack of environmental control. First the study documented adverse environmental exposure, indicative of lack of environmental control then described specific actions for controlling the environment. The sample of this study included children and adolescents (2–16 years of age); 55%–60% of them had smokers in the home. Sixty percent of the participants were males, and 99% were African American. Study investigators determined asthma impairment by the number of ED visits and regular sick visits during the 12 months before the study. Participants had an average of two ED visits and slightly more than one regular sick visit related to the child's or adolescent's asthma. Researchers indicated lack of environmental control in that cockroaches were found in significant levels in 45% of the homes of the children and adolescents. Environmental control measures used by these children and adolescents included: pillow case covers (used by 7%–12% of participants) and mattress covers (added to bed by 12%–16% of participants). The lack of environment control also is indicated in the needed use of medications for the allergic response. At baseline, 42%–44% of the participants used $beta_2$ agonists, but a high rate (88%–96%) of participants used anti-inflammatory medication, an indication of exposure to allergens.

A study by Butz et al. (2011) utilized a randomized trial of air cleaners and a health coach to decrease the adverse of secondhand smoke. The study was comprised of children (96.8% African Americans) 6–12 years of age (mean age of 9.1 years) who had persistent asthma (79.4%). Within that categorization of persistent asthma, 16.7% had mild, 31.7% had moderate, and 31.0% had severe. Study participation eligibility included children who had frequent asthma symptoms and/or frequent controller medication use and who lived with a parent who smoked at least five cigarettes per day. The study measured air quality in the home, air nicotine, and urine concentrations. Families randomized to the control group received four home visits by nurses to provide asthma education and environmental assessments. The study included two intervention groups: one that received the usual care plus a high-efficiency particulate air (HEPA) air cleaner and one that received the usual care, a HEPA air cleaner, and a health coach for the asthma education and smoking behavior modification program. Changes in the indoor air quality were significantly lower in both air cleaner groups; however, investigators noted no differences in air nicotine or urine cotinine concentrations. Both air cleaner groups compared with the control group experienced slightly increased symptom-free days (Butz et al., 2011).

The literature identified one study that examined differences in adverse environmental exposure and asthma outcomes among urban Latino, African American, and non-Latino White children. Everhardt et al. (2011) conducted a study with 133 children (6–13 years of age) and their caregivers to assess the environmental control of families. This study is one of the few reviewed that used the Asthma Control Test (ACT) to determine the children's level of asthma control. Based on the ACT scores, researchers identified poor asthma control in 28% of Latino, 23% of non-Latino White, and 30% of African American children (Everhardt et al., 2011). The sample identified ethnic differences in exposure to triggers. Everhardt and colleagues report that non-Latino White families were significantly more likely than Latino families to report a cat in the home, and both African American and Latino families were significantly more likely than Latino families to report cockroaches in the home (2011). Everhardt et al.'s study (2011) reported the highest percentage of reported cockroaches in the home of African American children, the second highest in exposure to smoke, and more functional limitations (frequency of symptoms and asthma episodes, intensity of the asthma episodes).

The literature review identified only one adolescent study that examined adverse environmental exposure and environmental control decisions. In Bruzzese, Chew, and Evans' study in the schools (2002), they found that some students were aware of their allergies and environmental control factors. However, other students did not know if they were allergic to dust mites (22%), mold (22%), or cockroaches (15%). Such lack of awareness of allergens could decrease self-management behaviors related to environmental control. Study results also indicated cigarette smoking, in association with the participant's degree of asthma severity, as an issue among these ninth graders. Thirty percent of the adolescents had mild intermittent asthma, 23% had mild persistent, 33% had moderate persistent, and 14% severe persistent. Eight percent of those with mild intermittent asthma smoked cigarettes, 26% with mild persistent, 17% with moderate asthma, and 5% with severe persistent asthma. Cigarette smoking, as an environmental asthma trigger, could not only contribute to worsening asthma symptoms, it also could cause other pulmonary conditions. This study did not address race and gender.

Summary of environmental control literature. The review of the literature for environmental control reflected several common characteristics. Most of the studies primarily focused on adverse environmental exposure rather than descriptions of the environmental control measures used with asthma self-management. However, environmental exposure is an indicator of the lack of environmental control. Five of the six studies assessed the participants' homes for the presence of cockroaches (Bryant-Stephens & Li, 2008; Butz et al., 2011; Everhardt et al., 2011; Morgan et al., 2004; Turyk et al., 2006). Cockroaches were present in 45%–68% of the homes. Morgan et al. (2004) also evaluated the homes for dust mites, and they were found in 84% of the participants' bedrooms. Exposure to smoke can cause asthma exacerbations for many children and adolescents with asthma. Five of the six studies indicated the number of smokers that lived in the homes of their participants (Bryant-Stephens & Li., 2008; Butz et al., 2011; Everhardt et al., 2011; Morgan et al., 2004; Turyk et al., 2006). The percentage of smokers in the homes of those studies ranged from 16%–66%.

Bruzzese et al. (2002) was the fourth study reviewed, and it focused on ninth grade adolescents with asthma. Cigarette smoking was an issue among the participants themselves with the highest percentage (26%) associated with adolescents with mild persistent asthma and the lowest percent (5%) but reported by adolescents with severe persistent asthma. All six studies not only identified adverse environmental exposure but also the high rates of symptoms and control medication required for their participants. The majority of the participants in five of the studies were African American and at least 60% in each study were males (Bryant-Stephens & Li, 2008; Everhardt et al., 2011; Morgan et al., 2004; Turyk et al., 2006). Bruzzese et al. (2002) did not address the race or gender of their participants.

Self-management and Gender

Literature reviewed. Studies on the asthma self-management behaviors in relationship to gender among adolescents are limited. Tollefsen et al. (2007) examined the associations between symptom management, environmental control, and gender in a study conducted through the Nord-Tondelag Health Study (Norway). Participants were 13–15 years of age at baseline with 53.3% females. Females (*n* = 94) were more symptomatic than males (*n* = 66) and reported more current asthma, especially wheezing at baseline. The study found a higher rate of inadequate environmental control of cigarette smoke among the females in the study. Twelve percent of the females were involved with daily or occasional smoking as opposed to 7.6% among males. The authors pointed out the lack of inadequate environmental control as exhibited by 49.7% of females' high exposure to second-hand smoke in the home environment. Exposure to smoke in the home was a result of a parent or sibling who smoked. This is one of the studies in the literature that reported the high percentage of female adolescents who exhibited poor environmental control by smoking.

Venn, Lewis, Cooper, Hill, and Britton (1998) studied the effect of gender on asthma symptoms. They conducted a study in Norway with 27,826 adolescents, of whom 51% were males. Investigators recruited students 11–16 years of age from area public schools. In Venn et al.'s study (1998), the adolescents completed questionnaires about lifetime and current asthma. Females tended to over-report asthma symptoms (wheezing) and males to deny their symptoms. It is important to note the behaviors exhibited by both genders in order to determine if there is a pattern of such reports among males and females.

Although findings on the influence of gender on adolescents' self-management are limited, studies with adult samples indicate that there are gender differences. Rhodes, Moorman, and Redd (2005) conducted an eight-state study of gender differences for many asthma-related variables, and some reflect poor self-management. Respondents for the study included 12,803 males and 18,815 females, adults 18 years of age or older, who were predominately Caucasian. Females in the study were more likely to report taking medication in the previous 30 days (medication management), use the ED for asthma exacerbations, and schedule a doctor's visit for worsening symptoms. Males had a higher mean number of days of activity limitation (55.5 compared to 31.8 days for females). The increased limitation in activity among men could be attributed to poor symptom management.

Naleway, Vollmer, Frazier, O'Conner, and Magid (2006) reported differences in the self-management behaviors of adult males and females. This study also had a predominately Caucasian (92%) sample. Participants (617 females and 574 males) completed questionnaires for the study. Females (9% versus 6% of males) reported higher medication management in terms of their use of peak flow meters. Males reported more use of over-the-counter medication to control asthma than females (29% versus 16%, $p < 0.0001$), which could be an indication of inadequate medication management (Naleway et al., 2006).

Cydulka et al. (2001) contributed to the asthma self-management and gender literature. Adults included in the study were between 18 and 54 years of age, with a diagnosis of acute asthma. The study compared 489 men's and 796 women's reports of symptoms during an asthma exacerbation. The participant's objectively measured level of airway obstruction identified the level of asthma impairment. The male participants had more severe airway obstruction than women. The men had an initial peak expiratory flow rate of 41 ± 15 versus 47 ± 16, $p < .001$ for women (Cydulka et al., 2001). However, their symptom management did not coincide with their degree of airway obstruction. Despite severe obstructions, male participants reported less frequent, less distressful asthma symptoms, and less severe activity limitations than females (Cydulka et al., 2001). The self-management behaviors reported in the males in this study were similar to those in previous studies (Rhodes et al., 2005; Venn et al., 1998).

Summary of self-management and gender literature. The author reviewed five studies that focused on self-management and gender in this section. Out of the five studies, two (Tollefsen et al., 2007; Venn et al., 1998) had adolescent populations. The studies conducted by Rhodes et al. (2005), Naleway, et al. (2006), and Cydulka et al. (2001) had adult populations. Four of the five studies had greater percentages of females participating in the studies. Two of the studies (Tollefsen et al., 2007; Venn et al., 1998) measured symptom management; three (Cydulka et al., 2001; Naleway et al., 2006; Rhodes et al., 2005) measured medication and symptom management and one (Tollefsen et al., 2007) assessed environmental control regarding smoking. In the studies with adolescents and adults, females reported more asthma symptoms and increased utilization of health care as a part of their symptom management. There was a commonality among studies with male adolescents and adults; they displayed poor symptom management by denying symptoms despite increased airway obstruction and increased days of activity limitations. More extensive studies on self-management and gender have been conducted with adults than adolescents. Further research is required to determine if the same characteristics are exhibited by male and female adolescents. The limited number of studies available for review portrays the gap in the literature on asthma self-management and gender.

Self-management and Race

Literature reviewed. Studies have documented racial differences in asthma self-management behaviors, including those of African Americans. Studies reviewed in this section focused on the self-management behaviors of African Americans and targeted children and adolescents, adolescents, or adults.

Boudreaux, Emond, Clark, and Camargo (2003) investigated self-management and racial/ethnic differences among children with acute asthma who presented to the ED. Among 1,095 children and adolescents aged 2–17 years, 679 (62%) were African American, 256 (23%) were Hispanic, and 160 (15%) were White. In this study, the percentage of females according to race/ethnicity was 38% African American, 43%

Hispanics, and 45% White. Therefore, the study had a higher percentage of males than females. African American and Hispanic children had higher rates of hospitalization (lifetime and previous year). They also had more ED visits in the previous year and were far more likely to state that they used the ED as their primary source of asthma care and prescriptions. They categorized African American, Hispanic, and White children by a severity score of 1 (*mild*) to 4 (*severe*). All racial groups exhibited similar severities upon evaluation in the ED. The study also evaluated the participants' symptom management and medication management behaviors. African American participants (73%) exhibited inadequate symptom management and poor medication management (delayed or no use of inhaled steroids, increased $beta_2$ agonist). Hispanic children and adolescents were highest (77%) in reporting inadequate use of inhalers, and White participants (71%) had the lowest level of inadequate symptom and medication management.

Yeatts, Maier, and Shy's (2000) study focused on medication management, and they evaluated their findings by ethnicity. The study examined inhaler use among 13- to 14-year-old eighth graders. Out of 296 adolescents, 51% were females, 102 African Americans, and 194 White adolescents. Yeatts et al. (2000) did not assess participants with the asthma impairment criteria identified in this study; however, they described asthma control through reports of symptoms, inhaler use, and healthcare utilization. Among the participants, 14% had used an inhaler during the previous year. African American adolescents were slightly more likely to use their inhaler medication only when needed (83%) compared with White adolescents (75%). Study participants provided no direct information to the study researchers regarding the type of medication delivered by the inhalers. Based on the description of using the inhaler as needed, the authors assumed that the adolescents were probably using beta agonists. Both African American and children of low socioeconomic status were less likely to take their medication every day and had higher rates of losing inhalers. Yeatts et al. (2000) also addressed the issue of adolescents' self-management of their asthma in the school setting. Females and adolescents with severe asthma were more frequently allowed to carry their medications in school compared with males. There was no difference among races in being allowed to carry inhalers. An important significant finding among the total adolescent sample was the high (26%) level of smokers among inhaler users, an indication of inadequate environmental control.

Fisher et al.'s (2009) randomized control trial evaluated the effect of community health workers on children's hospitalizations for asthma. The comparison was in asthma self-management behaviors based on usual care versus a two-year coach intervention. The coaches were African Americans from the participant's community who had been trained to serve as asthma coaches. The sample of 306 was comprised only of African American children, two to eight years of age who had Medicaid coverage. The participants were primarily the parents of children who had been hospitalized recently for asthma. Usual care included asthma education, discharge planning, an asthma action plan, and a follow-up appointment with their healthcare provider. In addition to the usual care, the intervention group received two years of coaching that involved asthma education and reinforcement of key management behaviors conducted through home visits and phone calls tailored to the caregiver (Fisher et al., 2009). The parents had an average of 21.1 contacts with the coaches over the 24-month intervention. During that time period, rehospitalizations occurred in 36.5% of the asthma coaches group and 59.1%

of the usual care group (Fisher et al., 2009). The parents' surveys following the study and the objective evidence of rehospitalizations reflected the importance of the asthma coach's role (Fisher et al., 2009).

Kaul's (2011) descriptive correlational study of 7- to 12-year-old African American children (N = 81) measured asthma self-management and self-efficacy. In that sample, 59% had mild asthma, 21% mild persistent, 16% moderately persistent, and 4% severe persistent. There was statistically positive correlation ($r = .53$, $p < .01$) between the child's self-efficacy and self-management behaviors. The results indicated that participants who scored higher on the self-efficacy belief scale also scored higher on the self-management behaviors scale (Kaul, 2011).

Clark et al. (2010) conducted a randomized controlled trial to study asthma self-management among preteen students with asthma. The sample was one of the few reviewed that consisted of 100% African Americans 10–13 years of age. The uniqueness of this study was that it was a longitudinal study, implemented in the middle school and with a large sample (n = 1,292) of African American preteens. The study consisted of a control group that received the "Open Airways at School" asthma education program, an adult led, problem-centered approach to teaching asthma self-management. The intervention was a two-step program: first, an adaptation of "Open Airways at School" that was created for preteens and included more developmentally appropriate problem-solving activities; and second, a peer component of older adolescents with asthma who mentored younger preteens with asthma. The study involved two intervention groups, one that received only the first step of the program and the second group who received the combined intervention steps. The study measured students' asthma symptoms, quality of life, and academic performance, self-regulation, and asthma management practices. Significant results of the study were enhanced self-regulation in the intervention group associated with the peer support program (for the two-step participants only) and improved academic performance (for the first intervention group). The combined intervention group did not have gains in academic performance, and the author related that to the group's lower baseline grades (Clark et al., 2010). One of the reported outcomes of the study was the identification that more developmentally focused interventions may be needed for students at the preteen transitional stage.

Joseph et al.'s (2007) study examined asthma self-management for African American adolescents. They developed a tailored self-management program and targeted urban African American high school students (aged 15–19 years). Fifty-two percent of the participants were males. Baseline data for the 314 participants reflected inadequate medication management and environmental control. Inadequate medication management was documented through the lack of adherence to medication: adherent to use of controller medication in previous seven days (8.6%) and not adherent with controller medication (25.0%). Lack of environmental control was identified through the participants' smoking habits or exposure to smoke: exposed to household tobacco smoke (59.2%), smoked greater than or equal to two cigarettes on days smoked in previous 30 days (5.2%). Therefore, the baseline data illustrates African American adolescents' self-management behaviors including their poor medication management (non-adherence to medication) and lack of environmental control (cigarette smoking).

The purpose of Sin, Kang, and Weaver's (2005) study was to examine the relationships among asthma knowledge, self-management, and social support in African

American adolescents with asthma. They conducted the study using a convenience sample of 53 identified asthmatic adolescents from three metropolitan high schools in Alabama. Fifty-five percent of the subjects (n = 29) were male and 45% (n = 24) were female. Subjects were included in the study if they self-identified as African Americans, between 15 and 17 years of age, and had been diagnosed with asthma. Several descriptions of asthma status characterized asthma impairment: if the individual had asthma since childhood (68%), the number of hospitalizations within the previous three months (one participant), and occasional use of a bronchodilator (52 students). The findings for the self-management component were as follows: 23% reported never seeking help at the first sign of an asthma exacerbation; 49% reported always stopping playing and taking it easy. Both behaviors exhibited the symptom management of the students.

Two studies conducted with mixed races of individuals identified associations between asthma self-management behaviors, race, and gender. Murray et al. (1997) performed a retrospective study of 1,739 individuals, aged 5–34 years. The study was conducted for patients from 1985 to 1992 who received care at a large inner city hospital in Indiana. The self-management behaviors and healthcare utilization patterns of African American patients (n = 1,155) were compared to White patients (n = 633). The study included data for 931 females and 837 males. Patients' prescriptions helped to determine the level of asthma impairment or severity. African American males (64%) had significantly ($p < 0.0001$) higher use of oral adrenergic agonists followed by White males (51%), African American females (44%), and White females (34%). White females had the highest use of inhaled glucocorticoid therapy (14%), followed by White males (9%)

and African American males (8%) and females (7%), which potentially reflect the participants' adherence to their prescribed medication. African American males (48%) most often used oral corticosteroids, whereas use among the other groups ranged from 36% to 40% (p = 0.002). Oral steroids often are added to the regular medication regimen when the patient is having more severe asthma symptoms. African American males also had significantly greater use of cromolyn inhalation (27%), followed by White males (21%), African American females (14%), and White females (10%). Cromolyn is a medication used to prevent asthma symptoms. Based on the prescriptions, African American males had more medications used for asthma exacerbations or increased asthma inflammation. Poor self-management skills were reflected in the rates of prescription refills, use of emergency rooms, and hospitalizations. Prescription refills were lowest among African American males and females. African American males had the lowest total number of outpatient clinical encounters but had the highest age-adjusted rate of ED use and hospitalizations for asthma. The poor medication management, delays in treatment, and use of the ED by African American adolescent males in this study reflect the behavior of other African American adolescent males in the literature. Those asthma management behaviors put African American adolescent males at increased risk for more severe asthma exacerbations and potentially death.

Pawar and Smith (2006) reported the medication adherence and healthcare utilization of 635 African Americans who were recipients of West Virginian Medicaid. The study included participants aged 64 and under, although 66% of participants were children and adolescents up to 21 years of age. There was a greater proportion of females (53.7%) compared to males (45.8%), but males under 21 years of age comprised a majority of the total sample (38.6%). Medication management was an issue in this study. Overall, it appeared that African American recipients were under-using controller medication, including inhaled corticosteroids. Participants' filled their short-acting beta agonist more frequently (3.2 mean claims per recipient) than inhaled corticosteroid prescriptions (2.3 mean claims per recipient). Their higher incidence of ED visits and hospitalizations could be attributed to poor medication management.

Summary of self-management and race literature. The investigator reviewed nine studies in order to obtain an overview of asthma self-management among African Americans. One study only (Fisher et al., 2009) included parents; two of the studies (Boudreaux et al., 2003; Kaul, 2011) included children; one (Clark et al., 2010) was conducted with preteens only; three (Joseph et al., 2007; Sin et al., 2005; Yeatts et al., 2000) were conducted specifically with adolescents; and two studies (Murray et al., 1997; Pawar & Smith, 2006) included children, adolescents, and adults. Six of the nine studies were designed specifically for African American participants (Clark et al., 2010; Fisher et al., 2009; Joseph et al., 2007; Pawar & Smith, 2006; Sin et al., 2005; Yeatts et al., 2000). The review of the nine studies revealed the following summarized findings related to self-management behaviors. First, nonadherence to medication regimens, increased use of beta agonists, and decreased use of inhaled corticosteroids displayed poor medication management. Second, the reports of asthma exacerbations and decisions about managing symptoms, especially delays in seeking care for exacerbations reflected inadequate symptom management. Third, compared to other races, inadequate symptoms management and poor medication management led to the need for health care for exacerbations. African Americans had a higher number of ED visits and hospitalizations related to exacerbations. Fourth, the author included two studies (Murray et al., 1997; Pawar & Smith, 2006) in the review because they address self-management behaviors, African Americans, and gender differences in asthma self-management. The common thread in those two studies was poor symptom management among African American males, especially delaying seeking care for asthma exacerbations. Finally, Joseph et al. (2007) and Yeatts et al. (2000) measured the number of adolescents who smoked and as such exhibited poor environmental control.

Self-management and Asthma Impairment

Literature reviewed. The investigator identified no studies that were designed specifically to measure self-management behaviors according to the newer term asthma control or the level of asthma impairment identified in the "Practical Guide for the Diagnosis and Management of Asthma: Expert Panel 3 Report." Six studies (Bruzzese et al., 2002; Cloutier, Jones, Hinckson, & Wakefield, 2008; Motlow & Ozuah, 2003; Raherison, Tunon-de-Lara, Vernejoux, & Taytard, 2000; Scarfone, Zorc, & Capraro, 2001; Shah, 2001) did describe examining self-management according to degree of symptoms, an indication to asthma impairment or control. One study (Cloutier et al., 2008) reported findings according to the participants' degree of asthma impairment or severity in relation to race.

Motlow and Ozuah's (2003) study of 160 high school students, 13–18 years of age, with asthma examined asthma self-management and degree of symptoms (level of asthma impairment). The study targeted urban adolescents, and 26% of the participants were African Americans. The study examined patterns of asthma severity and use of anti-inflammatory medication. Results were not broken down by race, but they portrayed the self-management behaviors of adolescents. The study categorized subjects according to the frequency of their symptoms (i.e., daily, weekly, or monthly). Seventy-two percent of the adolescents had symptoms once per month (comparable to being well controlled), 33% had weekly symptoms (compared to being not well controlled), and 14% had daily symptoms (comparable to being poorly controlled). Variables in the study were use of bronchodilator versus inhaled steroid and/or other anti-inflammatory medication such as cromolyn or montelukast. Seventy-three percent of adolescents with daily symptoms reported using a $beta_2$ agonist. Only 33% with daily symptoms reported using inhaled corticosteroids. Inadequate self-management was indicated by which medication the adolescent tended to use. Although not the recommended self-management behavior, participants tended to use their bronchodilators more than their inhaled steroids. Thirty-three percent of subjects with daily symptoms reported using inhaled steroids, and 73% of them also used a bronchodilator. Of those with weekly symptoms, only 24.5% reported using inhaled steroids, but 70% of them used a bronchodilator. Adolescents with monthly symptoms used their inhaled steroids 6.5% of the time, but they used their bronchodilator 71% of the time. The findings suggest that among those with the highest level of symptoms, medication management is inadequate.

Self-management, asthma impairment, and race were three of the variables in a study of 2,724 children and adolescents (6 months to 18 years of age) with asthma (Cloutier et al., 2008). The specific behavior assessed was filling inhaled steroid prescriptions, an essential behavior in medication management. In all three categories (mild persistent, moderate persistent, and severe persistent), African American children were less likely than Hispanics to get their inhaled steroid prescription filled. About 25%

of African American children with severe persistent asthma did not have medication 12 months after receiving the prescription, another aspect of inadequate medication management.

Bruzzese et al. (2002) documented adolescents' poor management and asthma impairment. The medication management of ninth grade New York students was measured and categorized by asthma impairment and control. No gender or racial/ethnicity descriptions were reported for the students. Out of the sample of 334, 30% had mild intermittent asthma, 23% mild persistent, 33% moderate persistent, and 14% severe persistent (Bruzzese et al., 2002). Only 3% of students with mild persistent, 11% with moderate persistent, and 36% with severe persistent were taking daily medication. These results showed that there was poor adherence to the medication management among all levels of asthma impairment with the greatest level of poor adherence among adolescents with mild persistent asthma. Medication regimens will differ according to levels of asthma impairment and often individuals with mild persistent asthma will have less complex daily medication than individuals with more severe symptoms. However, in this study, only 3% of the adolescents with mild persistent asthma were following their daily medication regimen. Even those adolescents with severe asthma exhibited poor self-management of their asthma medication.

Scarfone et al. (2001) used asthma impairment levels as the basis for measuring the medication management of 433 children and adolescents (2–18 years of age) who received ED care. The patient characteristics included 60% males, 93% African Americans, 36% mild intermittent, and 64% persistent asthma. Sixty-six percent of the participants did *not* use peak flow meters. Although use of peak flow meters is optional for assessing level of asthma symptoms, the fact that the population received care in the ED suggested the possibility the individual's asthma was not in control. Among the participants, 64% had persistent asthma and despite having prescribed medication only 38% took daily anti-inflammatory medication and only 18% used their daily inhaled corticosteroids. This sample depicted the symptom and medication management issues that existed even though the children and adolescents had persistent asthma. It could be anticipated that having persistent asthma would mean increased adherence to medication regimens but this sample did not support that premise.

Shah (2001) conducted a randomized control trial that measured asthma impairment, quality of life, and school absenteeism among 272 adolescents. The study was conducted through two Australian schools and the mean ages of students per school were 12.5 years and 15.5 years of age; 65% were females. The control group received asthma education and monitoring of asthma impairment as well as school absenteeism. The intervention group participated in a three-step peer-led asthma education program. Step 1 was an eight-hour training session or peer leaders by the research staff, Step 2 was peer-led health sessions, and Step 3 was key asthma messages delivered to peers through skits and songs. In Shah's study (2001) there was a significant improvement in the mean total quality of life of the sample and clinical improvement in asthma impairment in 25% of the interest group and 12% of the control group. The effect of the intervention was greatest among tenth grade females. Improvements in the activities and emotions domains were greatest in the males. School absenteeism was decreased slightly in the intervention group and asthma attacks at school increased in the control group only

(Shah, 2001). In the discussion of their study, the authors emphasized that young people prefer peer educators and that peer educators enhance program effects.

The final study in this section focused on children's and adolescents' medication management during exacerbation of asthma symptoms. Raherison et al. (2000) conducted the study in Bordeaux, France, and included children aged 6–7 years and adolescents aged 13–14 years. The sample was comprised of 154 children (78 boys and 76 girls) and 205 adolescents (109 boys and 96 girls). The authors based their age groups on the youngest age children in school (6–7 years) to the age when mortality related to asthma generally begins (13–14 years of age). Questionnaires for the study were translated into French. Although the participants were not identified according to race/ethnicity, since the questionnaires were in French, the author assumed that the participants spoke French. In the study, compliance with prescribed medication was better in children (92.3%) than in adolescents (77%). When there were mild asthma exacerbations, 9.3% of children and 38.7% of adolescents delayed taking medication until the end of the exacerbation. Further analysis of the overall group showed that 19.6% of adolescents did not take medication for an exacerbation at all. Furthermore, 19% of adolescents with severe asthma exacerbations used medication other than their prescribed beta agonist or corticosteroids, but parents of children adhered to the prescribed medication.

The study by Raherison et al. (2000) was the only one identified that characterized aspects of medication management according to asthma severity (impairment). The study assessed adolescents for their frequency in taking medication at the onset of their exacerbation of symptoms. Adolescents with moderate asthma (38.9%) took their medication at the onset followed in percentage by those with mild asthma

(32.3%) and severe asthma (20.2%). The study also determined the number of adolescent participants who took medication if the exacerbation of symptoms was long-lasting. The participants with moderate asthma (31.8%) were the highest category again followed by those with mild asthma (20.7%) and only 4.8% of participants with severe asthma. The results of the study were surprising because participants with moderate asthma had better self-management behaviors than those with mild or severe asthma. In both scenarios of taking medication at the onset or taking it for long-lasting symptoms, the participants with severe asthma had the worst medication management of all levels of asthma impairment.

Summary of self-management and asthma impairment literature. Level of asthma impairment is suggested to influence asthma medication management in four of the six studies (Bruzzese et al., 2002; Motlow & Ozuah, 2003; Scarfone et al., 2001; Shah, 2001). However, there was still inadequate medication management among those with severe asthma. Furthermore, the study by Raherison et al. (2000) presented findings that varied from the usual pattern of asthma impairment and self-management behaviors. African Americans had the worst symptom management regardless of level of impairment (Cloutier et al., 2008). The "Practical Guide for the Diagnosis and Management of Asthma: Expert Panel 3 Report" uses new descriptions of asthma control and asthma impairment (NHLBI, 2007). There is a gap in the literature of self-management and asthma impairment studies that are based on the new terminology in the "Practical Guide for the Diagnosis and Management of Asthma: Expert Panel 3 Report" (NHLBI, 2007).

Summary of Asthma Self-management Studies

In this review of the literature, the findings consistently show that asthma self-management, whether medication, symptom, or environmental controls, is a problem for adolescents. The study investigator reviewed a total of 35 studies in the preceding sections related to asthma self-management. The categories of ages of participants and number of studies are as follows: adolescents (12), children and adolescents (18), adults (3), and a combination of children, adolescents, and adults (2). The majority of the studies described the highest percentage of participants as Caucasians. However, 12 of the 35 studies identified African Americans as the highest number of participants and 3 studies were designed specifically for African Americans. Four of the 28 studies were conducted in Europe, Austria, Finland, and France. Of the total number of studies reviewed, males were represented in higher percentage than females. Everhardt et al. (2011) was the only study reviewed that used the asthma impairment criteria described for the current study. Although the same criteria were used to categorize the asthma impairment levels, Everhardt et al. (2011) used the descriptions of well asthma control and poor asthma control. The current study used well controlled, not well controlled, and very poorly controlled. The asthma impairment definition for this study was based on the "Practical Guide for the Diagnosis and Management of Asthma: Expert Panel 3 Report" (NHLBI, 2007). In this review of the literature, studies used a wide range of criteria and older terminology to identify the participants' asthma impairment (e.g., asthma severity and asthma control).

Self-management behaviors were reviewed in three categories: medication management, symptom management, and environmental control. Six studies were included in the review of medication management. The major problem identified for adolescents is poor medication management. Two studies compared the adherence rates of children and adolescents and found that adolescents are less adherent than children. Lack of adherence also was supported in non-comparison studies. A common problem of medication management was the use of beta agonist to control asthma rather than inhaled corticosteroids. Even adolescents with persistent asthma used beta agonist as routine medication rather than inhaled steroids or an anti-inflammatory medication. There was a significant difference in adherence among Caucasian and non-Caucasian adolescents; non-Caucasians were less adherent in taking medication. Two studies were used to review symptom management. In those studies, poor symptom management was identified through reports of inability to recognize asthma symptoms and make appropriate changes. Waiting too long to seek assistance with exacerbations was a critical problem. Environmental control behaviors were reviewed through six studies. Cockroaches and dust mites were the two major contributors to asthma exacerbations. Behaviors related to control of those allergens were a prominent component of environmental control. The findings of three studies reported increased smoking among adolescents with asthma. Daily smoking by the individual with asthma and second-hand smoke in the home environment were two environmental control issues.

The author reviewed studies that addressed self-management and gender, self-management and race, and self-management and asthma impairment. The study investigator reviewed five studies associated with self-management and gender. Females tended to report more asthma symptoms, had better medication adherence, and sought healthcare assistance as a part of their symptom management. Males were more reluctant to acknowledge symptoms, reported increased activity limitations, and delayed seeking care as a component of symptom management. The findings related to self-management and race centered on inadequate symptom management and poor medication management. African American adolescents used more beta agonist instead of inhaled corticosteroids. In one study, prescriptions for African American adolescents were filled at a slower rate or not at all. Additionally, there was increased use of the ED because of delays in seeking care for exacerbations. There were repeated reports of denial of symptoms or delays in symptom management among African American males. Finally, six studies on self-management and asthma impairment were reviewed. Because of the limited use of asthma impairment, associated descriptions of asthma severity were reviewed. Inadequate medication management was identified, despite the severity of asthma.

The 35 studies reviewed in this section support the problems of self-management behaviors (symptom management, medication management, and environmental control) among adolescents. Gaps in the literature also support the need for further study of the self-management behaviors of African American adolescents with asthma.

Illness Representations Related to Asthma

Literature Reviewed

In order to broaden identification of potential cognitive and emotional illness representations (perceptions and beliefs) of adolescents, the author also reviewed research on illness beliefs and illness perceptions. When possible, the author connected beliefs and perceptions with cognitive representations (identity, timeline, consequences, cause, and control) or emotional representation (Leventhal et al., 2003).

The study investigator identified only one study that investigated the cognitive illness representations identified with the self-regulation model and included adolescents in the sample. Paterson, Moss-Morris, and Butler (1999) used cognitive illness representations questionnaires to measure the effect of the illness experience. They compared the illness representations of a group of children with asthma to their own representations of a cold. They also compared the illness (a cold) representations of children who did not have asthma. The sample included 182 children and adolescents, 7–14 years of age (Paterson et al., 1999). The participants were comprised of 78 males and 108 females from several primary, intermediate, and secondary schools in Auckland, New Zealand. Races/ethnicities represented included European/Pakeha (72.5%), Maori (11.5%), Pacific Islands (6.6%), and Other (9.3%). Of the total 182 participants, 35 identified themselves as having asthma. Asthma impairment was reported as relatively mild (n = 15), moderately severe (n =10), and severe (n = 10). The illness representations cause, timeline, and control were the most prominent representations among the participants with asthma. This study provides support for the assumption that children and adolescents have illness representations that are influenced by experiences (such as asthma) as noted by Leventhal et al. (2003).

Naimi et al. (2009) explored the beliefs and attitudes of older adolescents with asthma and their potential influence on adherence (medication management). The study had 40 participants who were 15–18 years of age. Forty-eight percent of the participants were females, and 75% were African American. The description of their lung status, forced expiratory volume in one second (FEV_1), had a mean of 98% (ranging from 68% to 127%) of predicted value, which indicates that the participants' airways were open to not well open. There was no difference in the responses by gender or race/ethnicity. The study used qualitative measures to examine the adolescents' beliefs about medication and quantitative measures to validate adherence to their inhaled corticosteroids. Investigators interviewed participants for baseline data, monitored electronically for one month for adherence to inhaled medication then interviewed a second time. Adherence was measured by self-report through interviews and objectively through the use of an electronic monitor. Median adherence was 48% (range 25%–62%). Thirty-eight of the participants (*N* = 40) admitted to not adhering to the fluticasone/salmeterol, a frequently prescribed controller medication. Sixteen adolescents expressed beliefs that they controlled their asthma and did not see the benefit of taking the medication. Thus, the control illness representation was potentially influencing adherence to the medication. In addition, the identity illness representation could have impacted the participants' lack of acknowledging and monitoring their asthma symptoms. Adherence was not directly measured for a relationship between it and beliefs or illness representations. Naimi et al.'s (2009) study supported the need for a study with adolescents to determine whether there is a relationship between illness representations and self-management behaviors.

Illness representations are reflected in a study of adolescents' perceptions of asthma, specifically perceived barriers to asthma self-management (Rhee et al., 2009). A sample of 126 adolescents, 13–20 years of age, including 62 White, 40 African Americans, and 14 Hispanics participated in the study. The sample included 75 females and 51 males. All of the adolescents had been diagnosed with asthma longer than or equal to one year and either used controller medication or had persistent asthma as defined in the "Practical Guide for the Diagnosis and Management of Asthma: Expert Panel 3

Report” (NHLBI, 2007). The most frequently endorsed barrier to asthma self-management was the adolescents’ unwillingness to relinquish elements that physicians had identified as detrimental to asthma control, which is consistent with the illness representation of control. Many adolescents had a discrepancy between symptom perception and symptom reports, particularly among those adolescents who were not well controlled; this could be a reflection of the illness representation of identity. The illness representation “consequences or control” was reflected in adolescents’ perceptions that “nothing bad would happen to them if they did not follow their regimen” (Rhee et al., 2009, p. 186). This ethnically diverse sample of adolescents with persistent asthma had beliefs or illness representations that could influence their asthma; however, beliefs were not differentiated for gender or race or stage of adolescence.

Several illness representations are reflected in perceptions about asthma reported by Ayala et al. (2006). Fifty, students in grades six through eight participated in focus groups associated with a study of asthma self-management behaviors. Ages of the students were not identified, but the mean age was listed as 12.46 years and percentages in grades were sixth (42%), seventh (26%), and eighth (32%). Ethnicity was listed as African American (48%), Caucasian/White (40%), and Other (12%). Fifty-six percent of the participants were females. Students believed that (a) their asthma was not severe enough to need medication (reflective of identity), (b) exposure to cigarette smoke was unavoidable (reflective of control), and (c) asthma was not as severe as attention deficit disorder or diabetes (reflective of identity). This ethnically diverse sample of adolescents, who on average were in early adolescence, had beliefs or representations that could influence their asthma management; however, this study did not examine differences according to gender or race or asthma impairment.

Illness representations of consequences are reflected in perceptions about asthma reported by Zebracki and Drotar (2004). Participants included 77 adolescents, 11–17 years old, and their caregivers. They characterized their asthma as mild intermittent (16.9%), mild persistent (16.9%), moderate persistent (27.3%), and severe persistent (39.0%). The sample was comprised of 40 males and 37 females and 46 White, 26 African Americans, and 5 Other. The study used questionnaires to assess adolescents' adherence to treatment in addition to outcome expectancy and self-efficacy. Zebracki and Drotar (2004) found that adolescents tend to focus on the immediate consequences of their behaviors rather than the long-term effects of adherence to their medication. This ethnically diverse sample of adolescents who were in early, middle, and late stages of adolescence had beliefs about short-term consequences that could influence their asthma self-management. This study combines the findings from participants who are in early, middle, and late stages of adolescence. There are cognitive developmental changes that occur during each stage of adolescence, and these changes could influence illness representations. Therefore, there is a need to design studies, such as the current study, to examine the illness representations of adolescents in specific stages of adolescence. This study targets individuals in middle adolescence.

Houle et al. (2010) investigated what African American adolescents and their caregivers understand by "wheeze." In a study of 35 adolescent and caregiver pairs, all of the caregivers were females; 48.6% of the adolescents were in seventh through ninth grades, and 51.4% were in tenth through twelfth grades. The sample was comprised of

65.7% females, and the adolescents were described as “currently having asthma.” During the study, the participants were shown a video clip of an adolescent wheezing then asked to describe the breathing as shown in the video and to indicate whether they had ever had that type of breathing. Most of the caregivers described the breathing as sounds alone (61.8%) while 55.8% of the adolescents described wheeze as something they felt. Only 5.8% of the participants used “whistling” in their description. Nearly one-fourth of the caregivers and one-third of the adolescents felt that the adolescent’s breathing was never similar to that shown in the video. The researcher in this study concluded that caregivers’ and adolescents’ descriptions of wheeze may be different from each other and both may be different from the clinician, which is an important consideration (Houle et al., 2010).

Illness representations also were characterized in adolescents’ perceptions described in Cohen, Franco, Motlow, Reznik, and Ozuah’s study (2003). A quantitative study was conducted with 160 Bronx, New York, high school students with a mean age of 15.7 years. The authors described the sample as 63% females, 68% Hispanics, 26% African Americans, and 24% immigrants. In that sample, 70% reported feeling in control of their asthma symptoms. Feeling in control of asthma symptoms is a positive perspective of the control illness representation. That positive sense of control could contribute to exhibiting good asthma self-management behaviors. However, this study did not measure the effect of illness representations on self-management behaviors. The fear of death was reported by 39% of the students and 42% of them reported feeling anxiety in relation to their asthma. Feeling fearful and anxious reflect emotional illness representations that were reported by the students. Again, this study offers support for measuring adolescents’ beliefs or representations because of their potential influence on asthma management. A limitation of the study is the lack of differentiation of beliefs according to potential influential variables of gender, race/ethnicity, and asthma impairment.

Emotional illness representations were indicated in data from the 1999 study by Kyngas. The large sample of 266 adolescents, 13–17 years of age, with asthma were recruited from a Finnish Social Insurance Institution register. The participants were equal among males and females, 133 for each gender. Their asthma was categorized as mild (34%), moderate (60%), and severe (6%). The adolescents shared the following information: 45% expressed fears of asthma attacks, and 75% expressed fears of complications (Kyngas, 1999). The fears reported by adolescents in this study suggested emotional illness representations that could influence asthma self-management behaviors. Like previously reported studies, this study does not differentiate beliefs according to gender, race/ethnicity, and asthma impairment.

Illness representations were associated with the findings from focus groups with adolescents 12–17 years of age (van der Meer et al., 2007). The sample was comprised of 35 adolescents, 17 males and 18 females, who could speak Dutch. The focus groups were stratified according to asthma control (well controlled or poorly controlled), age (12–14 years and 15–17 years of age), and by gender. None of the participants in van der Meer et al.'s (2007) study perceived asthma as a serious disease. One participant stated that "[asthma is] just something you've got. Medications do help but you just have these symptoms" (van der Meer et al., 2007, p. 117). These descriptions reflect the beliefs or identity illness representations that adolescents might have about asthma. Perceptions of being helpless or feeling unable to do anything about asthma symptoms indicate the control illness representations that adolescents might report. This study provides support that early and middle adolescents who are Dutch and have asthma have beliefs that could be categorized as identity and control illness representations. Although the sample represented both well and poorly controlled asthma, beliefs were not differentiated according to asthma impairment.

Joseph et al.'s (2006) study of 63 African American adolescents and caregivers compared the adolescent's perceptions of the severity of asthma with the caregiver's perception. The adolescents were 15–18 years of age, and the sample included 30 males and 33 females. Researchers asked adolescents and caregivers to categorize the adolescents' asthma in terms of *not being a serious thing* to the converse label of *a medical condition you can die from*, which reflects identity. The teenagers consistently reported their asthma as mild, even when caregivers described it as severe (Joseph et al., 2006). The variations in categorization of the severity of asthma support the premise that adolescents have inaccurate identity beliefs that could influence their asthma management.

Houle et al. (2011) analyzed the congruence between urban adolescents and caregiver responses to questions about the adolescent's asthma. The baseline data was from Joseph et al.'s (2007) Web-based study that was reviewed previously in the asthma self-management and race section of this review. Houle et al.'s (2011) study was comprised of 215 students; 91% were African American; 63.7% were females. Correlations between adolescent and caregiver reports of the adolescent's symptoms and functional status were weak. Adolescent and caregiver reports of symptoms and functioning were more likely to be in agreement if the adolescent was older, if school personnel were unaware of the student's asthma, and if the adolescent's asthma was classified as mild intermittent. Questions concerning the frequency of hospitalizations, ED visits, and physician visits had moderate correlations, although there were still individual differences. Houle et al. (2011) emphasized that their results indicated the differences in adolescents' and caregivers' reports of the adolescent's symptoms and functioning and indicated that it is important that clinicians recognize the importance of ways to communicate in order to get accurate information.

Woodgate's study (1998) of 23 adolescents with chronic illness, including 5 with asthma, categorized individuals' beliefs about the development and duration of their asthma. The sample included 12 female and 11 male adolescents who ranged from 13 to 16 years in age. The study included Caucasians (*n* = 19), Asians (*n* = 2), and Canadian Aboriginal (*n* = 1). The description, "getting used to it but continuing to want to get rid of it and hope that it would go away" (Woodgate, 1998, p. 217), reflected a timeline representation. Another adolescent in the same study explained that "not as many people have the chronic asthma but a lot of people have bits and pieces of it" (Woodgate, 1998, p. 214). The findings document that middle-age adolescents have representations that could influence their self-management. However, the findings were not differentiated by race/ethnicity, gender, or asthma impairment.

A study by Velsor-Friedrich et al. (2004) identified another portrayal of illness representations. In their study, 24 high school students, aged 14–18 years, 13 females and 11 males, made up four focus groups. The authors acknowledged that the groups had representatives from Caucasian, African American, and Hispanic populations; however, they did not identify the number of representatives. Study investigators obtained the students' asthma history through reports that 85% of the students had been diagnosed between birth and four years of age. One adolescent's representation of the timeline of asthma was reflected in the statement, "asthma comes and goes" (Velsor-Friedrich et al., 2004, p. 145). One adolescent went to the extent of sharing the desire to be equal to his friends, not below them, reflecting the consequences representation. There was a profound consequences representation described by an adolescent of losing consciousness as a result of not managing his asthma during a soccer game and the coach's not allowing him to leave the game. Such descriptions support the need for illness representations, illness beliefs, and illness perceptions research.

Adolescents created visual narratives of living with asthma as participants in a study by Rich, Patashnick, and Chalfen (2002). Study investigators recruited 10 males and 10 females who had moderate to severe asthma from inner city clinics and urban hospitals. The sample represented diverse racial/ethnic groups including African American (*n* = 10), White (*n* = 7), Latino (*n* = 6), and Biracial (*n* = 3). The participants' ages ranged from 8 to 25 years with a median of 15 years of age. The adolescents reported several different illness representations. One of the adolescents gave a graphic depiction of asthma as "having life sucked out of you or putting a plastic bag on your head and having a tiny hole" (Rich et al., 2002, p. 444). That description was suggestive of the adolescent's identity illness representation of asthma. Another representation was the physical consequences of asthma and "not being able to breathe or run" (Rich et al., 2002, p. 447). Rich et al. (2002) found one explanation related to the cause representation of an adolescent's asthma. The individual described being taken outside in below zero degree weather, having an asthma attack then having asthma since that time. That sentinel event was attributed to the reason for frequent hospitalizations and the need to take medication, including steroids. Several of the adolescents' comments in this study could be attributed to their control illness representations. Most of the adolescents described not having any control over their asthma or as their asthma controlling them. Several responses in the study reflected beliefs that asthma is unpredictable and the adolescents did not have any control over their asthma. The participants also gave descriptions of lifestyle changes and experiences because their asthma was controlling them. Medication was the one way that several participants felt they could have control over their asthma. However, several also shared concerns about the side effects of medication. Emotional illness representations were reflected in the adolescents' concerns about dying. All the participants reported a common description of living with asthma as the fear of sudden death. The adolescents expressed fears of not knowing whether the asthma attacks would take their lives and of being afraid of dying, gasping for air, for example. This study described multiple cognitive and emotional representations held by a diverse sample of adolescents representing a wide age range.

A study by Buston and Wood (2000) identified adolescents' illness representations and beliefs about asthma. Investigators conducted in-depth interviews with 49 adolescents, aged 14–20 years, who were attending hospital asthma clinics in Greater Glasgow in the United Kingdom. The study identified the adolescents' gender (29 females and 20 males), but did not report race or ethnicity for this study. The participants' levels of asthma impairment could be inferred as not well controlled to poorly controlled because 28 respondents had been prescribed oral steroids at their last visit and 20 had been hospitalized within the previous year. Participants had beliefs that related to asthma self-management and with the illness representation of identity with asthma. Several participants described denying their asthma symptoms and not taking medication hoping that their asthma would go away. There were also responses to the interview about living with asthma that depicted the control that some adolescents felt they had over their asthma while others questioned their control over asthma. Such variations in beliefs about asthma indicated the variations that adolescents might have in their control illness representations. Finally, adolescents reported fears about side effects of the medication and their fear of dying from asthma. Those fears reflected the emotional illness representations that adolescents with asthma might experience. The beliefs of adolescents in this study support the need to determine adolescents' beliefs and illness representations associated with their asthma.

Knight (2005) conducted a study in Hawaii with 10 adolescents who were 13–18 years of age. Five males and five females participated in interviews for the study. Asthma severity was described as mild (n = 4), moderate (n = 5), and severe (n = 1). Several of the participants' responses reflected the consequences illness representations: "Some people say…[asthma] holds you back, but it doesn't. It helps me to try harder, a little bit more" (Knight, 2005, p. 76). Another consequences description was: "I'm in track and when I have [asthma], I can't run…can't run, gonna die. It's kinda bad, but, I cope" (Knight, 2005, p. 76). Other responses identified in Knight's study (2005) could be categorized into the control illness representation. Those responses pertained to having an inhaler available and relying on themselves to manage their asthma. Another adolescent emphasized exercise and suggested that staying in shape and not getting sick helps to prevent asthma. This study describes positive and negative aspects of illness representations that might be reported by adolescents.

Rystrom, Hartmen, and Segesten (2005) used interviews and focus groups as opportunities to obtain information from 23 adolescents, 13–18 years of age. Rystrom and colleagues conducted their study in Sweden with a sample comprised of 12 females and 11 males with moderate to severe asthma. One participant explained that as a *consequence* of wanting to be like others, the individual denies having asthma. Another adolescent shared that adolescents drink a lot of Coca Cola® because they think such a treatment made breathing easier. Those descriptions suggest how errors in consequence or control illness representations could lead to inadequate symptom management.

Summary of Illness Representations Related to Asthma Literature

Seventeen studies were reviewed in this section on illness representations, beliefs, perceptions, and asthma. A larger number of studies were identified that targeted adolescents than in some previous sections in this chapter. Thirteen of the 17 studies focused on adolescents. Two studies in this section had samples that included younger children and adolescents (7–14 years of age and 8–25 years of age). Two studies had samples of older children and adolescents (11–17 years of age and sixth through eighth grades with no ages cited). It is recognized that some developmentalists would consider the 11-year-olds and sixth graders to be adolescents (Steinberg, 2008). Although a wide range of ages were included in the studies reviewed, there is still a lack of examination of differences for stages of adolescence. Overall, the studies reflected a slightly higher number of female participants than males who participated. Races/ethnicities represented as the majorities among the studies were White (five studies), African American (five studies), and Hispanic (one study) with studies conducted in New Zealand, Finland, the Netherlands, the United Kingdom, and Hawaii. Asthma impairment was described using a variety of terminology but ranged from mild (well controlled) to severe (not well controlled). There is a gap in the studies that relate to the lack of examination of race/ethnicity and gender.

Beliefs and perceptions from these 17 studies are reflective of illness representations and provide support for relevance of these concepts in relation to asthma self-management among adolescents. In the summary that follows, the findings have been categorized according to the cognitive and emotional illness representations.

Identity. Illness representation of identity comprises the components of symptoms and illness labels. Nine descriptions of beliefs or perceptions were categorized with the illness identity. Those descriptions ranged from a simple description of the symptoms being annoying (van der Meer et al., 2007) to the graphic depiction of “having life sucked out of you or putting a plastic bag on your head and having a tiny hole” (Rich et al., 2002, p. 444).

Timeline. Individuals’ beliefs about the development and duration of their asthma were categorized as the illness representation of timeline. Four descriptions were selected from the review of findings. The first explanation was associated with thoughts of getting used to it but continuing to want to get rid of it and hope that it would go away (Woodgate, 1998). The second portrayal was that asthma “comes and goes” (Velsor-Friedrich et al., 2004, p. 145). The final description was “not as many people have the chronic asthma but a lot of people have bits and pieces of it” (Woodgate, 1998,

p. 214). These two examples relate to the individual's perception of whether asthma is acute, chronic, or episodic/cyclical (Leventhal et al., 2003).

Cause. Beliefs of the external, internal, and behavioral causes of asthma would be captured through the illness representation of cause. This review identified two studies (Paterson et al., 1999; Rich et al., 2002) that related the causes of an adolescent's asthma. For example, one person described being taken outside in below zero weather, having an asthma attack then having asthma since that time (Paterson et al., 1999).

Consequences. Individuals' beliefs about the consequences of their asthma were identified through six participants' reports in the literature. The illness representation of consequences focuses on the short- and long-term effects of asthma and the perceived physical, social, economic, and emotional consequences of the disease. The responses capture all aspects of the consequences from the physical aspect of difficulty with breathing or running (Rich et al., 2002; Rydstrom et al., 2005) to the developmental aspect and social norm of being like their peers (Rydstrom et al., 2005; Velsor-Friedrich et al, 2004).

Control. The highest number of beliefs and perceptions in the findings were associated with the illness representation of control. Thirteen portrayals of adolescents' control of their asthma were identified in the literature review. Ten of the beliefs related to the adolescents' treatments or the self-management of their asthma. However, four of the articles reviewed described adolescents' representations of not having any control over their asthma or of their asthma controlling them.

Emotional representations. Emotional illness representations also are included in the common sense self-regulation model (Leventhal et al., 2003). Participants' expressions of their fears were the only emotional representations acknowledged in this section of the literature review. Strong statements reflective of fears of asthma attacks, complications, or death were noted by adolescents. Four studies were identified that discussed participants' fears of dying, and in Cohen et al.'s (2003) study, 39% of the adolescents voiced fears about dying.

Findings of studies, such as those presented in this section increase awareness of adolescents' beliefs, perceptions, and illness representations as well as how they might influence self-management behaviors. These beliefs and perceptions, as well as the lack of studies on adolescents' illness representations, also support the need for future research on adolescents' illness representations and self-management behaviors.

Illness Representations and Gender

Literature reviewed. Many of the studies on illness beliefs, perceptions, and illness representations related to gender have been conducted with adult women. In order to obtain information that might be pertinent to differences in gender-related adolescent behavior, the study investigator reviewed literature for pertinent research related to adult men and women as well as adolescents with asthma. Additionally, the investigator incorporated studies from sociology and psychology in order to gain a broader perspective on the topic.

Gender differences in the illness representation of timeline were reflected in a study of 198 adults with asthma by Halm et al. (2006). The sample was predominately female (78%), Hispanic (62%), and African American (28%). The 12-month study was conducted with patients hospitalized in an East Harlem, New York, hospital. Asthma severity was described through details of patients' asthma history: 64% had asthma less than or equal to 20 years, 23% had prior intubation, 88% had prior oral steroid use, and 31% had used oral steroids all or most of the past year. Researchers conducted an interviewer-administered survey at three time points: while the patient was hospitalized for asthma, one month after discharge, and six months after discharge. Fifty-three percent of the sample said they only had asthma when they were having symptoms, reflective of the identity representation. The researchers labeled the acute episodic mental model, the “no symptoms, no asthma” disease belief that dramatically portrays the possibility of not managing asthma when individuals have this identity representation (Halm et al., 2006, p. 576). Males greater than 65 years of age were more likely to endorse asthma as an acute episodic disease representation (timeline) than females in that age group. Thus, this study would suggest that males have the potential to not properly manage their asthma because of their inaccurate belief in asthma being episodic.

Similar illness representations, beliefs, and perceptions are evident through comments by male adolescents with asthma. Males in Horner’s (1999) study also made comments that centered on the theme of “toughing it out.” Focus group data was collected from 25 middle school students who were White and 11–14 years old, of which there were 11 females and 14 males. Instead of using medication during asthma exacerbations, male participants described ignoring their symptoms and pushing to finish physical activities. The description indicates beliefs or activities associated with identity and control illness representations. This study provides support for differentiating the findings according to gender in order to identify inaccurate beliefs or illness representations.

Rydstrom et al.'s (2005) study used a grounded theory research design to conduct observations and interviews with 23 adolescents with moderate to severe asthma. Twelve females and 11 males who were 13–18 years of age participated in the study during an asthma camp held in Sweden. One male participant's comments reflected the perceptions or illness representations of an adolescent with asthma. For example, consequences illness representations were reflected in his description of not being able to run because of asthma. His description of ignoring asthma symptoms suggested association with his identity illness representation. Feeling reduced in society because of the inability to manage his asthma could be attributed to that participant's control illness representations. Control illness representations also could be indicated in the females' reports of pre-medicating themselves before challenging their asthma during sports and in the males' comments about ignoring their symptoms. Interviews with adolescent participants such as the ones in this study, contribute to the limited literature on studies that focus on the beliefs and perceptions of adolescents with asthma.

Williams (2000) explored how adolescents incorporate asthma into their personal and social identities; many of the findings reflect illness representations differences for males and females. Williams (2000) conducted in-depth interviews with 20 adolescents 15–18 years of age. Ten males and 10 females were in the sample recruited from South West London, England. Males were described to deny symptoms and "hold out" or delay seeking health care for their exacerbation in asthma symptoms. This holding out by males could be related to their social construction of masculinity according to Williams (2000). Adolescent boys were more likely than girls to say they could control their condition with their minds. Such beliefs could affect their self-management behaviors, including medication management. One of the participants in Williams' study demonstrated the emphasis he placed on control through the following quote:

> Asthma creeps up on you,…a lot of the time I know I'm having an attack, but if I'm playing football I'll say, now I'll ignore it and I'll play on, yes, and I'll fight through it. I'll say, look, I know what's happening and I'll take it slower, but you've just got to keep breathing and it goes away, it just goes because of my mental strength. (Williams, 2000, p. 395)

A negative consequence of that participant's action was the need to be rushed to the hospital for a severe asthma attack. The quotation from the male participant in Williams' (2000) study is indicative of the need to determine the control illness representations or beliefs that could make such a negative impact on the health status of an adolescent. This study is the fourth study in the section on gender that reported the male perspective of ignoring symptoms or controlling asthma through mental strategies.

Summary of illness representations and gender literature. Males and females with asthma differ in their responses to illness, symptom management, and medication use (Naleway et al., 2006). The four studies (Halm et al., 2006; Horner, 1999; Rydstrom et al., 2005; Williams, 2000) in this section depicted how males and females with asthma differ regarding illness representations (beliefs and perceptions). Females reported more asthma symptoms and shared more beliefs in the effectiveness of medication but expressed less confidence overall in controlling their asthma. Males had more inaccurate beliefs about "no asthma, no symptoms" (Halm et al., 2006, p. 516), delaying seeking care, and controlling symptoms with their mental attitudes. The samples in the studies reviewed also differed by age and race/ethnicity. Two studies (Halm et al., 2006; Horner, 1999) were conducted in the United States and those samples were primarily White or Hispanics. The other two studies (Rydstrom et al., 2005; Williams, 2000) were conducted in Sweden and England. One of the studies (Halm et al., 2006) was conducted with an adult sample and the other three studies (Horner, 1999; Rydstrom et al., 2005; Williams, 2000) were conducted with adolescents.

As in the previous section on illness representations and asthma, the author discussed the findings in this section according to their associations with illness representations that are categorized in the summary that follows. Two illness representations, cause and emotion, were not identified in the review of studies for this section.

Identity. The most prominent finding associated with the identity illness representation was based on the “no asthma, no symptoms” disease belief (Halm et al., 2006, p. 576). That belief dramatically increased the potential for inadequate management of symptoms and lack of adherence to medication.

Timeline. The “no asthma, no symptoms” disease belief (Halm et al., 2006, p. 576) also was reflective of the timeline illness representation. That belief endorses asthma as an acute, episodic disease, leading to cyclical management of symptoms and medication.

Consequences. One description of the consequences of asthma was reviewed in association with Rydstrom et al.’s (2005) interviews with adolescents.

Control. Three of the four studies reviewed in this section had comments that were associated with the illness representation of control. Those descriptions were associated mainly with adolescent male participants’ descriptions of toughing it out, holding out, denying symptoms, and beliefs about mindsets about asthma (Horner, 1999; Rydstrom et al., 2005; Williams, 2000).

Illness representations (beliefs and perceptions) and gender were discussed in this section. Inaccurate illness representations, beliefs, and perceptions will contribute to the poor self-management behaviors.

Illness Representations and Race

Literature reviewed. The number of studies targeted toward African American adolescents with asthma, particularly their beliefs, perceptions, or representations regarding asthma, is limited. Therefore, this review included studies with African American adults as well as adolescents.

Peterson, Sterling, and Stout (2002) collected information from African American caregivers about family members' beliefs about asthma and the prescribed treatment, as well as decisions related to their healthcare behavior. The author reviewed this study because of the potential influence that family beliefs could have on adolescents' self-management behaviors. Peterson et al. (2002) interviewed 20 African American adult primary caregivers. Among the 20 caregivers, 19 were women and 16 were mothers. They were the caregivers of children in fourth through eighth grades. Half of the children's asthma was rated as moderately severe asthma, 30% of the children's asthma was rated as not severe, and 20% of the children's asthma was rated as severe. The caregivers were asked to state the treatment they thought their child should receive for his/her condition. Seven of the caregivers gave responses that the authors labeled as *medical protocol* which included administering a beta agonist and when it was too bad going to the ED or physician's office. These responses suggested the caregivers' identity illness representations. Five of the caregivers identified family regimens they would initiate without following the medical protocol or seeing a physician. Those self-management behaviors included such activities as drinking cold water, stopping the current activity, and sometimes, ingesting peppermint. Those activities indicated the caregivers' control illness representations and how they would manage asthma symptoms. It is beneficial for healthcare providers to be aware of the types of self-management behaviors used by families such as those reported in this study. Peterson et al.'s (2002) findings emphasized that families had their own explanations of asthma—some based on asthma knowledge from healthcare providers and other asthma information from family members and personal experience. An adolescent's identity illness representation could be influenced by the family's explanations of asthma. Therefore, some families weighed the healthcare provider's diagnosis and treatments against the family's beliefs and experiences. This study supports the need to examine the beliefs of African Americans and their association with asthma self-management. This study also provides information about family beliefs and how they might influence African American adolescents' beliefs about their asthma and the self-management behaviors that they exhibit.

Limited research has been conducted on the beliefs or perceptions of African American adolescents with asthma. Yoos and McMullen (1996) conducted one of the few studies identified in the literature. A total of 28 adolescents (10 Caucasian, 13 African American, and 5 Hispanic, Biracial, etc.) were included in the sample. The findings of this study were differentiated between 28 African American and Caucasian, school age versus adolescents (6–18 years old), lower versus higher socioeconomic status, and moderate versus severe asthma. Percentages of males and females in the sample were not reported. Sixty-four percent of the participants were African Americans. Eighteen percent of the participants identified themselves as Other ethnic groups; however, some of the results were grouped into Caucasian and African American categories. Yoos and McMullen (1996) used interviews to elicit children's and adolescents' perceptions of the impact of asthma. Themes from the data were reflective of illness representations; for example: (a) "I can't"—a listing of activities that the participants thought they could not do suggested the control illness representation of some participants; and (b) restrictions others imposed also indicated their perceptions of control. For some of the participants, descriptions of asthma symptoms and treatment dominated the discussion, reflecting identity and cause illness representations. Fears of death were prevalent topics during the participants' interviews indicating emotional illness representations. Concern about death from asthma was a predominate theme among African American children and adolescents and reflects their emotional representations. The authors reported that the theme of death was much more prevalent among African Americans than among Caucasians. Finally, descriptions of adaptation to asthma, increasing self-management of the illness and the impact of asthma on their daily lives suggested participants' consequences illness representations.

Yoos and McMullen's study (1996) was one of the few studies reviewed in the literature that differentiated their results based on race/ethnicity (African American versus Caucasian), age (school age versus adolescent), socioeconomic status (lower socioeconomic status versus higher socioeconomic status), and asthma severity (moderate versus severe). The investigators looked for common threads and analyzed participants' responses to: (1) "How much they worried about asthma" and (2) "How much their lives were different because of asthma" (Yoos & McMullen, 1996, p. 285). African American adolescents (80%) worried about their asthma more than Caucasians (50%). The adolescents' degree of worry could reflect the consequences illness representation. Additionally, higher levels of worry were identified among participants who were school age and of lower socioeconomic status and who had severe asthma.

When compared to Caucasians, African American participants perceived there to be a much greater difference in their lives due to asthma. The participants with severe asthma also felt that their lives were markedly different because of asthma. The responses of those two groups could indicate illness representations of consequences. In addition, lower socioeconomic status participants were slightly higher in responding that their lives were different because of asthma. Interestingly, in this sample, school age and adolescents were not different in how much their lives were different because of asthma. This study provides support for differentiating results based on race/ethnicity, age, asthma impairment, and socioeconomic status. As a result, beliefs, perceptions, and illness representations common among particular groups can be addressed.

Illness representations and perceptions were examined in Joseph et al.'s (2006) study of 63 African American adolescents (15–18 years of age). Although the sample included caregivers, the perceptions of adolescents provide support for the study of illness representations. Most adolescents (77.4%) felt their asthma was well controlled; this is a reflection of their identity illness representation. Almost 20% of caregivers felt the asthma was not controlled while the adolescents perceived the asthma as mild or moderately controlled; this points to the need to examine adolescents during an age when they become more involved in self-management. The illness representation with the next level of variation was the control of asthma through medication management. There was only 52.4% agreement about the use of the controller medication. There was higher agreement among adolescents and their caregivers on functional status (i.e., symptoms and activity limitations), healthcare utilization, and lack of environmental control (e.g., adolescents' smoking patterns). This study provides support for determining African American adolescents' illness representations, beliefs, and perceptions in order to determine their influence on self-management behaviors.

Summary of illness representations and race literature. Three studies (Peterson et al., 2002; Yoos & McMullen, 1996; Joseph et al., 2006) exist describing the illness representations (beliefs and perceptions) of African American adolescents with asthma. More studies have been conducted on the illness representations, beliefs, and perceptions of African Americans adults, yet the small number of studies conducted with African American adolescents and adults reflect inaccurate illness representations and beliefs as well as misperceptions of their asthma symptoms. The review of the study that targeted African American caregivers was beneficial because it identified illness representations and beliefs that families hold about asthma. Those beliefs could influence the illness representations and influence the self-management behaviors of middle adolescents. Furthermore, the two studies that were conducted with African American adolescents supported several of the inaccurate beliefs and illness representations that were presented in the studies of African American adults. The inaccurate beliefs and illness representations can contribute to the poor self-management behaviors of African American adolescents with asthma.

Illness Representations and Asthma Impairment

Literature reviewed. Severity of asthma (asthma impairment) may influence an adolescent's perceptions. Rhee et al. (2008) identified patterns of asthma control perception in relation to actual symptom reports of adolescents. The participants were categorized into one of four groups: well controlled accurate group (those who perceive symptoms to be well controlled and they are); inaccurate group 1 (perception that daytime symptoms are better than they are); inaccurate group 2 (perception of symptoms was poor and nighttime symptoms are poor); and poorly controlled accurate group (perception of asthma is poor and symptoms are not well controlled). Of most concern to the author were the participants who had high levels of inaccuracy, even over 31% of inaccuracy. Non-Whites (i.e., African American, Hispanics, and Biracial) were four times more likely to be grouped in the inaccurate 2 group compared to the well controlled accurate group. Furthermore, the study cited that the inaccurate 2 group was comprised of the highest number (specific number not reported) of non-White adolescents. The inaccurate 2 group with its poor perception of symptoms and increased nighttime symptoms meant that the participants' asthma was not well controlled or was poorly controlled. Additionally, adolescents who fail to recognize their symptoms will have more poorly controlled asthma.

Summary of illness representations and asthma impairment literature. Only one study was found in the literature that identifies subgroups based on adolescents' perceptions and asthma symptoms. The findings of Rhee et al. (2008) support the need for studies of the perceptions, beliefs, and illness representations of adolescents and particularly African American adolescents according to asthma impairment.

Summary of Illness Representations Related to Asthma Studies

In this review of the literature, the findings show that adolescents have inaccurate illness representations and beliefs as well as misperceptions about their asthma. The author reviewed a total of 25 studies in sections related to illness representations, beliefs, and perceptions. Thirteen of the 25 studies only included participants who were adolescents. Three studies with adult participants were reviewed. Females were the predominate gender in the studies associated with illness representations, beliefs, and perceptions. Seven of the 22 studies were conducted in Europe and Hawaii; the second highest representation was Caucasians. None of the studies reviewed used the asthma impairment criteria described for the current study. There was a wide range of criteria and terminology used to identify the participants' asthma impairment.

Illness representations, beliefs, and perceptions were reviewed in four categories: asthma, gender, race, and asthma impairment. The largest number of studies in this section related to the category of asthma (17 studies), followed by gender (4 studies), race (3 studies), and asthma impairment (1 study). Illness representations were either identified by the authors of the studies or labeled by the author of this study according to the described belief or perception. In order of highest to lowest, the illness representations identified were control, identity, timeline, consequences, cause, and emotional. There were frequent descriptions of either the control participants thought they had over their asthma or the lack of control they had over their illness. Even many of the participants who described their control over their illness had erroneous beliefs about the chronicity of asthma. Most concerning to the author of this study was the large number of inaccuracies in illness representations, beliefs, and perceptions regarding asthma symptoms and medication to treat those symptoms. In addition to the cognitive illness representations, numerous statements were identified in the literature concerning adolescents' emotional representations, mainly their fear of dying.

The review of illness representations analyzed by gender reflected errors in males' perceived control over their asthma, their ability to hold out on managing symptoms, and their delay in seeking treatment. These errors were identified in the adult and adolescent literature based on findings from male participants. There was a paucity of literature in the small number of studies that measured illness representations, beliefs, and perceptions according to race and particularly those of African American adolescents. The inaccuracies of adolescents in those studies support the need for further study of African American adolescents with asthma. The author identified only one study on perceptions of asthma symptoms and that study emphasized the under-perception of symptoms and poorly controlled asthma of minority adolescents. The findings support the need to obtain data from adolescents concerning their illness representations and to determine if there are differences according to gender, race/ethnicity, and asthma impairment. Furthermore, findings from the review of literature in this section suggest that adolescents' poor self-management behaviors could be influenced by inaccurate illness representations, beliefs, and perceptions.

Illness Representations Related to Asthma Self-management

Literature Reviewed

There is a lack of studies that examined the influence of illness representations, beliefs, and perceptions on asthma self-management among adolescents. The author found three studies that examined this relationship among adults with asthma. Illness representations and their association with adherence to inhaled preventive asthma medication were explored in a study of 330 adults (Jessop & Rutter, 2003). One hundred ten (33.3%) of the participants were males, 204 (61.8%) were female, and ages ranged from 17 to 87 years. Jessop and Rutter (2003) recruited participants from a healthcare database in Kent, in the south of England. Descriptions of asthma impairments were not provided in the study. However, inclusion criteria required that participants have a diagnosis of asthma and have a prescribed inhaled preventive medication. Such inclusion criteria of requiring a prescribed inhaled preventive medication would mean inclusion of individuals whose asthma is well controlled with the use of an inhaled preventive or those whose asthma is not well or is very poorly controlled. Illness representations were measured by the Beliefs about Asthma Questionnaire (Jessop & Rutter, 2003), which is designed to assess the five components of cognitive representations of asthma, emotional representations of asthma, and current adherence and intention to adhere in the future. Identity, cause, and control were illness representations that significantly predicted adherence to medication. Therefore, participants who believed they had asthma and thought it could be controlled or cured were more likely to adhere to medication regimens than those who attributed the cause of their asthma to an external factor. Their study also revealed that age (older individuals) and gender (females) were predictors of adherence.

Illness representations, beliefs, and perceptions of African Americans related to their medication were described in the study by Le et al. (2008). The participants were self-identified minorities including African Americans. The sample included a total of 86 adults; 66 were minorities, and 61 of the 66 minorities were African Americans with asthma. The participants were 19 years of age or older, predominately female (71.2%), and had an active prescription to use an inhaled corticosteroid, which indicates not well or very poorly controlled asthma. Many African American participants held negative beliefs that they did not need as much medication as had been prescribed or that they might develop a tolerance to their medications; these beliefs are reflective illness representations of identity and consequences. African Americans also did not endorse the statement that inhaled corticosteroid therapy was safe; this is reflective of the identity illness reflection. Adherence was lower among participants who agreed with one or more negative beliefs or disagreed with the positive belief about inhaled corticosteroids (24% adherence in African Americans versus 40% for those participants who had no problematic beliefs, $p = .002$). The odds of a high negative beliefs index score (≥ 3) in minority patients was nearly seven times higher as compared to Caucasian participants. The findings of this study demonstrate that African American adults hold illness representations about asthma and that they hold more negative ones than do Caucasians. This study provides support of the influence of negative beliefs about asthma medication on such self-management behaviors as adherence to medication.

Wells et al. (2008) measured beliefs about asthma medications and other factors influencing medication adherence. They examined differences in the responses of 336 African American and 614 White adult participants to survey questions about inhaled steroid use. Seventy-one percent of the participants were females. The participants had been diagnosed with asthma for at least one year. They had a prescription for an inhaled corticosteroid that is indicative of not well controlled or very poorly controlled asthma impairment or well controlled asthma that has improved with medication management. The study measured internal and external factors that could influence adherence to inhaled corticosteroids. Internal factors (i.e., beliefs about asthma and asthma controller medication, readiness to take medication, perceived control over medication, and trust in physicians) were more influential than were external factors. Among White participants, 23% of the variance in inhaled steroid adherence was accounted for by their perceived necessity of the medication, readiness to take inhaled steroids, and knowledge about asthma and doctors' perceived source of control. Among African American participants, readiness to take the inhaled steroids was found to be significantly associated with inhaled corticosteroid adherence. Their readiness to take inhaled steroids, reflective of the control illness representation, accounted for 5.6% of the variance in inhaled steroid adherence. The authors acknowledged that nonparticipants could have altered their findings because the majority of participants who did not agree to participate were male African Americans.

Summary of the Illness Representations Related to Asthma Self-management Literature

The author identified three studies that examined the relationship between illness representations (beliefs and perceptions) and self-management behaviors. The three studies (Jessup & Rutter, 2003; Le et al., 2008; Wells et al., 2008) were conducted with adults. No studies were found that directly measured adolescents' illness representations and their influence on asthma self-management. Jessop and Rutter's (2003) study was the only study identified that examined the relationship between cognitive and emotional illness representations and one of the self-management behaviors (medication management). Jessop and Rutter's (2003) study examined the relationship between cognitive and emotional illness representations and adults' adherence to their inhaled corticosteroids. Identity, cause, and control were illness representations that significantly predicted adherence to medication. Although the other two studies did not directly measure the relationship between illness representations and self-management behaviors, their findings contributed to the broad literature of illness representations (beliefs and perceptions) and asthma self-management. In those two studies (Le et al., 2008; Wells et al., 2008), beliefs and perceptions about asthma were reflective of identity and control illness representations, which are similar to the direct findings of Jessop and Rutter (2003). The beliefs and perceptions identified in this section of the review were primarily associated with two self-management behaviors: symptom management and medication management. All three of the studies were comprised of over 65% female participants. Although the results of those studies were not differentiated by gender, the high percentage of female participants permits some association of the findings with females. One of the studies (Le et al., 2008) had a predominately African American sample. Another study, Wells et al. (2008), differentiated their findings by race and, therefore, the results of African Americans were reported. African Americans in Le et al. (2008) and Wells et al. (2008) tended to have beliefs reflective of identity and control illness representations and those beliefs influenced medication management. One of the medication management issues identified in those studies was adherence to inhaled corticosteroids. Asthma impairment was either not identified or it fell into the not well controlled or poorly controlled asthma category. Therefore, some participants potentially could have held beliefs or illness representations that influenced their self-management behaviors resulting in their asthma being not well controlled or poorly controlled. The limited number of studies in this section also reflects the gap in the literature in studies that measure illness representations and self-management behaviors of African American adolescents with asthma.

Summary of the Review of the Literature

Three major topics were examined in this review of the literature: (1) asthma self-management (see Table B1), (2) asthma illness representations (beliefs and perceptions; see Table B2), and (3) relationship of illness representations with asthma self-management (see Table B3). The literature review revealed the following broad findings regarding asthma self-management. First, adolescents exhibit poor daily medication management. Second, symptom management has been documented to be inadequate among adolescents with asthma. Third, although environmental control was not examined directly, the prevailing poor environmental control is indicated indirectly through adverse environmental exposure in many of the studies reviewed; adolescents are exposed to cockroaches and dust mites and to smoke either by smoking themselves or by second-hand smoke. Fourth, the review of self-management by race/ethnicity and gender revealed similar deficiencies for African Americans in symptom management and medication management as in the larger population. However, males and African Americans had such inadequate symptom management and poor medication management that they led to increased asthma exacerbations. There are a limited number of studies that focus on self-management behaviors of males and females and African Americans. Fifth, the review of the literature revealed a paucity of literature on studies related to asthma impairment or studies that differentiated findings based on levels of asthma impairment. Finally, there is a paucity of the literature on the self-management behaviors of adolescents and particularly African American adolescents with asthma.

Illness representations were the second broad topic discussed in the review of the literature. There is a paucity of literature on illness representations and adolescents with asthma. The author reviewed adolescents' beliefs and perceptions in order to gain more information on factors influencing adolescents' self-management behaviors. The expansion of the topic revealed adolescents' inaccurate beliefs and misperceptions related to asthma. Illness representations (beliefs and perceptions) also were reviewed for their association with gender, race, and asthma impairment. Although there were limited studies in those categories, the literature reviewed revealed inaccurate illness representations, beliefs, and perceptions that could influence the self-management behaviors of adolescents.

The third major area reviewed was the relationship of illness representation and asthma self-management. There is a paucity of literature on the illness representations (beliefs and perceptions) and asthma self-management. However, of the limited number of studies reviewed, there was either a measured relationship between identity, cause, and control illness representations and self-management behaviors or the beliefs indicated identity and control illness representations. The studies primarily examined relationships between illness relationships, beliefs, and perspectives and two self-management behaviors: medication adherence and symptom management. Only one study was identified that measured the relationship of illness representations and medication adherence and that was with adult participants. The author identified no studies that targeted adolescents with asthma, and studies with adult participants revealed inaccurate beliefs and perceptions. This review of the literature revealed that there is a paucity of literature on illness representations and self-management behaviors of African American adolescents with asthma. Further research is needed on the relationship of illness representations and the self-management behaviors of African American adolescents with asthma. Furthermore, research is needed to determine if there are differences in the illness representations based on gender or asthma impairment and how illness representations and self-management behaviors interact with gender and asthma self-management.

CHAPTER III METHODS

This chapter describes the design of the study; research aims; settings, sampling, and recruitment; protection of human subjects; measures; data collection procedures; description of setting; and data analysis.

Design

This study was a descriptive correlational study of 133 African American adolescents with asthma. The study investigator collected data at a single point in time and explored relationships among concepts to address research aims.

Research Aims

The specific aims and research questions of the study were:

Specific Aim 1: To explore differences in illness representations (cognitive and emotional) and self-management behaviors (symptom management, medication management, and environmental control) by gender, asthma impairment (well controlled and not well controlled), and gender by asthma impairment among African American adolescents (aged 14–16 years) with asthma.

Study questions for Specific Aim 1 included:

1. What are the differences in the means of cognitive representations of identity, timeline, consequences, cause, and control by gender, asthma impairment (well controlled and not well controlled), and gender by asthma impairment for African American adolescents (aged 14–16 years) with asthma?
2. What are the differences in the means of emotional representations by gender, asthma impairment (well controlled and not well controlled) and

gender by asthma impairment for African American adolescents (aged 14–16 years) with asthma?

3. What are the differences in the means of self-management behaviors of symptom management, medication management, and environmental control by gender, asthma impairment (well controlled and not well controlled), and gender by asthma impairment for African American adolescents (aged 14–16 years) with asthma?

Specific Aim 2: To explore relationships between illness representations (cognitive and emotional), asthma self-management behaviors (symptom management, medication management, and environmental control), gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma.

Study questions for Specific Aim 2 included:

1. What are the bivariate relationships between cognitive (identity, timeline, consequences, cause, and control) and emotional representations and asthma self-management behaviors (symptom management, medication management, and environmental control) in African American adolescents (aged 14–16 years) with asthma?
2. What are the associations between symptom management and the set of cognitive representations (identity, timeline, consequences, cause, and control), emotional representations, gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma?
3. What are the associations between medication management and the set of cognitive representations (identity, timeline, consequences, cause, and

control), emotional representations, gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma?

4. What are the associations between environmental control and the set of cognitive representations (identity, timeline, consequences, cause, and control), emotional representations, gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma?

Settings

This study used three general categories of settings for recruitment: schools, clinics, and community organizations. The investigator approached a total of twelve school corporations and two clinical agencies as potential settings for recruitment and data collection. The study investigator utilized 63 community settings to distribute recruitment material. Approval was obtained from five school corporations and two clinical agencies for recruitment and data collection. Both clinical and school sites were chosen to assure diversity in asthma impairment. The clinical sites were chosen to increase the likelihood of obtaining a sizable number of participants with poorly controlled asthma. The investigator selected schools that had a high percentage of African Americans within the targeted age range. The community organizations were used to increase the sample size and to increase the potential for participants in all three impairment groups: well controlled, not well controlled and very poorly controlled.

Schools

A total of 22 schools in 5 school corporations were the settings for recruitment and data collection. Each school corporation is described in this section according to enrollment, graduation rate, ethnicity, categories of lunch payment (which reflects income status of system), and grades of the schools used for the study. The information for each school system was obtained from the state's department of education Web site and was based on 2010–2011 data (Indiana Department of Education [IDOE], n.d.). The National School Lunch Program (United States Department of Agriculture, 2009) is a federally assisted meal program in which eligibility is based on the family's income. Children from families with incomes at or below130% of the poverty level are eligible for free meals. Those with incomes between 130% and 185% of the poverty level are eligible for reduced price meals. Children from families with incomes over 185% of the poverty level pay a full price. The percentages of students in the free, reduced, and full pay categories indicate the income ranges of the families in each school system (United States Department of Agriculture, 2009).

Inner City Schools Public Schools. "Inner City Schools" is located in the state capital of a Midwestern U.S. city, and considered by the state's department of education as a metropolitan school district. The city is one of the largest cities in U.S. and is one of the larger three cities in the Midwest (ranking just behind cities such as Chicago and Detroit). The 2010–2011 enrollment was 33,079, and the graduation rate was 64.6% (IDOE, 2012). The ethnicities represented by students included: 17,900 African American; 7,626 White; 5,793 Hispanic; 1,568 Multiracial; 134 Asian; and 55 American Indian (IDOE, 2012). The National Lunch Program provided free lunches for 25,243 students; reduced-price lunches for 1,594 students; and full-price lunches for 6,242 students (IDOE, 2012). The schools used for recruitment and data collection were identified as middle and high schools, which included students in the target age of 14–16 years old.

Metropolitan School District of Township One. This school district is located in the west central portion of the state and is considered to be a metropolitan school district. The enrollment for the “Metropolitan School District of Township One” in 2010–2011 was 16,003, and the graduation rate was 86.4% (IDOE, 2012). The ethnicities represented by students included the following: 7,129 White; 4,962 Black; 2,775 Hispanic; 935 Multiracial; 172 Asian; and 27 American Indian. The National Lunch Program provided free lunches for 9,591 students; reduced-price lunches for 1,563 students; and full-priced lunches for 4,849 students. The seventh-, eighth-, and ninth-grade centers as well as the high schools included the target age of 14- to 16-year-olds; therefore, they were utilized for recruitment and data collection.

Academy Charter School. This school, located in the state capital, is identified as a public charter school, sponsored and supported by the Greater Education Opportunities Foundation. The school houses grades Kindergarten through 12. The enrollment for “Academy Charter School” was 375, and the graduation rate was 88.2% (IDOE, 2012). The ethnicities represented by students in 2010–2011 included: 336 African American, 31 White, and 7 Multiracial (IDOE, 2012). The National Lunch Program provided free lunches for 295 students, reduced-priced lunches for 28 students, and full-priced lunches for 52 students. African American students with asthma and 14- to 16-year-olds were recruited from Academy Charter School.

Metropolitan School District of Township Two. This metropolitan school district is located in the northern section of the state capital. The enrollment for the “Metropolitan School District of Township Two” in 2010–2011 was 11,155, and the graduation rate was 83.2% (IDOE, 2012). The ethnicities represented by students included: 3,800 White; 4,616 Black; 1,587 Hispanic; 769 Multiracial; 367 Asian; and 14 American Indian. The school provided free lunches for 5,267 students; reduced-priced lunches for 827 students; and full-priced lunches for 5,061 students (IDOE, 2012). The schools used for recruitment and data collection were identified as seventh-, eighth-, ninth-grade centers, and high schools.

Metropolitan School District of Township Three. The schools in the "Metropolitan School District of Township Three" are located in the northwest section of state's central metropolitan county. The 2010–2011 enrollments were 11,074, and the graduation rate was 91.8%. The ethnicities represented by students included: 6,538 African American; 1,496 White; 1,940 Hispanic; 792 Multiracial; 295 Asian; and 9 American Indian. The National Lunch Program provided free lunches for 5,684 students; reduced-price lunches for 902 students; and full-priced lunches for 4,488 students. The schools used for recruitment and data collection were identified in Metropolitan School District of Township Three as middle and high schools, which included students in the target age of 14–16 years old.

Clinics

Recruitment and data collection sites included two medical clinics: the "County Adolescent Care Team in Our Neighborhood (ACTION) Health Center" and the "Children's Hospital High Risk Asthma Clinic."

County ACTION Health Center. The County ACTION Health Center is a highly regarded resource for providing comprehensive health care to area youth. The County ACTION Health Center is one of the clinic services of the county health department. The study investigator selected it as a site because of the potential to recruit the target race (African American), the age range (14–16 years old), and adolescents whose asthma was not well controlled or poorly controlled.

Children's Hospital High Risk Asthma Clinic. The "Children's Hospital High Risk Asthma Clinic" offers specialized clinic services to high-risk children and adolescents with asthma. Therefore, the patient population included the study's target age of 14–16 years old. The out-patient clinic is associated with the hospital and provides service for patients from around the state. The study investigator selected this as a recruitment site because of the type of patients seen through that clinic: those who are considered high risk because their asthma is not well controlled or is poorly controlled for a number of reasons including self-management behaviors.

Community Recruitment Settings

In addition to the recruitment and data collection through the schools and clinics, the investigator made efforts to recruit participants through "snowballing" and through private pediatricians' offices, youth agencies, churches, and community organizations. Snowballing is a method of recruitment where a participant of the study informs a peer or relative then that person contacts the primary investigator (PI) for potential inclusion in the study (Sadler, Lee, Lim, & Fullerton, 2010; Wasserman, Pattison, & Steinley, 2005). The PI distributed study flyers (see Figure C1) and brochures (see Figure C2) to private pediatrician's offices, youth agencies, churches, health fairs, and community organizations, and at community events with large numbers of African Americans in attendance. A list of community recruitment settings is presented in Table 1.

Table 1

Community Recruitment Settings

Community Recruitment Setting	Number Used for Recruitment
Private pediatricians offices	5
Youth agencies	3
Churches	12
Health fairs/community events	9
Community organizations	19
Minority Health Coalition Expansion Sites	15

The state's Minority Health Coalition (MHC) is one of the primary community organizations that provided an opportunity to recruit participants for the study. The MHC is a non-profit organization that strives to decrease health disparities. Its health programs are implemented statewide through community affiliates. The study investigator distributed flyers and brochures to the MHC community affiliates in 15 of the state's counties.

Inclusion and Exclusion Criteria

The goal for the proposed sample was at least 120 African American adolescents (60 males and 60 females), aged 14–16 years, whose asthma impairment was classified as well controlled, not well controlled, or very poorly controlled. Inclusion criteria for the study included: (a) self-identification as an African American; (b) aged 14–16 years according to self-reported birthdates; (c) self-reported treatment for asthma in the past year; and (d) school placement in a regular classroom, based on self-report of classroom placement.

Exclusion criteria for the study included: (a) self-identification of race other than African American; (b) under the age of 14 years or 17 years of age and older; (c) no self-report of asthma treatment in the past year; (d) school placement in special education, self-reported; (e) person with a cognitive or developmental delay as indicated by being one grade or more behind students of the same age that would impede completion of the forms as well as influence the participant's representations and self-management abilities; (f) inability to speak English; and (g) potential participant has another self-reported serious chronic illness that would interfere with current asthma self-management. Self-reported serious chronic illnesses identified as potentially interfering with asthma management were (1) cystic fibrosis, (2) obvious and serious psychiatric conditions, and (3) disorders causing increased fatigue and difficulties self-managing asthma such as current cancer treatment, lupus flares, debilitating cardiac conditions, and rheumatoid arthritis.

The study investigator limited the study to African Americans because of need identified in national and state statistics. There is strong evidence nationally of disparities for African Americans, including adolescents, in asthma prevalence, decreased asthma control, and mortality (CDC, 2006; Indiana State Department of Health's Asthma Program, & Indiana Joint Asthma Coalition, 2008). Furthermore, the disparities for African Americans and Whites in the state followed the national patterns (Indiana State Department of Health, 2008). The study of illness representations and asthma self-management behaviors of African American adolescents was based on several considerations. The literature supported the need for research that investigated reasons for the disparities that exist in the asthma population. The reasons for health disparities are complex (Smedley, Stith, & Nelson, 2003; Thomson, Mitchell, & Williams, 2006); however, illness representations (such as beliefs about consequences, cause, and control of asthma) are factors that help to explain health disparities.

The researcher identified the age group of 14–16 years of age (middle adolescence) as the target sample for implementation of the study for several reasons. First, this age group is in the middle of adolescence and exhibits greater cognitive maturity, abstract thinking, and decision-making skills than do younger adolescents. All of those attributes are needed in order to self-manage a chronic illness like asthma and because of these capabilities many adolescents manage their asthma rather than their parents doing so. Second, the rationale for selecting 14- to 16-year-olds was to have a homogenous group and to limit the potential for variation with age for sample size. Third, individuals in this age group (14- to 16-year-olds) with asthma encounter the challenges of wanting to be "normal" and like their peers, while facing the complex treatment regimens of asthma. It is important to address inadequate self-management behaviors of 14- to 16-year-olds before they become young adults and even more independent. Fourth, the investigator chose middle age adolescents because this is the age when adolescents start to spend more time away from home and carry out more of their asthma self-management. Finally, 14- to 16-year-olds have been documented with increased prevalence, poor asthma control, inadequate self-management behaviors, and increased mortality (Akimbami et al., 2009; Bruzzese et al., 2008; Joseph et al., 2006, Rhee et al., 2009). Therefore, the study investigator identified several factors to support the need to study the self-management behaviors in adolescents, specifically middle adolescents (14- to 16-year-olds) with asthma.

Justification of Sample Size

The purpose of this study was to generate preliminary data (a) to explore differences in illness representations and self-management behaviors by gender and level of asthma impairment and (b) to explore relationships between cognitive and emotional illness representations, asthma self-management behaviors, gender, and asthma impairment. Prior to the study, the study investigator determined that an adequate sample size would be 120 African American adolescents (14- to 16-years-old) with asthma (S. Perkins, personal communication, November 25, 2007). Enrollment was planned for approximately 20 adolescents in each of the six asthma impairment/gender combinations: well controlled/female, well controlled/male, not well controlled/female, not well controlled/male, very poorly controlled/female, very poorly controlled/male (S. Perkins, personal communication, November 25, 2007).

Procedure for Recruitment

Recruitment Material

The investigator used flyers (see Figure C1) and brochures (see Figure C2) as a recruitment strategy for this study. The author created flyers to capture the attention of potential adolescent participants. The design and colors of the flyer incorporated considerations of adolescents' interests.

The target population of African American adolescents served as the impetus of including photographs of African American adolescents on the flyer. The investigator's goal was to encourage the adolescents to read the flyer and to gain interest in the study so they would take the flyer and brochure home for their parent(s) or guardian(s) to read. During the developmental stage, a group of adolescent males and females reviewed the flyer for appeal to potential participants. The brochures included a brief description of the study, inclusion criteria, requirement for consent and assent, incentive details, and the

PI's contact telephone number and e-mail address for interested adolescents and/or their parents or guardians to use to learn more about the study.

Another recruitment strategy used in the flyers and brochures was to include a brief introduction of the PI, the PI's interest in conducting the research study, and the PI's photograph. The review of the literature reflected that small numbers of African Americans participate in research studies and that few studies have been conducted with African American adolescents. The purpose for including information about the PI was so that adolescents and their parents or guardians could establish a sense of trust in the PI and in the PI's goal of improving asthma care for adolescents in the future.

Recruitment Strategies

Recruitment for this study used two approaches: primary recruitment and secondary recruitment (see Figure 2). The PI's initial recruitment goal was to enroll a total of 120 African American adolescents, 20 in each of six asthma impairment/gender categories (i.e., well controlled/female, well controlled/male, not well controlled/female, not well controlled/male, very poorly controlled/female, very poorly controlled/male). In order to obtain sufficient numbers, the PI over-recruited to 209 adolescents in order to obtain a final sample of 133 participants with complete data.

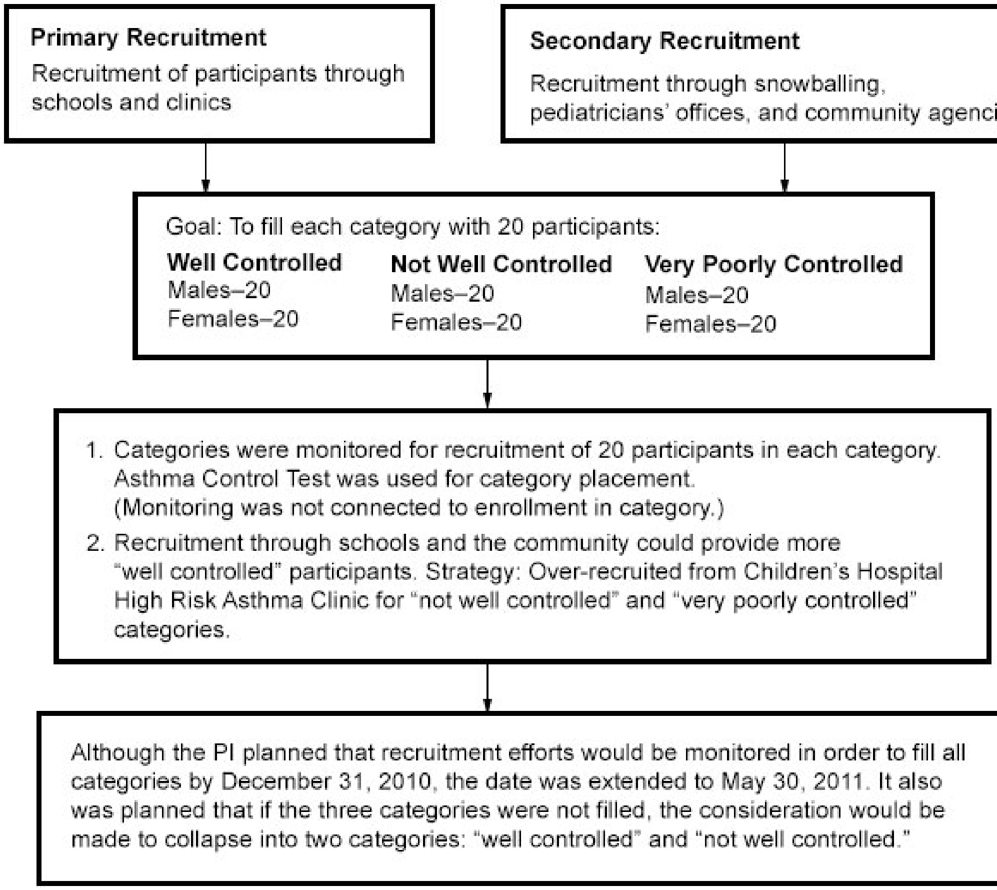

Figure 2. Flowchart depicts the primary and secondary recruitment and monitoring of asthma impairment categories.

Primary recruitment. The investigator defined the term "primary recruitment" to describe the recruitment process in the schools and clinics. The PI monitored the recruitment categories (i.e., the six asthma impairment/gender categories) throughout the recruitment process and made every effort to fill each category; however, enrollment into the study was not tied to the monitoring of the categories. Although participants for all categories were recruited through the schools and clinics, the PI recognized that recruitment through the schools could provide a higher number of participants for the "well controlled" categories. Therefore, the investigator made attempts to over-recruit for the "not well controlled" and "very poorly controlled" categories through the Children's Hospital High Risk Asthma Clinic and the County ACTION Center clinic. The PI planned that if recruitment efforts to complete all six categories were unsuccessful, the participants would be collapsed into two categories: well controlled and not well controlled.

Procedures for recruitment from school corporations and medical clinics are identified in flowcharts in this section.

Schools. School corporations identified 14- to 16-year-old students (some school corporations specified 14- to 16-year-old African Americans) from their records. The flowchart for recruitment of participants through schools is presented in Figure 3.

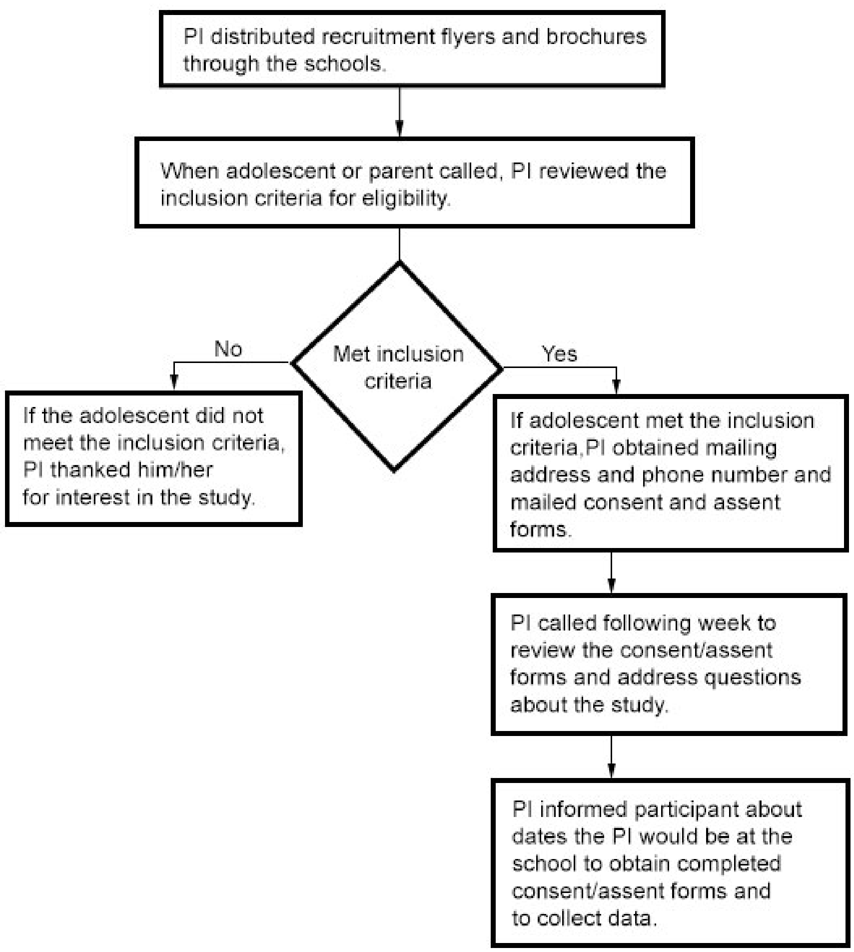

Figure 3. Flowchart depicts recruitment of participants through schools.

The PI provided all of the flyers and brochures, described previously in the Recruitment Material section, to be distributed to the identified pool of 14- to 16-year-olds. The school liaisons distributing the materials requested that students carry the flyers and brochures home to share with their parents or guardians. The PI provided additional flyers and brochures for the school liaisons (e.g., the school nurse or administrator's designee) to post in the schools, if approved, to assist with recruitment.

The PI followed up on e-mail inquiries to request a phone number to contact the potential participant. When the adolescent or parent/guardian telephoned, or during e-mail follow-up contacts, the PI screened participants for the eligibility criteria and obtained a mailing address and phone number. The investigator then sent the family a parental consent form (Figure D1) and an adolescent assent form (Figure D2) with an envelope to enclose the completed forms for their return at school.

The PI followed-up with a telephone call within one week to review the consent/assent forms with both parent/guardian and adolescent and to address any questions about the study or consent/assent forms. The PI reviewed the following sections of the consent/assent forms with the adolescent and his or her parent(s) or guardian(s): (a) purpose of the study, (b) number in study, (c) procedures, (d) risks of the study, (e) benefits of the study, (f) alternative to participation, (g) confidentiality, (h) cost, (i) payment, (j) compensation for injury, (k) contacts for study, and (l) voluntary participation in the study. The investigator informed participants that both the parent/guardian and the adolescent needed to agree about participation in the study. The PI also informed participants of the dates that the PI would be at their school to obtain the consent/assent forms and to collect data. The time of day of data collection was determined by each participating school. Each of the schools chose to have the students complete the data collection after school. In some instances, parents requested the collection of data after school.

Clinics. Figure 4 presents the flowchart for recruitment of participants from the clinics. The clinic liaison notified the PI on a weekly basis of the days when a large number of African American adolescents with asthma in the age range had appointments. The PI attended clinic on those days. Clinic staff gave the potential participants the recruitment flyers and brochures and asked adolescents and parents if they were willing talk with the PI about the study. If the adolescents and parent(s) granted verbal permission, the PI explained the study to them, screened potential participants according to inclusion and exclusion criteria, reviewed consent/assent forms (Figures D1/D2), and obtained consent/assent before data collection. The investigator informed participants that both the parent and the adolescent needed to agree to be in the study.

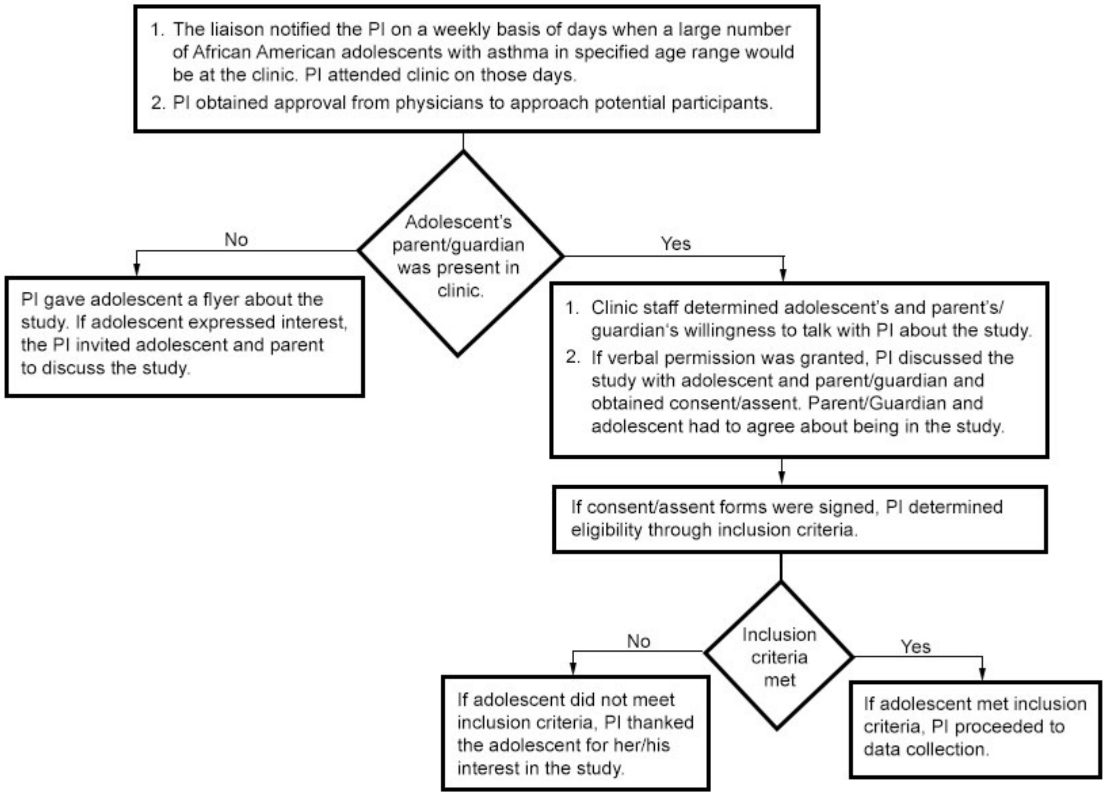

Figure 4. Flowchart depicts recruitment of participants through clinics.

Secondary recruitment: Snowballing. In addition to the primary recruitment sites, the study investigator recruited participants through snowballing of private pediatricians, youth agencies, churches, and community organizations (see Figure 5). Snowballing is a method of recruitment where a participant of the study informs a peer or relative then that person contacts the PI for potential inclusion in the study (Sadler et al., 2010; Wasserman et al., 2005).

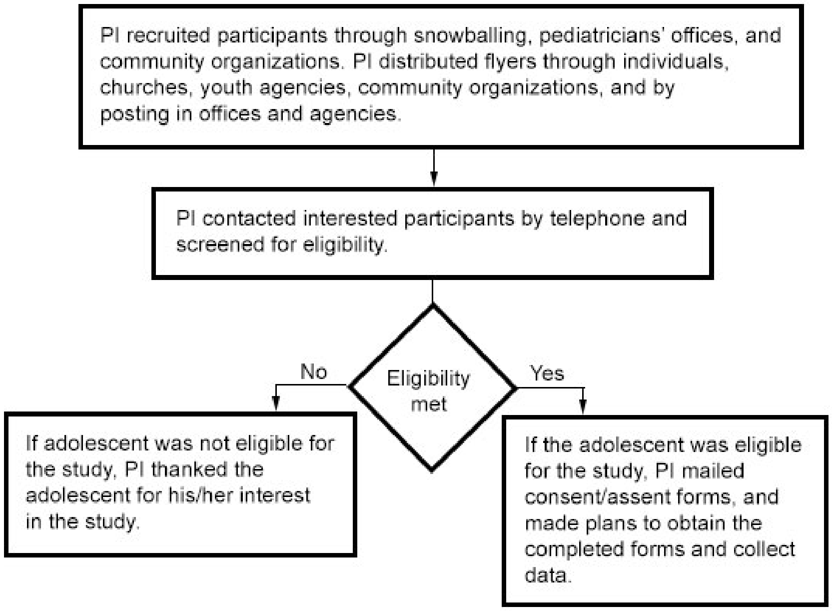

Figure 5. Flowchart depicts recruitment of participants in community.

At the completion of data collection, the PI gave flyers and brochures to adolescents who were accepted into the study to share with other 14- to 16-year-old African American adolescents with asthma. The investigator posted flyers and brochures about the study in libraries and community centers and distributed them to private pediatrician's offices, churches, and community organizations such as the YMCA and at community events where large numbers of African Americans were in attendance.

The PI followed up on e-mail inquiries to request a phone number to contact the potential participant. When the adolescent or parent/guardian telephoned, or during e-mail follow-up calls, the PI screened participants for the eligibility criteria and obtained a mailing address and phone number. The investigator then sent the family a parental consent form (Figure D1) and an adolescent assent form (Figure D2).

The PI followed-up with a telephone call within one week to review the consent/assent forms with both parent/guardian and adolescent and to address any questions about the study or consent/assent forms. The PI reviewed the following sections of the consent/assent forms with the adolescent and his or her parent(s) or guardian(s): (a) purpose of the study, (b) number in study, (c) procedures, (d) risks of the study, (e) benefits of the study, (f) alternative to participation, (g) confidentiality, (h) cost, (i) payment, (j) compensation for injury, (k) contacts for study, and (l) voluntary participation in the study. The investigator informed participants that both the parent/guardian and the adolescent needed to agree about participation in the study. After the explanation of the consent/assent forms, the PI asked the parent and participant if they were still willing for the adolescent to participate in the study. If their interest was confirmed verbally, the PI proceeded to discuss meeting to obtain the consent/assent forms and to collect the data.

Participants obtained through the community completed the instruments at a public location selected by the parent(s)/guardian(s) and PI with input from the adolescent. Public libraries and community centers are examples of public locations. Identification of a public location and data collection date concluded the telephone conversation with the participant and parent(s) or guardian(s).

Recruitment Incentives

The study investigator used incentives, specifically gift cards, to recruit African American adolescents with asthma. The author used two articles as the basis for considerations of providing incentives for adolescent participants. Rice and Broome (2004) recommended that investigators should consider several factors when deciding on the type and level of incentive. Incentive considerations applicable to this study included:

> (1) the incentive should be age appropriate, (2) in general, monetary incentives for a child should be based on the wage payment model and separate from incentives offered to parents, (3) if the child was the research participant, and the parent was not also a participant, parents

> should be reimbursed according to the reimbursement model for expenses only, and (4) if a parent and child disagreed about whether to participate in a study, the researcher should carefully consider whether the incentives offered might be considered coercive. (p. 172)

In the "wage payment model, child participants and their parents [are] viewed as working in a study which would [necessitate] reimbursement for their time, effort and burden at minimum wage rates" (Jones & Broome, 2001, p. 168). Additionally, the investigator based the consideration of providing an incentive on findings from Jones and Broome's (2001) focus groups study with African American adolescents. One of the recruitment strategies recommended by participants in Jones and Broome's (2001) study was to provide an incentive (including monetary) for participants. The wage payment model (Rice & Broome, 2004) and adolescents' recommendations for incentives (Jones & Broome, 2001) influenced the PI's decision to provide an incentive and the amount for the incentives. Incentives, specifically gift cards, were needed for this study in order to recruit from an adolescent population because these adolescents were members of a minority population that historically has participated little in research. Further, the adolescents and parents were potentially less trusting if the researcher offered an incentive in the form of a check; therefore, the investigator believed a gift card would be more amenable to them. Second, adolescents prefer more immediate rewards; waiting for a check would decrease the likelihood of participation. Thus, a gift card would be more palatable to this population of adolescents. Participants who completed the required consent/assent process, met the inclusion and exclusion criteria, and completed all of the forms and instruments were provided a $20.00 gift certificate from Wal-Mart or Target.

Recruitment Progression

Obtaining participants through the school corporations—primary recruitment—was slowed because of administrative delays and changes in school policies; therefore, the investigator increased secondary recruitment efforts locally and statewide. The opportunity to recruit statewide was a result of networking and presentations about the study to numerous individuals, agencies, churches, community organizations, and MHC affiliates. Primary and increased secondary recruitment efforts resulted in the distribution of flyers and brochures to 15 counties throughout the state.

Data Collection

Primary Sites

The primary sites for data collection were the schools and clinics previously identified in this study. After Institutional Review Board (IRB) approval (see Figure E1) was obtained, the study investigator contacted a liaison for each site and conducted orientation related to the study, recruitment protocol, data collection protocol, HIPAA (the Health Insurance Portability and Accountability Act of 1996), Federal Education Rights and Privacy Act, and issues related to protection of human subjects. The liaisons assisted the PI with communication at each site and in determining the specific data collection process for that school/agency.

Schools. The investigator collected data at a single point during a day specified by each school for participants obtained through participating schools. All participants had completed the recruitment and consent process (see Figure 6).

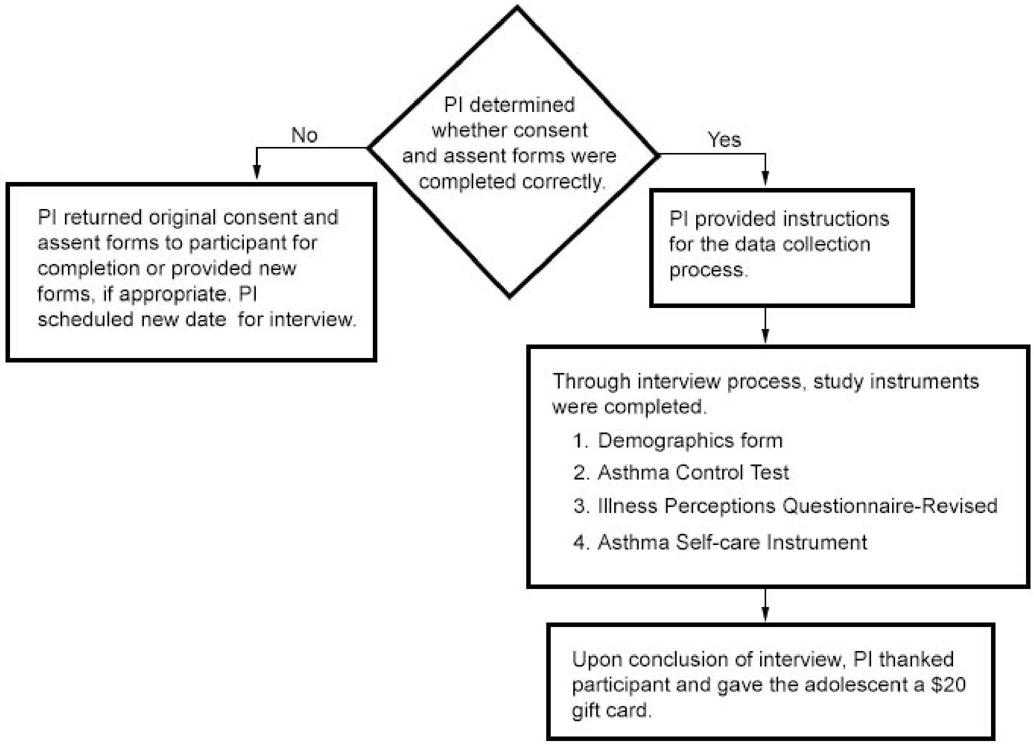

Figure 6. Flowchart depicts the data collection of participants at school sites.

Each participating school determined the time of day for data collection. The study investigator collected all data in a face-to-face meeting with the adolescent at the school. The PI requested a private room from school officials to facilitate data collection. The school designated primarily after school hours. The actual data collection process was the same for all locations (i.e., introductions, description of the study, explanation of data collection methods, and collection of data). The investigator distributed paper copies of the tools to each participant and asked the adolescent to complete the demographics form first then respond to the ACT, followed by the Illness Perceptions Questionnaire-Revised (IPQ-R), and last, the Asthma Self-Care Practice Instrument (ASCPI). The PI was available to address questions, to interpret meaning of words, or to read the items if necessary. The data collection lasted for approximately 25–30 minutes.

Participants who completed all four instruments received a $20.00 gift card to Wal-Mart or Target. Figure 6 further identifies the process for data collection in the schools.

Clinics. Data collection for the County ACTION Health Center and the Children's Hospital High Risk Asthma Clinic participants occurred on a scheduled appointment day after completion of the previously described recruitment and consent process. The data collection (see Figure 7) occurred prior to or after the physician visit. The investigator collected data in a private location identified in consultation with physicians and clinic coordinators. The study investigator first screened each participant for inclusion criteria, and if criteria were not met, thanked the adolescent for interest in the study. If the adolescent met the inclusion criteria, the PI continued with data collection. The actual data collection process (i.e., introductions, description of the study, explanation of data collection methods, and collection of data) was the same as for the school sites. The author distributed paper copies of the tools to each participant and asked the participant to complete the demographics form first then respond to the ACT, followed by the IPQ-R, and last, the ASCPI. The PI was available to address questions, to interpret meaning of words, or to read the items if necessary. The data collection lasted for approximately 25–30 minutes. Participants who completed all four instruments received a $20.00 gift card to Wal-Mart or Target. Data collection for the clinics is depicted in Figure 7.

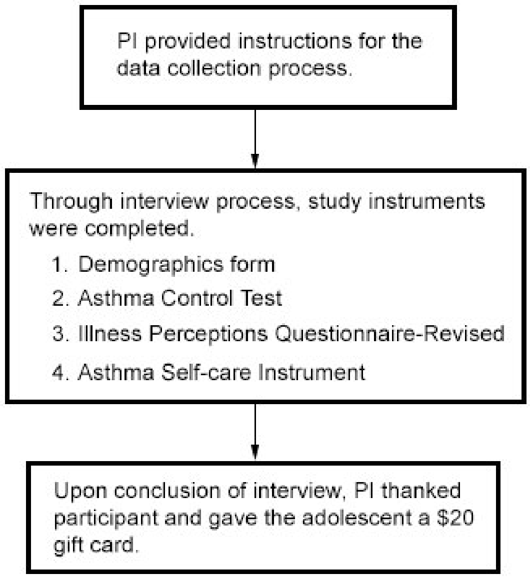

Figure 7. Flowchart depicts the data collection of participants at clinic sites.

Secondary Sites: Community

The secondary sites for data collection were public locations in the community. The study investigator scheduled the data collection for participants obtained through the community at a public location previously agreed upon by the parent(s) or guardian(s) and PI (see Figure 8). Examples of public locations used included public libraries, churches, and community centers. The investigator identified a private place within the facility for data collection. The adolescents and parents took the signed consent and assent forms to the data collection location. The actual data collection process (i.e., introductions, description of the study, explanation of data collection methods, and collection of data) was the same as for the schools and clinics. The researcher distributed paper copies of the tools to each participant and asked each participant to complete the demographics form first then respond to the ACT, followed by the IPQ-R, and last, the ASCPI. The PI was available to address questions, to interpret meaning of words, or to read the items if necessary. The data collection lasted for approximately 25–30 minutes.

Participants who completed all four instruments received a $20.00 gift card to Wal-Mart or Target. Data collection for the clinics is depicted in Figure 8.

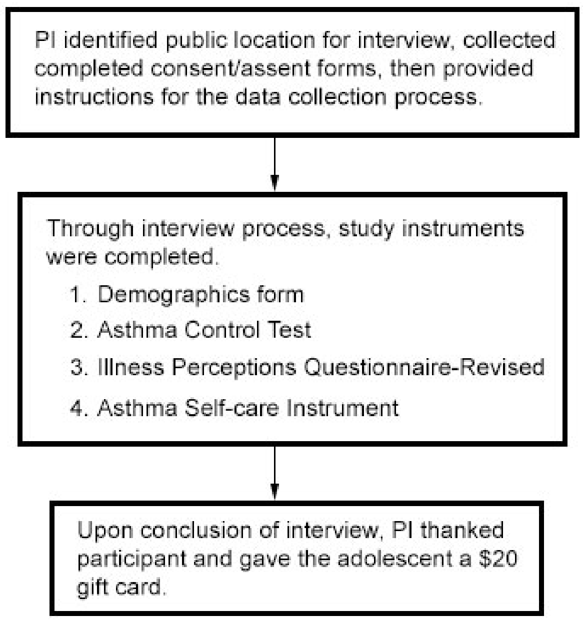

Figure 8. Flowchart depicts the data collection of participants in the community.

Measures

This section presents measures for each variable in the theoretical framework. The researcher used four instruments to collect data for this study: (1) ACT (asthma impairment variable; see Figure F1, instrument, and Figure F2, permission to use); (2) ASCPI (self-management behaviors variables; see Figure G1, instrument, and Figure G2, permission to use); (3) the IPQ-R (cognitive and emotional illness representatives variables; see Figure H1, instrument, and H2, permission to use), and (4) a demographics form (see Appendix I).

Asthma Impairment

The study investigator operationalized asthma impairment by use of the ACT, which differentiates level of impairment as well controlled, not well controlled, and poorly controlled asthma (Nathan et al., 2004). The classification was based upon participant responses to five items that address the level of disruption in school and home activities because of asthma symptoms, frequency of asthma symptoms, nighttime awakenings, use of short-acting beta agonist medication, and self-evaluation of asthma control (see Figure F1). The assessment, based on the participant's previous four weeks, contained items on a Likert-type response scale. The three levels of control are as follows:

Well controlled. Well controlled is defined by the NHLBI as:

> Symptoms less than or equal to 2 days/week; nighttime awakenings $\leq$ 2x times/month; no interference with normal activity; short-acting $beta_2$ agonist use for symptom control less than or equal to 2 days per week; lung function greater than 80% predicted/personal best; and exacerbations requiring oral systemic corticosteroids 0–1/year. (2007, p. 76)

Not well controlled. Not well controlled is defined by the NHLBI as:

> Symptoms greater than 2 days/week; nighttime awakenings 1 to 3 times/week; some limitation with normal activity; short-acting $beta_2$ agonist use for symptom control greater than 2 days/week; lung function 60% to 80% predicted/personal best; and exacerbations requiring oral systemic corticosteroids greater than or equal to 2 times per year. (2007, p. 77)

Very poorly controlled. Very poorly controlled is defined by the NHLBI as:

> Symptoms present throughout the day; nighttime awakenings greater than or equal to 4 times per week; extremely limited normal activity; short-acting $beta_2$ agonist use for symptom control several times per day; lung function less than 60% predicted/personal best; and exacerbations requiring oral systemic corticosteroids greater than or equal to 2 times per year. (2007, p. 77)

During the data collection phase the PI monitored the number of participants entering the well controlled, not well controlled, and very poorly controlled categories. The original plan was to divide the sample into three categories by gender with 20 participants in each of the categories (i.e., well controlled, not well controlled, and very poorly controlled); however, the number of participants for the not well controlled and very poorly controlled categories was small and did not provide adequate numbers for both of those categories. Therefore, the PI decided that the ACT's recommendation to contact a doctor for a total score of 19 and under would be used to differentiate between well controlled and not well controlled (Nathan et al., 2004). All participants with scores 19 and under then were collapsed into the not well controlled category. Participants with scores of 20 to 25 were classified as well controlled. The final asthma impairment categories consisted of 55 well controlled (35 males and 20 females) and 78 not well controlled (30 males and 48 females).

Nathan et al. (2004) initially reported the reliability and validity of the ACT with an internal consistency reliability of .84 and correlation between ACT and specialist's ratings at 0.45, $p = .0001$. Schatz, Clark, and Camargo (2006) reported further reliability and validity in patients not previously followed by specialists, with reliability at baseline 0.85 and 0.79 at a follow-up visit. Schatz et al. (2006) also observed fairly strong correlations between ACT scores and specialists' ratings ($r = 0.52$, $p < .001$). The ACT has been used to evaluate adolescents at risk for poorly controlled asthma (Nathan et al., 2004). The reliability of ACT scores was 0.82, sensitivity and specificity was 70% and 77%, respectively, and correct classification of patients was 74% (Nathan et al., 2004).

The investigator obtained routine pulmonary function test (PFT) results (i.e., spirometry), heights, and weights from the medical records of the Children's Hospital High Risk Asthma Clinic participants and used that objective data for concurrent validity of the self-reported ACT. The spirometry results revealed airway narrowing and obstructions which would produce symptoms that should be self-reported in the ACT. The investigator obtained the following spirometry results from the participant's medical record: (a) FEV_1, (b) forced vital capacity (FVC), and (c) FEV_1 /FVC. Initially, the study investigator planned that fractional exhaled nitric oxide levels would be obtained on each of the Children's Hospital High Risk Asthma Clinic participants. The fractional exhaled nitric oxide reflects inflammation of the bronchial mucosa, helps to distinguish those patients who do or do not have asthma, and assists in determining asthma severity; however, the clinic discontinued that procedure during the course of this study. Therefore, the fractional exhaled nitric oxide result was not included in data collection. The director of the Children's Hospital High Risk Asthma Clinic (who was also a consultant for the study) assisted the PI in analyzing the spirometry with the self-reported ACT results.

Asthma self-management. Asthma self-management (symptom management, medication management, and environmental control) was measured through the ASCPI (Fitzpatrick & Frey, 1993). The original 21-item instrument was designed to measure asthma self-care practices of children and adolescents and has four subscales: symptom management (12 items), medication management (6 items), environmental control (2 items), and general asthma self-management (1 item). The participants self-care practices are measured according to the percentage of time participants perform the behaviors. A ratio scale of 0% to 100% was used for each item to indicate the percentage of time the behavior was performed. A panel of physicians and pediatric nurses established content validity for the original instrument. Total scale alphas in previous studies ranged from 0.87 to 0.89 (see Figure G1).

The PI revised the ASCPI (Fitzpatrick & Frey, 1993) during PhD course work and independent work with faculty sponsor. Refinement of the instrument included the addition of four environmental control questions, five medication management questions, and one general self-management question. The refined instrument, therefore, included a total of 31 questions: 12 symptom management items, 11 medication management items, 7 environmental control items, and 2 general self-management items. Although participants in this study completed the full revised ASCPI, the PI did not include the self-management subscale data in the statistical analyses. Since the total score from the ASCPI included the two general self-management questions, the PI did not use the ASCPI total as a total self-management behaviors score. Instead, the PI used the three subcategories of symptom management, medication management, and environmental control as subscales and analyzed participants' responses to each subscale statistically.

The investigator scored the symptom management, medication management, and environmental control subscales following the instructions of the original instrument. The PI altered the format so the ratio scales were viewed under each question. A total score for the original instrument was achieved by summing the items, and a higher total score indicated a greater level of asthma self-management. The total score for each of the three subscales (symptom management, medication management, and environmental control) was obtained by summing the items for that scale. A higher total score for each of the three subcategories indicated a greater level of that specific self-management behavior.

The PI piloted the revised instrument for clarity of instructions and questions as well as the length of time to complete the instrument. Five adolescents (14–16 years of age, three females and two males) completed the instrument. According to their responses to questions and feedback about the instrument, the PI revised several questions further.

Piloting the instrument also provided feedback on the length of time it would take to complete the instrument. Completion times ranged from seven to nine minutes.

The investigator conducted psychometric testing during the study in order to determine if the adapted ASCPI had adequate reliability. The ASCPI used a 0% to 100% ratio scale that was located only in the instructions of the instrument, creating the potential for more measurement error (Dillman, 2007). The PI altered the format so the ratio scales were viewed under each question.

Internal consistency reliability of scales was evaluated based on several statistical analyses. They include Cronbach's alpha and inter-item correlations. The desired level of Cronbach's alpha and Cronbach's alpha with standardized items is 0.7 to 0.8 (Field, 2005). Inter-item correlations should range from 0.30 to 0.70 (Ferketich, 1991; Netermeyer, Bearden, & Sharma, 2003).

Gender

Gender was operationalized by self-report on the demographics form (Appendix I). One question had a heading of gender and asked the participant to place a checkmark to identify himself or herself as male or female.

Illness Representations

Illness representations were operationalized by the measures of cognitive and emotional representations in the IPQ-R (Moss-Morris et al., 2002). The original IPQ, designed to investigate only the cognitive components of patients' representations, limited its capacity to describe patients' responses to illness. Therefore, the PI added the measurement of the emotional representations to the IPQ-R by Moss-Morris et al. (2002; see Figure H1). The investigator chose the revised instrument because the reliability of the subscales was improved and the opportunity to measure emotional representations was incorporated. The IPQ-R includes 56 questions with Likert-scale type 5-point responses that are related to causes of asthma, how the person views his/her asthma, and emotions exhibited as a result of asthma. The Likert scale uses the anchors: *strongly disagree*, *disagree*, *neither agree nor disagree*, *agree*, and *strongly agree*. The cognitive illness representations measured by the IPQ-R are identity, timeline, consequences, control, cause, and illness coherence (Moss-Morris et al., 2002). The emotional illness representations are measured by one emotional representations subscale. There is no total IPQ-R score and research supported the six cognitive illness representations subscales as six constructs rather than one construct (Moss-Morris et al., 2002). The illness representations for two of the constructs, timeline and control, are categorized further for measurement into acute/chronic and cyclical timeline subscales and personal and treatment control subscales (Moss-Morris et al., 2002). The causes construct is measured by two sections of the IPQ-R. First, the participant responds to 18 causal items using the Likert-type format of the scale. In the second section, the individual writes three primary causes of his or her asthma, either selecting from one of the 18 causal items provided or self-identifying the causes.

Cognitive and emotional illness representations subscales. There are eight cognitive illness representations subscales and one emotional illness representations subscale. The subscales are described in Table 2.

Table 2

Cognitive and Emotional Illness Representations Subscales

Subscale	Items	Description
Identity	28	The subscale requires a yes-no response to whether 14 symptoms had been experienced and whether the symptoms were related to asthma. Therefore, the participant provides a total of 28 responses. The total score is comprised of only the yes responses to symptoms related to asthma.
Acute/Chronic Timeline	6	The participant's perceived chronicity of the illness is assessed, whether asthma is an acute or chronic illness.
Cyclical Timeline	4	This subscale focuses on variations in the participant's asthma condition and whether the individual's asthma is perceived as cyclical or episodic in nature.
Consequences	6	The perceptions of the functional, social, psychological, and economic consequences of having asthma are identified.
Personal Control	6	The extent to which the participant believes the condition is amenable to her/his control is measured.
Treatment Control	5	Beliefs in medical treatments for an individual's conditions and treatment outcomes are measured through the treatment control subscale.
Causes	21	There are two sections, the 18-item causes subscale and the participant's identification of the three most important factors believed to cause her or his asthma.
Emotional	6	The questions relate to such emotions as fear, anger, distress, and anxiety.

Moss-Morris et al. (2002) added illness coherence to the revised instrument to represent a dimension of how much patients understand or comprehend their illness; however, illness coherence was not a cognitive illness representation that was included in Leventhal's model and the theoretical framework for this study. Although participants completed the full IPQ-R scale, the illness coherence subscale data was not analyzed in the study.

Reliability and scoring of the IPQ-R. Cronbach's alpha for each of the subscales ranged from 0.75 to 0.89 (Moss-Morris et al., 2002). Internal consistency (Cronbach's alpha) was performed for this sample as outlined by DeVellis (2003). A version of the IPQ-R that phrases the questions for asthma patients further supported the use of the IPQ-R for this study (see Figure H1). As with the chronically ill adolescents in the current study, the IPQ-R has been used to study the illness representations of a variety of chronically ill patients including adolescents with diabetes. The author of the instrument provided instructions for scoring the IPQ-R and included guidelines for the items that are reverse-scored. High scores on the identity, timeline, consequences, and cyclical dimensions represent strongly held beliefs about the number of symptoms attributed to the illness, the chronicity of the condition, the negative consequences of the illness, and the cyclical nature of the condition. High scores on the personal control, treatment control, and coherence dimensions represent positive beliefs about the controllability of the illness and a personal understanding of the condition. Instead of a total score for the 18-item causal dimension, Moss-Morris et al. (2002) recommended factor analysis of the responses. In their study, principal computing analysis was used and the items loaded into four factors: psychological attributions, risk factor, immunity, and accident or chance.

Sociodemographic Questions

The following information was obtained through the demographics document (Appendix I): self-reported birth date, educational level, site of primary care for asthma (e.g., general physician's office, health department clinic, specialist's office, or ED), whether the participant completed a formal asthma education program (and if so, when, where, and how long it lasted), whether the adolescent smoked, whether smoking was permitted in the home or car, level of hunger, relative with whom the adolescent lived, and the parent or guardian's education and general income. Because most adolescents do not know the exact income of parents, the demographics questionnaire measured family income by a question with these potential responses: *have enough*, *just enough*, or *more than enough money* for food and housing. The survey obtained zip codes with the addresses so the characteristics of the participants' counties could be described (see Appendix J). The descriptions of the counties included the population by gender and age, educational levels, employment settings, and air quality indexes.

Pulmonary Function

In addition to the previously described information, the investigator obtained objective data routinely assessed during clinic appointments from the medical records of the Children's Hospital High Risk Asthma Clinic participants including results from the spirometry (PFTs): (a) FEV_1, (b) FVC, and (c) FEV_1 /FVC. In addition, the investigator obtained heights and weights from the adolescents' records. Those measures were examined with the Children's Hospital High Risk Asthma Clinic participants to provide concurrent validity of the self-reports of asthma impairment in the ACT. The Clinic's director assisted the PI to analyze the pulmonary function and ACT data for concurrent validity of the self-reports.

Protection of Human Subjects

Information in this section describes actions that the investigator took or procedures put into place for the protection of human subjects.

Human Subject's Involvement and Characteristics

The PI obtained human subject approval through the Indiana University–Purdue University Indianapolis/Clarian IRB May 4, 2010 (Appendix E). Because the study was designed for adolescents 14–16 years of age, the investigator followed the IRB procedure for obtaining consent for minor subjects and asked the parent or guardian to sign the consent. In addition, each adolescent signed an assent form to assure that he/she was willing to participate and was not being coerced.

Recruitment and Informed Consent/Assent

In order to protect subjects through the recruitment and data collection process, the PI identified specific actions. First, approval from the school corporation superintendent at each of the sites was obtained. The school administrator (principal) designated the site liaison and approved the date for data collection. Second, liaisons for the school and clinics were oriented. Once the PI obtained IRB approval, a liaison for each site was contacted and orientation was conducted related to the study, data collection protocol, recruitment protocol, HIPAA, Federal Education Rights and Privacy Act, and issues related to protection of human subjects.

The PI created recruitment procedures for the schools and sent a flyer (Figure C1) and brochure (Figure C2) describing the study and eligibility to potential participants (African Americans who were 14–16 years of age) to the liaison (i.e., school nurse or administrator's designee). The documents included the Pl's telephone number and e-mail address as contact information to learn more about the study. When the adolescent or parent called, the PI reviewed the eligibility criteria and obtained a mailing address and phone number. The PI followed-up on e-mails by requesting a phone number so information could be shared with the potential participant and his/her parent(s) or guardian(s). The PI sent the family a parental consent form and an adolescent assent form then followed-up with a telephone call within the next week to address any questions about the study or consent/assent forms. The PI reviewed the following sections of the consent/assent forms with the adolescent and his or her parent(s)/guardian(s): (a) purpose of the study, (b) number in study, (c) procedures, (d) risks of the study, (e) benefits of the study, (f) alternative to participation, (g) confidentiality, (h) cost, (i) payment, (j) compensation for injury, (k) contacts for study, and (l) voluntary participation in the study. Participants were informed that both the parent and the adolescent needed to agree on study participation. The PI also informed participants about the date that the PI would be at their schools to obtain the completed consent/assent forms and to collect data.

Recruitment from the clinics occurred in the following manner. The liaison notified the PI on a weekly basis of the days when a large number of African American adolescents with asthma in the study’s specified age range would be seen. The PI attended clinic on those days. Clinic staff asked adolescents and parents if they were willing talk with the PI about the study. If verbal permission was granted, the PI discussed the study with adolescents and parents and obtained consent/assent before data collection. Participants were informed that both the parent and the adolescent needed to agree on study participation.

Recruitment from the community proceeded in the following manner. When the adolescent or parent called, the PI reviewed the eligibility criteria and obtained a mailing address and phone number then sent the family a parental consent form and an adolescent assent form. The PI followed-up with a telephone call within the next week to address any questions about the study or consent/ assent forms. The PI reviewed the following sections of the consent/assent forms with the adolescent and his or her parent(s) or guardian(s): (a) purpose of the study, (b) number in study, (c) procedures, (d) risks of the study, (e) benefits of the study, (f) alternative to participation, (g) confidentiality, (h) cost, (i) payment, (j) compensation for injury, (k) contacts for study, and (l) voluntary participation in the study. Participants were informed that both the parent and the adolescent needed to agree on study participation.

Data Collection Protocol

Data collection in the schools and center/clinic proceeded in the following manner. First, the PI screened each participant for inclusion criteria and if criteria were not met thanked the adolescent for his/her interest in participating in the study. If the adolescent met the inclusion criteria, the PI collected asthma impairment data to categorize them into one of three impairment groups. Data collection continued with the adolescent in a face-to face meeting. During the face-to-face meeting, the PI asked the participant to complete a paper-and-pencil version of the remaining instruments. The PI was available to address questions, interpret meaning of words, or to read the items if necessary. However, consideration of being supportive but not coercive was maintained during all communication with participants. Those completing all data collection received a total incentive of $20.00 in the form of a gift card.

Data collection of participants recruited from the community proceeded in the manner described for school and center/clinic participants; however, the PI and/or parent/guardian identified a public location such as a public library, church, or community center that had to be agreed upon by the parent(s) or guardian(s) and the PI.

A private place within the public facility was identified for data collection. Those participants completing all data collection instruments selected a $20.00 gift card from Wal-Mart or Target.

Privacy and Confidentiality

The PI met participants from the schools, centers/clinics, and community face-to-face in a private location for data collection. The design of the questionnaires was such that the participant read and marked questions. Furthermore, the instruments contained identification numbers rather than names. Only the PI handled data and not school or clinic personnel, and the investigator transported collected data immediately to locked files and kept in a locked office at the PI's place of employment.

The PI followed HIPPA guidelines in the schools and clinics. The investigator also completed any additional responsibilities required to conduct research within the committed school corporations.

Data Collection Material and Storage

The PI collected data through several questionnaires as outlined previously in the Methods section. The data collection lasted approximately 25–30 minutes. The investigator entered data into a database stored in a password-protected computer. The PI assigned codes to the data forms so no names were associated with the data. The data were being collected specifically for this study; therefore, the data will not be publicly available. However, the findings of the study will be shared with the public through publications.

Potential Risks

The study had slight psychological and emotional risk because the participants have asthma and the PI asked them to respond to questions. Adolescents have the potential to be embarrassed if they cannot read the questionnaire or if they feel as though they are taking too long to complete the questionnaire. There is also the potential for feeling slightly anxious about their responses to the questions. The researcher used the following strategies to minimize the risks: (1) thoroughly explained everything to each participant; (2) emphasized voluntary participation; (3) conducted the interview in a respectful, nonjudgmental manner; and (4) repeated or explained information when necessary. There was also a risk for loss of confidentiality. The investigator put strategies into place to decrease the potential for loss of confidentiality. For example, without identifying the rationale for absence from a class, a school liaison accompanied the identified student to a private area for data collection on the designated day. Another strategy related to the consent forms: the PI stored consent forms separate from the questionnaires. The investigator coded the questionnaires with identification numbers and kept them in locked file cabinets and the data in a password-protected computer. All identifying data will be kept for at least seven years after the conclusion of the study.

Potential Benefits of the Proposed Research to the Subjects and Others

The researcher had a written statement to acknowledge the time taken to participate in the study. Additionally, participants were exposed to questions about their thoughts, beliefs, and emotions regarding their asthma. The investigator asked questions about how well participants managed asthma symptoms, medication, and their environments. These questions might have increased participants’ awareness of their beliefs, emotions, and self-management behaviors. The researcher reinforced the adolescent's contribution to understanding African American adolescents' illness representations, self-management behaviors, and how that information will influence future nursing interventions.

Risk/Benefit Ratio

The risks to the subjects were minimal in comparison with increasing knowledge about illness representations and asthma self-management of African American adolescents. Asthma is a significant public health problem among African American adolescents. This study provided an understanding of the association of illness representations with asthma self-management among African American adolescents. This understanding will guide the development of patient-centered interventions for African American adolescents with asthma. The study employed the use of self-reported questionnaires. Since the questions are personal, some participants could have felt uncomfortable in talking about beliefs, illness, or why their self-management is inadequate. The researcher discussed the packet of questionnaires in a professional manner and continued to observe the participants for signs of increased anxiety or discomfort through body language and mannerisms while they completed the questionnaires. The risks to participants were reasonable in relation to the importance of the knowledge about illness representations and asthma self-management behaviors that are expected to result.

Inclusion of Women and Minorities

The sample included 133 African American adolescents (65 males and 68 females), with males and females recruited equally for the study. The research aims addressed one racial/ethnic group (African Americans) and proposed to fill a research gap on African American adolescents with asthma. Therefore, other races were excluded from the study.

Inclusion of Children

The study focused on the illness representations and self-management behaviors of African American adolescents (14–16 years of age) with asthma. Selection of that age range was based on several factors: (a) Although adolescents have one of the lowest rates of office visits, hospitalizations, and ED visits, they have one of the highest rates of mortality; (b) Relative to all racial and ethnic groups, African American adolescents have the highest prevalence of asthma as well as higher rates of ED visits, hospitalizations, and deaths; (c) Inadequate self-management is a significant problem in adolescence; (d) Adolescents in the 14–16 years of age range are developing self-management behaviors that will be used to manage their asthma during adulthood; and (e) Few studies have been conducted solely on adolescents with asthma and even fewer studies have been conducted on African American adolescents.

The researcher possesses the educational and clinical preparation to conduct a study with adolescents. The researcher has a master's degree in child health and clinical experience with adolescents with asthma (see Curriculum Vitae).

Data Analysis

The investigator used paper copies of the instruments for data collection. The PI transferred data collected during the interview to a computerized database then verified data for accuracy by comparing the computerized data with the paper copy of the data. The PI reviewed scales for missing data and deleted no subjects or scales because of missing data. The PI used the Statistical Package for the Social Sciences (SPSS), version 19.0, for all data analyses for the study and performed descriptive statistics on all of the variables. For example, the investigator ran frequencies on impairment and gender as well as a bivariate distribution for gender and impairment. In addition, the PI calculated means, standard deviations, and ranges for all continuous variables within each of the six gender/impairment combinations. The investigator assessed internal consistency reliability of scales and subscales using Cronbach's alpha. This section provides descriptions of the data analysis, and Chapter IV presents the results.

Analysis for Validity of ACT with Lung Function

Pearson Correlations were the statistical analysis used to analyze the relationship of the ACT and lung functions. The investigator used the asthma impairment scores, interval data obtained through the ACT, as the basis for the Pearson Correlations. Lung function tests included: (a) FEV_1, (b) FVC, and (c) FEV_1 /FVC. The PI analyzed those measures with the results of the ACT (asthma impairment scores) to provide concurrent validity of the self-reports of asthma impairment in the ACT.

The PI closely monitored the gender and asthma impairment of the participants on an ongoing basis and made every effort to obtain 20 participants per gender-impairment group. However, the investigator excluded no participants who met the inclusion criteria. It was anticipated that those with poorly controlled asthma would be fewest in number. The PI also anticipated that the County ACTION Center and the Children's Hospital High Risk Asthma Clinic participants would have more poorly controlled asthma. The investigator planned that if by December 31, 2010, sufficient numbers of adolescents with poorly controlled asthma were not obtained, the co-sponsor would assist the PI in collapsing the data into two asthma impairment groups (well controlled and not well controlled). The PI extended the date to May 30, 2011, in order to increase the number of participants and for the potential of increasing the numbers in each impairment group. However, the PI was unable to obtain sufficient numbers of adolescents with poorly controlled asthma; therefore, the sample was collapsed into two asthma impairment groups (well controlled and not well controlled).

The study had two specific aims and seven research questions. The following information describes the analysis for each aim; however, Chapter IV presents the results.

Specific Aim 1: To explore differences in illness representations (cognitive and emotional) and self-management behaviors (symptom management, medication management, and environmental control) by gender, asthma impairment (well controlled and not well controlled), and gender by asthma impairment among African American adolescents (aged 14–16 years) with asthma.

The investigator conducted the data analyses for this aim using Two-way Analysis of Variance (ANOVA) and Multivariate Analysis of Variance (MANOVA). ANOVA is used to test the equality of means among several variables and the interaction of pairs of factors (Norusis, 2010; Tabachnick & Fidell, 2007). Therefore, ANOVA was appropriate to analyze differences in means of the illness representations (cognitive and emotional) by gender, asthma impairment, and the interaction of gender by asthma impairment. The cognitive illness representations are comprised of five separate constructs and Factorial ANOVA was used to analyze differences in the means of each construct as well as gender, asthma impairment, and the gender by asthma impairment interaction (Norusis, 2010; Tabachnick & Fidell, 2007). MANOVA is an analysis that facilitates the examination of the differences among groups (Munro, 2001; Tabachnick & Fidell, 2007). MANOVA was used with self-management behaviors as one construct with three dimensions (symptom management, medication management, and environmental control). It supported the examination of mean differences in self-management behaviors among gender and asthma impairment groups as well as the interaction of gender and asthma impairment.

Specific Aim 2: To explore relationships between illness representations (cognitive and emotional), asthma self-management behaviors (symptom management, medication management, and environmental control), gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma. The Pearson product-moment correlation is used to measure relationships between variables (Tabachnick & Fidell, 2007). It is appropriate that Pearson correlations were calculated to determine relationships between the illness representations variables and asthma self-management variables. Multiple regression analyses are used to assess the relationships between several independent variables and a dependent variable (Munro, 2001; Tabachnick & Fidell, 2007). Therefore, multiple regression analyses were used to explore associations between each self-management behavior (symptom management, medication management, and environmental control) and the set of cognitive representations (identity, timeline, consequences, cause, and control), emotional representations, gender, and asthma impairment. Each of the three asthma self-management variables was modeled separately to explain the interrelationships among the self-management, illness representation, gender, and asthma impairment variables. The assumptions of multiple regression analysis were considered, as identified by Tabachnick and Fidell (2007) and Pallant (2010). According to Tabachnick and Fidell (2007), the sample size needed can be calculated with the formula, $N \geq 50 + 8m$, m = number of independent variables). The sample size needed for this regression analysis is 50 + 8m, $m = 10$, so $N = 130$. However, the sample size of 133 was not large enough to include gender by asthma impairment interaction as an independent variable in the analysis, but gender and asthma impairment were included as independent variables.

Summary

Chapter III presented the design of the study; research aims; settings, sampling, and recruitment; protection of human subjects; measures; data collection procedures; description of setting; and plans for data analysis. Chapter IV will present the results of the data analyses.

CHAPTER IV RESULTS

This chapter contains the results of the analyses conducted and guided by the conceptual framework presented in Chapter I. The first section contains descriptions of data screening and cleaning procedures conducted prior to data analyses. The second section provides descriptions of the setting, sample, and variables. The third section presents the results specific to each aim and research question. The investigator used SPSS, version 19.0, for all statistical procedures in this study.

Data Screening and Cleaning Procedures

Data were screened with SPSS 19.0 for completeness, out of range scores, and presence of outliers. Data were screened for 133 cases (participants). The analysis of missing data, descriptive statistics, means, standard deviations, ranges, and normality are described in the sections below. As identified in the subheadings, the management of missing data, skewness, kurtosis, and outliers were determined according to the recommendations of the statistical resource.

Missing Data

Less than 5% of the data was randomly missing from various scales. A total of 1.5% of the data was coded as missing from the demographics form. Two participants did not complete the year of diagnosis question. Those participants were adopted and the legal guardian did not know the required information. Data were missing for four cases, (3.2% of data) from the IPQ-R scale, two cases (1.6%) from the identity subscale, one case (0.8%) from the timeline (acute/chronic) subscale, and one case (0.8%) from the personal control subscale. Those responses were considered as randomly missed during completion of the instruments. No systematic pattern of missing data was identified.

Missing data were dealt with by using the *exclude cases pairwise* option in SPSS 19, which "excludes the case (person) only if they are missing the data required for the specific analysis" (Pallant, 2010, p. 58). The cases were "included in any of the analyses for which [investigator has] the necessary information" (Pallant, 2010, p. 58). No missing data were identified for the ACT or the ASCPI. Missing data for the study were decreased because the participants completed the instruments in the presence of the PI. Although the participants did not request further guidance after reading the instructions, the investigator always explained that questions could be clarified for them. The effort to clarify information for the participants and the presence of the PI potentially decreased the number of questions that would have been left blank.

Normality and Distribution

The investigator conducted measures of normality and frequency distributions to assure that assumptions assessed for all independent and dependent variables were met. Descriptive statistics, means, medians, standard deviations, and ranges were examined for the continuous variables and subscales. Normality was assessed by inspection of histograms and the K-S test based on normality, if the significant value was > .05.

The histogram for the emotion subscale for illness representations was moderately positively skewed and had a skewness level of .721. Transforming the positively skewed emotion scores was considered as suggested by Tabachnick and Fidell (2007). However, this scale has not been used frequently with adolescents and particularly adolescents with asthma. The PI, therefore, made the decision to retain the scores and interpret the original scores (J. Wu, personal communication, June 7, 2011). Also, Tabachnick and Fidell (2007) emphasized that if a variable is only moderately positively skewed, a square root transformation could make the variable moderately negatively skewed. Therefore, there would be no advantage to transformation.

Positive kurtosis was identified in the histogram for the environmental control subscale and at the kurtosis level of .828; however, it had a K-S significance value of .08. According to Tabachnick and Fidell (2007), underestimates of variance associated with positive kurtosis disappear with samples of 100 or more. This sample had 133 participants.

The K-S test of normality indicated normality in the consequences subscale (.059), symptom management subscale (.200), and medication management subscale (.200). Violation of the assumption of normality ($p < .05$) as indicated by the K-S test was identified in the remainder of the scales. Therefore, normal probability plots were inspected for the identity, acute/chronic timeline, personal control, treatment control, timeline cyclical, emotion, and environmental control subscales. A reasonably straight line had been generated for all of the scales, suggesting a normal distribution (Pallant, 2010).

Further analysis of the distribution of scores was through boxplots. The boxplots were used to detect specific outliers identified with the scales. The largest number of outliers was identified with the cyclical timeline subscale for the IPQ-R scale. There were four cases with higher values and eight cases with lower values. The Factor 1-causes subscale (psychological attributes) yielded the second highest number of outliers. Six cases had higher values that were outside of the boxplot, and one case had a lower value. The scales with the other two outliers were the acute/chronic timeline for the IPQ-R scale (one outlier) and the symptom management subscale (one outlier). Each outlier was analyzed to assure no error in recording of the data or a participant not following the instructions on the questionnaire (Munro, 2001). As recommended by Tabachnick and Fidell (2007), the outliers were analyzed for possible deletion or transformation; however, most of the variables were related to IPQ-R subscales. Since that scale has not been used with adolescents with asthma and the ranges of scores could not be compared with other studies, the investigator decided to retain all of the outliers. The impact of outliers will be further considered with the analysis of each research question.

Description of Settings, Samples, and Variables

Settings

Participants were recruited from eight settings. Table 3 reflects the settings where the highest number of participants was obtained. The settings are listed in rank from highest to lowest according to the number of participants recruited from that setting.

Table 3

Settings Ranked by the Number of Participants Recruited

Site	# of Settings	Rank
School corporations	5	1
Clinics	2	2
IMHC affiliates	10	3
Community events	9	4
Pediatricians	5	5
Churches	12	6
Community organizations	19	7
Community agencies	3	8

Setting Characteristics by Counties

Recent asthma disparities studies have indicated differences in asthma outcomes as a result of racial and ethnic minority status, socioeconomic status, exposure to indoor and outdoor allergens, residence in inner city versus rural communities, residence in farm versus nonfarm communities, and the air quality of the community (Grineski, 2008; Weiss, 2007; Wright & Subramanian, 2007). Although all of these factors will not be explored in the aims of this study, Appendix J has been included to describe the counties represented by the sample. The 133 participants in the sample were recruited from 11 counties. The tables in Appendix J provides a broader characterization of the sample depicting the diversity in the populations, housing units, income, education, employment settings, and air quality for the counties.

Sample

A total of 133 participants (63.6%) were enrolled out of the 209 adolescents approached for recruitment for the study (see Table 4). Nineteen of the participants were ineligible as a result of not meeting the eligibility requirements; they were either younger than 14 years of age, older than 16 years of age, or had not used asthma medication within the previous 12 months. Fifty-seven potential subjects declined to participate prior to signing the consent/assent forms; those adolescents or parents contacted the PI and initially expressed interest in participating but did not complete the data collection process. Reasons for not participating included: The parent did not agree for the adolescent to participate; The adolescent did not want to participate; The family schedule did not permit time for data collection; and The participant and/or parent had concerns about participation in a research study. One adolescent wanted to participate but the parent expressed the concern that a research study was for guinea pigs and the daughter was not a guinea pig. Other evidence of declining to participate was recognized through adolescents and parents who scheduled the time for data collection but did not arrive for the appointment and did not return calls about rescheduling. The recruitment efforts resulted in 133 subjects enrolled in the study.

Table 4

Recruitment of Subjects

Category	# Represented (%)
Total number of subjects who consented	133 (63.6%)
Total number of subjects who failed screening	19 (9.1%)
Total number of potential subjects who declined to participate	57 (27.3%)

Sample Characteristics

The characteristics of the sample are presented in Table 5. The sample was comprised of 133 African American adolescents with asthma who met the criteria of being 14–16 years of age (*M* = 15 years, 2 months). The sample was almost equal according to gender: 51.1% males and 48.9% females. Grades 9 (32.3%) and 10 (33.1%) were the primary grade levels. Over 50% of the sample received their care at a general doctor’s office. Of note is the 6% who received most of their asthma care through the ED.

Table 5

Sample Characteristics

Demographics	*n*	Frequency (%)
Gender		
Male	65	48.9
Female	68	51.1
Race		
African American	133	100.0
Grade		
7	1	0.8
8	30	22.6
9	43	32.3
10	44	33.1
11	14	10.5
12	1	0.8
Sites of care		
General doctor	72	54.1
Health department	18	13.5
Specialist	34	26.3
ED	8	6.0

As depicted in Table 6, the marital status of the parents was dispersed among five categories with the two highest being married (34.6%) and never married (26.3%). The majority of the adolescents reported living with their mothers (54.1%) followed by those who lived with both parents (39.1%).

Table 6

Parents' Marital Status, Living Arrangements, Parents' Education

Demographics	*n*		Frequency (%)	
Parents' marital status				
Married	46		34.6	
Divorced	22		16.5	
Never married	35		26.3	
Separated	24		18.0	
One or both parents have died	6		4.5	
Lives with				
Mother	72		54.1	
Father	4		3.0	
Both parents	52		39.1	
Guardians	1		0.8	
Other	4		3.0	
Education level completed				
	Mother	Father	Mother	Father
Grade 11 or less	14	16	9.8	12.1
High school diploma	55	50	41.4	37.6
Associate/vocational degree	28	10	21.0	7.5
Bachelor's or higher	30	23	22.6	17.3
I don't know	7	34	5.3	25.6

The completion of high school was the highest category for the level of education for mothers and fathers. The questions about the number of days that the family went hungry and the family's money for living were asked in order to obtain proxy information about the family's income level. Three of the participants reported days when the family went hungry. Although the predominate response was that the family had just enough money (71.4%), 13.5% of the sample indicated that the family did not have enough money. It was the perception of 15% of the sample that they had more than enough money.

The prevalence of first- and second-hand smoke among the participants was assessed and the findings are presented in Table 7. Seven of the participants indicated that they occasionally smoked. The smokers in the home ranged from zero (63.2%), one (20.3%), two (12.8%) to three (3.7%). None of the participants identified having four or more smokers in the home. Most of the participants reported that smoking was not allowed in their homes or cars.

Table 7

Prevalence of Smoking

Demographics	*n*	Frequency (%)
How often you smoke		
Never	126	94.7
Occasionally	7	5.3
Daily	0	0.0
Number of smokers in the home		
0	84	63.2
1	27	20.3
2	17	12.8
3	5	3.8
≥4	0	0.0
Smoking options in the home		
No smoking allowed	95	71.4
Smoking permitted in section of home where I rarely go	25	18.8
Smoking is allowed in any common room	13	9.8
Smoking in the car		
No smoking allowed	98	73.3
Smoking permitted if windows down	27	20.3
Smoking allowed in car	8	6.0

The participants were requested to indicate the year they were diagnosed with asthma. The investigator conducted an analysis of that data to determine the number of years between the participant's diagnosis and the date of data collection for the current study. Those results reflected a range of 1 to 16 years since diagnosis, with a mean of 10.83 years since the asthma diagnosis and standard deviation of 4.679 (see Table 8).

Table 8

Years between Participant's Asthma Diagnosis and Completion of Study Instruments

Years	Frequency	Valid %	Cumulative %
1	7	5.3	5.3
2	4	3.1	8.4
3	5	3.8	12.2
4	4	3.1	15.3
5	4	3.1	18.3
6	2	1.5	19.8
7	4	3.1	22.9
8	7	5.3	28.2
9	4	3.1	31.3
10	9	6.9	38.2
11	12	9.2	47.3
12	4	3.1	50.4
13	13	9.9	60.3
14	21	16.0	76.3
15	16	12.2	88.5
16	15	11.4	100.0
Missing	2		

Of note is the percentage of participants diagnosed 13 to 16 years previous to the study (40%) that would indicate for a sample of 14- to 16-year-olds their diagnosis was made while they were infants and toddlers. The time since diagnosis is important because illness representations could be influenced by the number of years of having the illness. The years since diagnosis also could impact adolescents' self-management behaviors, especially if asthma management was emphasized with the parents during early diagnosis but not reinforced during adolescence.

Self-Management

Overall self-management and responsibility for management were assessed by two self-management questions on the ASCPI. Those questions were not included in the scores for subcategories (symptom management, medication management, and environmental control) that were analyzed for this study. These responses to the self-management questions are presented in Tables 9 and 10.

Table 9 captures the participants' responses to the following question: What percentage of your total asthma care (the things you do to take care of your asthma) are you yourself responsible for? The mean for the responses was 60.98 with a median of 80.00 and a possible range of 0%–100%. Thirty (22.55%) of the adolescents circled that they were responsible for 100% of their total asthma care. Eighty-two (61.65%) of the participants said they were responsible for 70%–100% of their total care. At the lower end of the range, 40 adolescents (30%) responded that they were responsible for 50% or less of their total care.

Table 9

Responsibility for Total Care

Demographics (%)	*n*	Frequency (%)
0	4	3.0
10	2	1.5
20	3	2.25
30	6	4.51
40	12	9.02
50	13	9.77
60	18	13.53
70	13	9.77
80	18	13.53
90	21	15.78
100	30	22.55

The "Practical Guide for the Diagnosis and Management of Asthma: Expert Panel 3 Report" (NHLBI, 2007) recommended that all people with asthma should receive a written asthma action plan to guide their self-management efforts. An asthma action (management) plan provides instructions and information on how to manage asthma symptoms on a daily basis, including exacerbations and the need for emergency care. The individualized plan also includes how to take medication appropriately and guidance on allergens and environmental irritants (NHLBI, 2007).

Table 10 depicts the participants' response to the question that asked: What percent of the time do you follow an asthma management plan? The mean response was 40.98% of the time, and the median was 50% of the time. Fifty-three (40%) of the participants either said they never followed or did not have an asthma management plan. Fifty-three (40%) of the participants who responded to following their asthma management plan did so 50% of the time or more.

Table 10

Asthma Self-management Plan

Demographics (%)	*n*	Frequency (%)
0	34	25.6
10	8	6.0
20	8	6.0
30	6	4.5
40	5	3.8
50	15	11.3
60	5	3.8
70	6	4.5
80	9	6.8
90	7	5.3
100	11	8.3
I don't have one	19	14.3

Variables of Interest

The variables of interest were asthma impairment, gender, illness representations, and asthma self-management behaviors. Descriptive statistics are presented in the following sections for all of the variables.

Gender. The participants self-identified gender on the demographics form. The sample was comprised of 65 males (48.9%) and 68 females (51.1%).

Asthma impairment. The asthma impairment levels of participants were measured through the ACT instrument. Frequencies and descriptive statistics for the ACT and asthma impairment variable are presented in Table 11. The ACT provides a total score as well as differentiates in the level of impairment as well controlled, not well controlled, and poorly controlled asthma (Nathan et al., 2004). The possible range of scores was 5–25 and the group's total scores ranged from 9–25 (males = 12–25; females = 9–25). The mean for the total ACT score was 18.44 (males = 19.82; females = 17.13) with a standard deviation of 4.27 and median of 19.00.

Table 11

Frequencies for Asthma Impairment Groups

Asthma Impairment Groups	*n* (%)	
Asthma impairment	Total	
Well controlled	55 (41.4)	
Not well controlled	78 (58.6)	
	Gender	
Asthma impairment	Males	Females
Well controlled	35 (63.6%)	20 (36.3%)
Not well controlled	30 (38.4%)	48 (61.5%)

The means for the responses to individual items for the ACT are provided in Table K1. Although levels of impairment are given, responses to individual items give a deeper understanding of the level of disruption in school and home activities because of asthma symptoms, frequency of asthma symptoms, nighttime awakenings, use of short-acting beta agonist medication, and self-evaluation of asthma control (see Table K1). The response to the question about level of disruption in school and home activities because of asthma symptoms ranged from *none of the time* to *all of the time*. The highest response to that question was *a little of the time* (37.6%). Shortness of breath once or twice a week was reported in 42.9%, the highest response for that category. The responses to nighttime waking to asthma symptoms varied from *not at all* (36.1%) to *once or twice a week* (32.3%) to *4 or more times a week* (11.5%). Forty-three of the participants (32.3%) indicated that they had not used their nebulizer at all within the previous four weeks and the other end of that range was use of the nebulizer *3 or more times a day* (eight participants, 6.0%). The participants' two highest ratings of their overall asthma control were *somewhat controlled* (36.1%) and *not controlled* (33.1%).

The original plan was to divide the sample into three categories with 20 participants in each of the categories of well controlled, not well controlled, and very poorly controlled. However, the number of participants for the not well controlled and very poorly controlled categories was small and would not provide adequate enrollment in both of those categories. Therefore, the investigator decided that the ACT's recommendation to contact a doctor for a total score of 19 and under would be used to differentiate between well controlled and not well controlled (Nathan et al., 2004). All of the scores 19 and under were then collapsed into the not well controlled category. Participants with scores of 20 to 25 were classified as well controlled. As seen in Table 11, 41.4% of the sample was categorized as well controlled and 58.6% as not well controlled. In relation to gender, 63.6% of the males were in the well controlled group, and 38.4% were classified as not well controlled. The well controlled females were represented by 36.3% of the sample, and 61.5% of females were categorized as not well controlled.

Illness representations. The cognitive and emotional illness representations were measured by the IPQ-R (Moss-Morris et al., 2002; see Figure H1). The illness representations questionnaire includes the cognitive subscales (identity, timeline acute/chronic, consequences, personal control, and treatment control, timeline cyclical, and causes) and emotional subscale. Table 12 presents the descriptive statistics and reliabilities for the IPQ-R subscales. Further discussion of the illness representations statistics in Table 12 is provided in sections for each subscale.

Table 12

Descriptive Statistics and Reliability for IPQ-R Subscales

Scale	*M* (*SD*)	*Mdn*	Range	Cronbach's α[a]	IPQ-R[b]
Cognitive Representations					
Identity	5.55 (2.33)	5.00	0–11	.394	.75
Timeline-Acute/Chronic	19.11 (4.62)	19.00	6–30	.763	.89
Timeline-Cyclical	12.92 (3.29)	13.00	4–20	.643	.79
Consequences	16.57 (4.65)	16.00	6–28	.735	.84
Personal Control	22.49 (3.61)	22.00	14–30	.611	.81
Treatment Control	18.75 (3.03)	19.00	11–25	.591	.80
Causes					
Psychological Attribute (Factored Analysis)	11.47 (3.93)	12.00	6–25	.747	.86
Emotional Representations	13.18 (4.67)	12.00	6–25	.786	.80

Note. *N*= 133 for each scale. [a]Current study. [b]Original study.

Reliability of the illness representations subscales. As depicted in Table 12, Cronbach's alpha coefficients for the IPQ-R subscales ranged from .75 to .89 (Moss-Morris et al., 2002). The Cronbach's alpha coefficients for the subscales for the current study ranged from .394 to .790. The Cronbach's alpha coefficients closest in range to the IPQ-R were for the emotional representations subscale (current study.79 and IPQ-R .80). The largest discrepancy was in Cronbach's alpha for the identity subscale (current study .394 and IPQ-R .790). The IPQ-R item selection initially was determined by principal components analysis in a sample of 711 patients with eight different illnesses. Moss-Morris et al. (2002) addressed the low coefficient in the following manner:

> Because the identity subscale consists of disparate symptoms and certain of these symptoms are more relevant to particular illnesses than others, internal consistency of the scale is less relevant than in other subscale. Nevertheless, the subscale does demonstrate a relatively high degree of internal reliability with a Cronbach of .75. This suggests that patients either attribute a relatively high or low number of symptoms to their illness. (p. 8)

Although the PI selected the asthma version of the IPQ-R for use with the current study, the identity subscale still included some general symptoms and that could have contributed to the low Cronbach's alpha. The means for nausea and loss of strength had the highest standards of deviation, .859 and .892, respectively. When Cronbach's alpha coefficient was rerun without those items, the identity subscale score increased to .548. The researcher considered that the major contributions to the identity subscale's low Cronbach's alpha were the scoring and interpretation of the directions. The adolescents were asked initially to rate whether or not they had experienced each symptom since their illness diagnosis using a yes/no response format. They were then asked whether or not they believed the symptom to be related specifically to their illness using the same format. The sum of the yes-rated items on this second rating forms the illness identity subscale. The participants were asked to select symptoms that were related to their asthma. The challenge for adolescents at their level of cognitive maturity was to decide whether symptoms were *related* to their asthma. The Cronbach's alpha was low, and the investigator interpreted identity results with caution because of the low score.

In Table 13, the statistics for each illness representations subscale were differentiated by gender and asthma impairment group. In the discussion of each subscale, the means by gender and asthma impairment group are addressed.

Table 13

Descriptive Statistics for Illness Representations Subscales by Asthma Impairment and Gender

Illness Representation by Asthma Impairment	Gender	
Well controlled	Male *M* (*SD*) *n* = 35	Female *M* (*SD*) *n* = 20
Identity	5.23 (2.25)	5.05 (2.28)
Timeline-Acute/Chronic	17.63 (4.98)	18.15 (5.02)
Timeline-Cyclical	11.80 (3.40)	11.95 (3.56)
Consequences	14.74 (4.79)	14.65 (4.04)
Personal Control	23.11 (4.16)	23.45 (3.86)
Treatment Control	19.86 (2.89)	19.95 (2.37)
Causes (Psychological Attributes)	10.94 (3.43)	9.45 (3.36)
Emotional Representations	11.29 (4.02)	12.40 (4.77)
Not well controlled	Male *M* (*SD*) *n* = 30	Female *M* (*SD*) *n* = 48
Identity	5.43 (2.33)	6.06 (2.37)
Timeline-Acute/Chronic	17.60 (3.48)	21.54 (3.85)
Timeline-Cyclical	13.10 (2.66)	13.60 (3.25)
Consequences	17.50 (4.37)	18.13 (4.33
Personal Control	22.57 (3.04)	21.58 (3.32)
Treatment Control	18.20 (2.76)	17.95 (3.19)
Causes (Psychological Attributes)	12.50 (3.79)	12.04 (4.27)
Emotional Representations	14.27 (4.97)	14.21 (4.65)

Identity subscale. The identity subscale requires a yes/no response to whether 14 symptoms had been experienced and whether the symptoms were related to asthma (Morris-Morris et al., 2002). The total score is comprised of only the yes responses to symptoms related to asthma. As reflected in Table 12, the sample mean was 5.55. The not well controlled females had the highest mean (6.06; see Table 13). Of all of the groups, the well controlled females had the lowest mean, which meant they had the least number of symptoms identified as specifically relating to their asthma. According to the analysis of the 14 items in the identity subscale, the top six responses to symptoms related to asthma were wheezeness (90.6%), breathlessness (88.8%), pain (69.9%), sleep difficulties (51.1%), loss of strength (47.4%), and fatigue (40.6%).

Acute/chronic timeline subscale. Table 12 provides the descriptive statistics for the acute/chronic timeline subscale. The acute/chronic timeline assesses the participant's perceived chronicity of the illness, whether asthma is an acute or chronic illness (Moss-Morris et al., 2002). The sample mean for the 6-item acute/chronic timeline subscale is 19.11. The females in the not well controlled group had the highest mean and the males (well controlled and not well controlled) had the lowest means of all of the groups (see Table 13). The participants' responses to the IPQ-R acute/chronic timeline questions reflected their varied perspectives about the duration or chronicity of their asthma. Although 31.6% of the sample thought their asthma would last a long time, 24.8% thought it would last a short time. Those responses were given after the PI explained that this question referred to having asthma as a condition, not the length of an asthma attack or episode. Sixty-two percent of the sample responded that their asthma would not pass quickly. While 48% of the participants thought their asthma would improve over time, 24% neither agree nor disagreed. The perspective that asthma is permanent was agreed by 36.8% of the adolescents; however, 24.1% disagreed that asthma is permanent rather than temporary. On the other hand, 39.8% of the participants agreed that their asthma would last a long time, but 24.1% disagreed. Among the participants, 39.1% agreed that they would have asthma the rest of their lives, but another 30% disagreed or strongly disagreed that their asthma would exist for the remainder of their lives.

Cyclical timeline subscale. This subscale focuses on variations in the participant's asthma condition and whether the individual perceives his or her asthma as cyclical or episodic in nature (Morris-Morris et al., 2002). There are four items included in the cyclical subscale, and the sample mean for the subscale was 12.92 (see Table 12). Although the female not well controlled group had the highest mean (13.60), both the male (13.10) and female not well controlled groups had higher means than the well controlled groups (see Table 13). The frequencies reflect the adolescents' perspectives of the variances in their asthma symptoms: 36.8% agreed or strongly agreed that their asthma symptoms change a great deal from day to day. However, the results also revealed that 44.4% either disagreed or strongly disagreed. There was another 18.8% that responded as neither agreeing nor disagreeing. Overall, there was not much differentiation in the responses to the remainder of the questions in the subscale. The majority of the sample agreed or strongly agreed that their symptoms come and go in cycles, are unpredictable, and that there are cycles of improvement and worsening of asthma symptoms.

Consequences subscale. The perceptions of the functional, social, psychological, and economic consequences of having asthma are identified in the consequences subscale (Moss-Morris et al., 2002). The mean for the consequences subscale is 16.57, and the scale range was 6–28 (see Table 12). The mean reflected that over 60% of the participants who believed that asthma is a serious condition, believed that asthma has a great effect on their lives. The mean also depicts the 60%–70% who responded that asthma does not affect the way others see them; asthma does not cause serious consequences; and asthma does not cause difficulties for those who are close to them. Although 41.3% of the sample agreed that asthma has major consequences on their lives, 38.4% disagreed with this belief, and 20.3% neither agreed nor disagreed. The highest mean for the 6-item consequences subscale was reported by females in the not well controlled group, and the lowest mean for the four groups was females who were well controlled (see Table 13).

Personal control subscale. The extent to which the participant believes the condition is amenable to her or his individual control is measured by the personal control subscale. Overall, there was a strong majority of the participants who believed their asthma was amenable to their control. Most responded that there was a lot they could do to control their symptoms (66.9%) and to determine whether their asthma improved or worsened (74.4%). The participants also responded that the course of their asthma depended on them (54.1%), that they had the power to influence their asthma (52.6%), and that their actions would affect their asthma (70.6%). The 22.4 sample mean for the 6-item subscale was the highest mean of all of the subscales that indicated positive beliefs (see Table 12). Well controlled females had the highest group mean followed by well controlled males. Not well controlled females had the lowest mean (see Table 13).

Treatment control subscale. The treatment control subscale measures beliefs in medical treatments for asthma and treatment outcomes (Moss-Morris et al., 2002). The subscale has five items; the sample mean was 18.75; the range was 11–25 (see Table 12 for the descriptive statistics). The females who were well controlled had the highest mean and the not well controlled females had the lowest of the four groups (see Table 13). The majority of the sample's responses reflected strong beliefs that their treatments could control their asthma (83%), improve their asthma (69.9%), and that a lot could be done to help their condition (82%). One of the questions asked if the participant thought the treatment could cure his/her asthma. While 15.8% disagreed or neither agreed nor disagreed with the cure (30%), 64.2% responded that their treatment would cure their asthma. A large percentage (57.9%) of the participants believed that the negative effects of their asthma could be prevented or avoided, but 15.8% of participants disagreed or strongly disagreed, and 26.3% neither agreed nor disagreed with that statement.

Causes subscales. There are two components to the measurement of the causes illness representations. The first component is the 18-item causes subscale. The participants selected from the 18 items the likely cause or causes of their asthma. The Likert scale previously used with other IPQ-R subscales also was utilized with the cause's component. However, the responses for the 18-item component were analyzed using factor analysis instead of a total. The scoring guidelines for the IPQ-R recommended that with a sample size ≥ 85, instead of a single causes scale, factor analysis should be used to identify groups of causal beliefs. Those factored groups would then serve as the causes subscales. Therefore, the 18 causes of asthma items for the IPQ-R were subjected to principal component analysis using SPSS version 19.0. Prior to performing principal component analysis, the investigator assessed the suitability of data for factor analysis. Inspection of the correlation matrix revealed the presence of many coefficients of .30 and higher as recommended by Tabachnick and Fidell (2007). The

Kaiser-Meyer-Olkin value was .801, exceeding the recommended .60 value and the Bartlett's Test of Sphericity at .000 reached statistical significance $p < .05$ (Tabachnick and Fidell, 2007).

Principal components analysis using Varimax rotation produced five components with eigenvalues exceeding 1, explaining 57.6% of the total variance (27.9%, 8.7%, 7.9%, 6.8%, and 6.3% of the variance respectively). The highest eigenvalues was 5.014 with a corresponding 27.85% of the variance. The second highest eigenvalues was 1.573 explaining 8.74% of the variance. An inspection of the screeplot revealed a break after the first component (see Figure K1). This was further supported by the results of Parallel Analysis (Watkins, 2000), which showed only one component had eigenvalues that exceeded the corresponding criteria for a randomly generated data matrix of the same size (18 items from causes subscale x 133 participants). The standard replications recommended for the Parallel Analysis is 100; therefore, the formula used for the calculation was 18 items x 133 participants x 100 replications (Pallant, 2010, Watkins 2000). Component 1 of the factor analysis had a total value of 5.014, which exceeded the Parallel Analysis corresponding value of 1.7152. The Parallel Analysis is included in Table K2.

The first component factor, which was labeled psychological attributes, accounted for 27.9% of the total variance (see Table K3). The term *psychological attribute* was used because it coincided with the label given the same factored items in the validation of the IPQ-R (Moss-Morris, 2002). Therefore, the cause subscale was identified as the *causes psychological attribute subscale* in various descriptions of the data analyses. Like the factor analysis for the IPQ-R, the psychological attributes subscale for this study included six of the seven psychological items: (1) my emotional state, (2) my attitude, (3) family problems or worries, (4) stress or worries, (5) overwork, and (6) my personality (see Table K3). The seventh item for the current study was aging. A difference in the loading for this study was *aging* as a cause item for Factor 1 (see Table K3). When the instrument was developed, aging loaded as a cause item for Factor 2.

For the current study, *my personality* loaded very closely (.001 difference) on two factors (.461-Factor 1; .462-Factor 4 was not used for this study). Tabachnick and Fidell (2007) address the issue of the complexity of determining the best factor solution, particularly because of the lack of an external criterion to test the solution. My personality was included in Factor 1 because it was appropriate for the combination of variables loaded as psychological attributes and for the overall interpretability of the factor with my personality included (Tabachnick & Fidell, 2007).

According to Moss-Morris et al. (2002), Cronbach's alpha coefficient for the psychological attributes subscale was .86. In the current study, Cronbach's alpha for the psychological attributes factor (Factor 1) was .747. The sample means for the items comprising the causes psychological attributes subscale ranged from 1–5 and the median was 2.00. The means from lowest to highest were 1.74 (my personality), 1.83 (my attitude), 1.88 (emotional state), 1.92 (family problems), 2.00 (aging), and the highest were 2.10 (stress or worry) and 2.47 (overwork). The highest psychological attribute means were overwork (not well controlled males 2.57 and females 2.54), family problems (not well controlled males 2.23 and females 2.04), stress and worry (not well controlled males 2.30 and females 2.25). For all of the psychological attributes, the male and female not well controlled groups had the highest means.

The second causes component required that the participants list in rank-order the three most important factors they believed caused their asthma. The participants had the option of using 3 of the 18 items from the causes subscale or using their own ideas (Moss-Morris et al., 2002). In the development of the original IPQ, Weinman et al. (1996) recommended eliciting the qualitative information in order to facilitate a deeper understanding of the participants' perspectives of causes of their illness. They also recommended the utilization of information obtained to expand the number of causes items in future studies (Weinman et al., 1996). The sample's results of the rank-order causes of their asthma items are presented in Table K4. The rank-order responses to causes of asthma were not used in the analyses of the aims for this study because of the in-depth qualitative analysis required. However, the rank-order items were used to compare the cause items identified in the IPQ-R as well as by the study participants. Additionally, the rank order items were included in the appendices to identify additional causes provided by study participants and to provide a deeper understanding of the perspectives of the participants in this study. A large number of the 18 cause items identified in the IPQ-R were selected by the participants as causes of their asthma. The highest percentages of causes identified from the 18 provided items were heredity, n = 95 (71.4%); pollution, n = 50 (37.6%); smoking, n = 41 (30.8%); and germ or virus, n = 18 (13.5%). The participants identified additional categories that were not included in the IPQ-R (see Table K4). The top four additional categories were activities, n =32 (24.1%); allergies, n = 17 (12.8); weather, n = 11 (8.3%); and birth problems, n = 10 (7.8%).

Emotional representations subscale. The questions for the emotional representations subscale relate to such emotions as fear, anger, distress, and anxiety

(Moss-Morris et al., 2002). The mean for the sample was 13.18 with a standard deviation of 4.67, which was the highest standard deviation of all of the illness representations (see Table 12). The not well controlled males were followed by the not well controlled females in the higher ranking means for emotional representations. The group with the lowest mean for the emotional representations was the well controlled males (see Table 13). The wide variances in emotions were reflected in participants' responses to each item. The sample strongly agreed or agreed that their asthma did not make them depressed (82.7%), upset (78.2%), or angry (78.9%). There were also a large number of participants that reported being worried (42.1%), afraid (21%), angry (13.6%), and anxious (12%) about their asthma.

Asthma self-management behaviors. The 31-item ASCPI (Fitzpatrick & Frey, 1993) was used to measure asthma self-management behaviors. The participants were asked to indicate the percentage of time they performed the actions on a ratio scale of 0% to100%. The instrument has four subscales, symptom management (12 items), medication management (11 items), environmental control (6 items), and overall self-management (2 items). The two self-management items were not used for data analyses because the aims of the study addressed the specific behaviors of symptom management, medication management, and environmental control. Therefore, a total ASCPI score was not reflected in the descriptive statistics. Instead, three of the subscales (symptom management, medication management, and environmental control) were used for this study's data analyses for the self-management variable. Each subscale had a total score that was based on the participant's responses to the corresponding items. A higher score for a subscale indicated a greater level of that type of self-management. Descriptive statistics for the three subscales are provided in Table 14. Total scale alphas in previous studies ranged from 0.86 to 0.89 (Fitzpatrick & Frey, 1993; Velsor-Friedrich et al., 2004; Velsor-Friedrich, Pigott, & Srof, 2005). No studies have been identified that used the subscales of the ASCPI; therefore, there are no comparisons with the subscale Cronbach's alpha coefficients reported in Table 14. However, the coefficients range from .72 to .79, which are considered acceptable (DeVellis, 2003, Pallant, 2010).

Table 14

Descriptive Statistics for the ASCPI Subscales

Scale	*M* (*SD*)	*Mdn*	Range	Cronbach's α
Symptom Mgmt	58.3 (20.5)	59.00	0–109	.748
Medication Mgmt	55.8 (21.0)	57.00	7–108	.723
Environmental Control	29.8 (14.1)	31.00	2–60	.785

Note. *N* = 133 for each scale.

In Table 15, the statistics for the symptom management, medication management, and environmental subscales were differentiated by gender and asthma impairment group. In the discussion of each subscale, the means by gender and asthma impairment group are addressed. Higher mean scores reflected better self-management behaviors. Further discussion of the descriptive statistics is provided in sections for each of the self-management behaviors.

Table 15

Descriptive Statistics for the ASCPI Subscales by Asthma Impairment and Gender

Self-management by Asthma Impairment	Gender	
Well controlled	Male *M* (*SD*) *n* = 35	Female *M* (*SD*) *n* = 20
Symptom management	55.20 (19.06)	57.40 (18.40)
Medication management	53.97 (18.92)	54.55 (20.02)
Environmental control	29.09 (15.75)	27.25 (16.32)
Not well controlled	Male *M* (*SD*) *n* = 30	Female *M* (*SD*) *n* = 48
Symptom management	62.53 (20.76)	58.33 (22.18)
Medication management	57.27 (18.13)	56.63 (24.64)
Environmental control	31.87 (12.57)	30.06 (12.89)

Symptom management. The adolescent's self-management of asthma symptoms was measured through the 12-item symptom subscale. The sample mean for the subscale was 58.3 with a standard deviation of 20.5 and responses ranging from 0 to 109 (see Table 14). The mean was reflective of the sample's percentage of time in carrying out such symptom management actions as: (1) asking doctors or nurses questions about their asthma, (2) avoiding playing sports when having trouble breathing, (3) asking a parent or teacher to call the doctor when an asthma episode was getting worse, or (4) taking a break when having trouble breathing. The males and females in the not well controlled groups had higher symptom management means than the well controlled groups (see Table 15). The not well controlled males had the highest means of all of the groups, indicating the best symptom management behaviors of the groups.

Medication management. The self-management actions related to medication also were measured using the ASCPI. The sample mean for the 11-item subscale was

55.8, and the medication management subscale also had a high standard deviation (21.0; see Table 14). The not well controlled males and females had higher medication management means than the well controlled groups. The not well controlled males had the highest mean of all four asthma impairment groups, which depicted that they exhibited the best medication management behaviors of the four groups (see Table 15). The subscale scores indicated the percentage of time adolescents carried out such medication management behaviors as: (1) asking physicians and nurses questions about their asthma medication, (2) giving themselves their own medication, (3) using their inhaler at the first sign of trouble breathing (if one was prescribed), and (4) using a spacer with the inhaler.

Environmental control. The final subscale measured by the ASCPI was environmental control. The subscale was comprised of six items and had a sample mean of 29.8. Similar to the other two subscales, the not well controlled males had the highest environmental management mean (see Table 15). Additionally, the male and female not well controlled groups had higher means than the well controlled groups. Examples of the environmental control measures used by the participants were staying away from people who were sick or had colds and avoiding triggers at home or school.

Results Related to Each Aim and Research Question

The first aim of the study was to explore differences in illness representations (cognitive and emotional) and self-management behaviors (symptom management, medication management, and environmental control) by gender and asthma impairment (well controlled and not well controlled) among African American adolescents (aged 14–16 years) with asthma.

Aim 1 Research Question 1 and Results

The first research question examined was: What are the differences in the means of cognitive representations of identity, timeline, consequences, cause, and control by gender, asthma impairment (well controlled and not well controlled), and gender by asthma impairment for African American adolescents (aged 14–16 years) with asthma?

The study investigator conducted a two-way between groups analysis of variance to explore the association of gender and asthma impairment with cognitive illness representations as measured by the IPQ-R. Participants were divided into two groups for gender (male and female) and for asthma impairment (well controlled and not well controlled). Table 16 presents the results of analysis of variance for the cognitive representations. Additionally, in Table 16 the cause subscale psychological attributes that resulted from factor analyses was used for data analyses.

Table 16

Analysis of Variance for Cognitive Illness Representations by Gender, Asthma Impairment and Gender by Asthma Impairment

Subscale	Sig. of Levene's Test	*F*(1,129)	Sig.	Partial Eta Squared
Identity	.910			
Gender		1.530	.595	.002
Asthma impairment		11.16	.152	.016
Gender by asthma impairment		.915	.341	.007
Acute/chronic timeline	.208			
Gender		8.162	.005**	.060
Asthma impairment		4.634	.033**	.035
Gender by asthma impairment		4.793	.030**	.036

continued

Cyclic timeline	.517			
Gender		1.079	.301	.008
Asthma impairment		6.634	.011**	.049
Gender by asthma impairment		.127	.723	.001
Consequences	.907			
Gender		.109	.742	.002
Asthma impairment		14.931	.000**	.104
Gender by asthma impairment		.198	.657	.002
Personal control	.380			
Gender		.246	.621	.002
Asthma impairment		3.418	.067	.026
Gender by asthma impairment		1.020	.314	.008
Treatment control	.298			
Gender		.089	.766	.001
Asthma impairment		12.980	.000**	.091
Gender by asthma impairment		.224	.637	.002
Psychological attributes	.849			
Gender		1.95	.165	.008
Asthma impairment		3.901	.050**	.029
Gender by asthma impairment		.549	.460	.004

** p < .05.

Table 16 provides the results indicating that the acute/chronic timeline was the only subscale with a significant main effect for gender $F(1, 129) = 8.16$, $p = .005$, asthma impairment $F(1,129) = 4.43$, $p = .033$, and gender by asthma impairment $F(1,129) = 4.79$, $p = .030$. In addition to the acute/chronic timeline, the main effect asthma impairment was statistically significant in the following subscales: cyclic timeline $F(1,129) = 6.63$, $p = .011$, consequences $F(1,129) = 14.93$, $p = .000$, treatment control $F(1,129) = 13.0$, $p = .05$, and psychological attributes $F(1,129) = 3.90$, $p = .000$. Cohen's (1988) classifications of effect size (also appropriate for SPSS calculated partial eta size squared) Effect size is further defined by Cohen (1988) as "the degree to which the phenomenon exists" (p. 4). Small effect size was identified as .01 or greater, medium as .06 or greater, and large as .138 or greater (Cohen, 1988; Pallant, 2010). Although for the acute/chronic timeline, the effect sizes were small for the main effects asthma impairment (partial eta squared = .035) and gender by asthma impairment interaction (partial eta squared = .036), the main effect for gender had a medium effect size (partial eta squared = .060). The effect sizes (partial eta squared) were of medium size for consequences by asthma impairment (.104) and treatment control by asthma impairment (.091). However, the effect sizes (partial eta squared) were small for the cyclic timeline by asthma impairment (.035) and psychological attributes (.029).

The investigator conducted a post hoc analysis in order to further analyze the gender by asthma impairment interaction associated with the acute/chronic timeline representation. A one-way ANOVA was conducted as a post hoc analysis in order to further explore the gender by asthma impairment interactions (Table H5). The analysis was run separately for males and females to determine differences in the asthma impairment groups (well controlled and not well controlled) as associated with their acute/chronic timeline representations. The post hoc comparison indicated that there was not a significant difference ($F(1, 64) = .001$, $p = .979$) in the mean scores for males well controlled ($M = 17.63$, $SD = 4.98$) and not well controlled ($M = 17.60$, $SD = 3.48$). There was a significant difference ($F(1, 67) = 9.09$, $p = .004$) in the mean scores for females well controlled ($M = 18.15$, $SD = 5.03$) and not well controlled ($M = 21.54$, $SD = 3.85$).

Aim 1 Research Question 2 and Results

The second research question examined the differences in emotional representations by gender, asthma impairment, and gender by asthma impairment. Table 17 depicts the two-way ANOVA results that were measured by the IPQ-R.

Table 17

Two-way Analysis of Variance of Emotional Representations by Gender, Asthma Impairment, and Gender by Asthma Impairment

Subscale	Sig. of Levene's Test	*F*(1,129)	Sig.	Partial Eta Squared
Emotional representations	.359			
Gender		.407	.525	.003
Asthma impairment		8.378	.004**	.061
Gender by asthma impairment		.502	.480	.004

** $p < .05$.

The gender by asthma impairment interaction effect for the emotional representations was not statistically significant, $F(1,129) = .502$, $p = .48$. Neither was the main effect for gender statistically significant, $F(1,129) = .407$, p = .52. There was a statistically main effect for emotional representations and asthma impairment, $F(1,129) = 8.38$, $p = .004$, and the effect size was identified as medium (partial eta squared = .061; Cohen, 1988).

Aim 1 Research Question 3 and Results

The final research question for Aim 1 examined the differences in means of self-management behaviors of symptom management, medication management, and environmental control by gender, asthma impairment (well controlled and not well controlled), and gender by asthma impairment. The investigator performed a multivariate analysis of variance to investigate differences in self-management behaviors. The three self-management subscales (symptom management, medication management, and environmental control) were used as the MANOVA dependent variables. The MANOVA independent variables were gender, asthma impairment, and gender by asthma impairment. Preliminary assumption testing was conducted to check for normality, linearity, univariate and multivariate outliers, multicollinearity, and homogeneity of variance-covariance, with no violations identified. Multivariate outliers previously identified and discussed in the Data Screening and Cleaning Procedures section did not create any violations. Levene's Test of Equality was conducted for the symptom management, medication management, and environmental control subscales. None of the values were less than .05, which would indicate a violation the assumption of equality (see Table K5).

As recommended by Tabachnick and Fidell (2007), the Wilks' Lambda test was conducted to determine differences among the self-management behaviors. There were no significant differences by gender ($F(3, 129) = .227$, $p = .88$; Wilks' Lambda = .90; partial eta squared = .005), asthma impairment ($F(3, 129) = .547$, $p = .65$; Wilks' Lambda = .90; partial eta squared = .013.), or gender by asthma impairment interaction ($F(3, 129) = .347$, $p = .79$; Wilks' Lambda = .90; partial eta squared = .008; see Table 18).

Table 18

MANOVA-Wilks' Lambda

Multivariate Tests[a]							
Effect		Value	F^b	Hypothesis *df*	Error *df*	Sig.	Partial Eta Squared
Intercept	Pillai's Trace	.900	379.069	3.000	127.000	.000	.900
	Wilks' Lambda	.100	379.069	3.000	127.000	.000	.900
	Hotelling's Trace	8.954	379.069	3.000	127.000	.000	.900
	Roy's Largest Root	8.954	379.069	3.000	127.000	.000	.900
Gender	Pillai's Trace	.005	.227	3.000	127.000	.878	.005
	Wilks' Lambda	.995	.227	3.000	127.000	.878	.005
	Hotelling's Trace	.005	.227	3.000	127.000	.878	.005
	Roy's Largest Root	.005	.227	3.000	127.000	.878	.005
Asthma impairment	Pillai's Trace	.013	.547	3.000	127.000	.651	.013
	Wilks' Lambda	.987	.547	3.000	127.000	.651	.013
	Hotelling's Trace	.013	.547	3.000	127.000	.651	.013
	Roy's Largest Root	.013	.547	3.000	127.000	.651	.013
Gender by asthma impairment	Pillai's Trace	.008	.347	3.000	127.000	.791	.008
	Wilks' Lambda	.992	.347	3.000	127.000	.791	.008
	Hotelling's Trace	.008	.347	3.000	127.000	.791	.008
	Roy's Largest Root	.008	.347	3.000	127.000	.791	.008

[a]Design: Intercept + Gender + Asthma Impairment + Gender by Asthma Impairment. [b]Exact statistic.

The second aim of the study was to explore relationships between illness representations (cognitive and emotional), asthma self-management behaviors (symptom management, medication management, and environmental control), gender and asthma impairment in African American adolescents (aged 14–16 years) with asthma.

Aim 2 Research Question 1 and Results

The first research question for Aim 2 was: What are the bivariate relationships between cognitive (identity, timeline, consequences, cause, and control), emotional representations, and asthma self-management behaviors (symptom management, medication management, and environmental control) in African American adolescents (aged 14–16 years) with asthma? The bivariate relationships between cognitive and emotional representations (as measured by the IPQ-R) and asthma self-management behaviors (as measured by the ASCPI) were investigated using the Pearson product moment correlation coefficient. The investigator conducted preliminary analyses to ensure no violation of assumption of normality, linearity, and homoscedasticity. The results of the correlations are presented in Table 19.

Table 19

Pearson Product-moment Correlations between Illness Representations and Asthma Self-management Behaviors

ASPCI Scale	*N*	Symptom Management	Medication Management	Environmental Control
Identity	133	.175*	.039	.203*
Acute/chronic timeline	133	.005	.122	.090
Consequences	133	.210*	.129	.149
Personal control	133	.090	.135	.183

continued

Treatment control	133	.248*	.120	.121
Cyclic timeline	133	.011	-.100	.003
Cause (psychological attributes)		.060	-.046	.003
Emotional	133	.060	-.014	.138

*p < .05.

Cohen's (1988) guidelines for evaluating the strength of relationships were used to interpret the results of this study. Correlations (*r* values) of .10 to .29 are considered small, .30 to .49 medium, and .50 to 1.0 large (Cohen, 1988). There were significant small correlations between identity illness representations and symptom management (r = .18, p < .05), and identity illness representations and environmental control (r = .20, p < .05). Another significant correlation identified was between the consequences illness representations variable and the symptom management variable, (r = .21, p < .05). Although the relationship between the treatment control variable and symptom management had the highest correlation (r = .25, p < .05), the strength of that correlation was still considered small using Cohen's guidelines (Cohen 1988, Pallant, 2010).

Aim 2 Research Question 2 and Results

The second research question for Aim 2 was: What are the associations between symptom management and the set of cognitive representations (identity, timeline, consequences, cause, and control), emotional representations, gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma?

Standard multiple regression was used to assess the associations between symptom management and the set of cognitive representations (identity, acute/chronic timeline, cyclic timeline, consequences, cause-psychological attributes, personal control, and treatment control), emotional representations, gender, and asthma impairment. The investigator considered assumptions of multiple regression analysis, as identified by Tabachnick and Fidell (2007) and Pallant (2010). The study's sample size of 133 met the sample size criteria (see Table 20).

Table 20

Multiple Regression Analysis for Symptom Management

Model	B	β	*t*	Sig.	R^{2a}
1 (Constant)	2.005		.109	.914	
Identity total	1.205	.137	1.521	.131	.023
Timeline acute/chronic total	-.073	-.016	-.163	.871	-.008
Consequences total	1.135	.258	2.427	.017	.037
Personal control total	-.097	-.017	-.184	.854	.000
Treatment control total	2.052	.304	3.069	.003	.054
Timeline cyclical total	-.809	-.130	-1.379	.170	-.008
Emotional total	-.182	-.042	-.384	.702	-.004
Cause (psychological attributes)	-.784	-.038	-.394	.694	-.008
Gender	-1.307	-.032	-.350	.727	-.007
Asthma impairment	5.949	.144	1.499	.136	.002

[a]R^2 = 9.4%; $F(10,122) = 2.37$, $p = .014$.

Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. There were correlations between the independent variables and dependent variable of symptom management above .3, and none of independent variables had a bivariate relationship of .7 or higher. Tolerance values were above .10 (.59–.85) and variance inflation factor (VIF) values were less than 10 (1.18–1.71). Normal probability plots of the regression standardized residual and scatterplots suggested no major deviations from normality. The influence of outliers was assessed through Cook's Distance. According to Tabachnick and Fidell (2007), cases with scores larger than 1.00 are suspected of being influencing outliers. The maximum value for Cook's Distance was .083. No violations of assumptions were identified for this model.

The regression model was evaluated and the total variance explained by the model was 16.2% of variance, ($F(10,122) = 2.367$, $p < .01$). The adjusted R^2 supports 9% of the variance. In the final model, neither gender nor asthma impairment was significant and only two illness representations were statistically significant. As indicated in Table 20, there was a beta value of treatment control subscale as .30, $p < .005$ and the consequences subscale recorded a beta value of .26, $p < .05$. Therefore, the treatment control subscale contributed 6.25% of the shared variance and a unique contribution of 5.4% to the explanation of variance in symptom management. The consequences subscale provided 4% of the shared variance and uniquely explained 3.7% of the variance in symptom management.

Aim 2 Research Question 3 and Results

The research question was: What are the associations between medication management and the set of cognitive representations (identity, timeline, consequences, cause, and control), emotional representations, gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma?

The PI used standard multiple regression to assess the associations between medication management and the set of cognitive representations (identity, acute/chronic timeline, cyclic timeline, consequences, cause-psychological attributes, personal control, and treatment control), emotional representations, gender, and asthma impairment. The assumptions of multiple regression analysis were considered, as identified by Tabachnick and Fidell (2007) and Pallant (2010). The study's sample size of 133 met the sample size criteria of 50 + 8m, $m = 10$, $N = 130$. The study investigator conducted preliminary analyses to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. There were correlations between the independent variables and dependent variable of medication management but none above .3, and none of independent variables had a bivariate relationship of .7 or higher. Tolerance values were above .10 (.59–.85) and VIF values were less than 10 (1.18–1.71). Normal probability plots of the regression standardized residual and scatterplots suggested no major deviations from normality. According to Tabachnick and Fidell (2007), cases with scores larger than 1.00, as measured in Cook's Distance, are suspected of being influencing outliers. The maximum value or Cook's Distance was .070. No violations of assumptions were identified for this model.

The investigator evaluated the regression model, and the total variance explained by the model was 9.8% of variance, $F(10,122) = 1.323$; however, the significance level was .226 so a $p > .05$ (see Table 21). The adjusted R^2 explained 2.4% of the variance. In the final model, none of the variables (cognitive representations, emotional representations, gender, or asthma impairment) were statistically significant. The highest beta coefficient was for the cyclical timeline at -.19. However, the significance level was .059; therefore, cyclical timeline did not make a significant contribution to medication management (see Table 21).

Table 21

Multiple Regression Analysis for Medication Management

Model	B	β	*t*	Sig.	R^{2a}
1 (Constant)	10.659	.543	.588		
Identity Total	-.044	-.005	-.052	.958	-.006
Timeline Acute/Chronic Total	.595	.131	1.254	.212	.007
Consequences Total	.837	.186	1.683	.095	.009
Personal Control Total	.349	.060	.621	.536	.011
Treatment Control Total	1.233	.178	1.733	.086	.007
Timeline Cyclical Total	-1.188	-.187	-1.903	.059	.002
Emotional Total	-.177	-.039	-.351	.726	-.007
Cause (Psychological Attributes)	-1.113	-.053	-.525	.600	-.005
Gender	-.873	-.021	-.220	.826	-.007
Asthma Impairment	4.570	.108	1.082	.281	-.004

R^2 = 2.4%; $F(10, 122) = 1.32$, $p = .226$.

Aim 2 Research Question 4 and Results

The final research question was: What are the associations between environmental control and the set of cognitive representations (identity, timeline, consequences, cause, and control), emotional representations, gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma?

The associations between environmental control and the set of cognitive representations (identity, acute/chronic timeline, cyclic timeline, consequences, cause-psychological attributes, personal control, and treatment control), emotional representations, gender, and asthma impairment were assessed through standard multiple regression. The assumptions of multiple regression analysis were considered, as identified by Tabachnick and Fidell (2007) and Pallant (2010). The study's sample size of 133 met the sample size criteria of 50 + 8m, $m = 10$, $N = 130$ (Tabachnick and Fidell, 2007). The investigator conducted preliminary analyses to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. There were correlations between the independent variables and dependent variable of environmental control but none above .3, and none of the independent variables had a bivariate relationship of .7 or higher. Tolerance values were above .10 (.59–.85) and VIF values were less than 10 (1.18–1.71). Normal probability plots of the regression standardized residual and scatterplots suggested no major deviations from normality. According to Tabachnick and Fidell (2007), cases with scores larger than 1.00, as measured in Cook's Distance, are suspected of being influencing outliers. The maximum value for Cook's Distance was .049. No violations of assumptions were identified for this model. See Table 22.

Table 22

Multiple Regression Analysis for Environmental Control

Model	B	β	*t*	Sig.	R^2
1 (Constant)	-7.852		-.603	.547	
Identity Total	.892	.147	1.597	.113	.034
Timeline Acute/Chronic Total	.173	.057	.551	.583	-.006
Consequences Total	.283	.094	.859	.392	.022
Personal Control Total	.492	.126	1.320	.189	.026
Treatment Control Total	.575	.124	1.220	.225	.007
Timeline Cyclical Total	-.459	-.108	-1.110	.269	-.008
Emotional Total	.395	.131	1.184	.239	.012
Cause (Psychological Attributes)	-1.436	-.102	-1.023	.308	.001
Gender	-2.409	-.086	-.916	.362	.002
Asthma Impairment	3.022	.106	1.080	.282	-.001

R^2 = 4.8%; F (10, 122) = 1.67, p = .095.

The regression model was evaluated and the total variance explained by the model was 12.0% of variance, F(10,122) = 1.670; however, the significance level was .095, $p > .05$ (see Table 22). The adjusted R^2 explained 4.8% of the variance. In the final model none of the illness representations were statistically significant and neither were gender and asthma impairment. The highest beta coefficient was for the identity subscale at .15. However, the significance level was .113; therefore, the identity illness representation did not make a significant contribution to environmental control.

Summary of Aims

Two aims were explored in this study: (1) the differences in illness representations (cognitive and emotional) and asthma self-management behaviors (symptom management, medication management, and environmental control) by gender and asthma impairment (well controlled and not well controlled) and (2) the relationships between illness representations (cognitive and emotional), asthma self-management behaviors (symptom management, medication management, and environmental control), gender, and asthma impairment (well controlled and not well controlled). The variables of interest were asthma impairment and gender and how they impacted the variables illness representations and asthma self-management. The variables also were examined as to whether asthma impairment, gender, and illness representations influenced asthma self-management behaviors.

The investigator explored the differences in illness representations and self-management behaviors by gender and asthma impairment through three research questions. The findings showed that acute/chronic timeline was the only illness representation that differed by gender, asthma impairment, and gender by asthma impairment. Moreover, the significant findings indicated strongly held beliefs about the chronicity of asthma for females (gender), not well controlled group (asthma impairment), and not well controlled females (gender by asthma impairment). In the following subscales, the significant main effect was asthma impairment and the identified group had the highest means: cyclic timeline (not well controlled), treatment control (well controlled), psychological attributes (not well controlled), consequences (not well controlled), and emotional representations (not well controlled). These findings not only identified certain significant illness representations, they also revealed the commonality of a significant finding between the not well controlled group as the asthma impairment group and five of six illness representations. Therefore, among the participants in this study, those participants who were not well controlled had different illness representations of their asthma than the well controlled participants. Finally, there were no significant differences in the means of the self-management behaviors by gender, asthma impairment, or gender by asthma impairment.

Four research questions were used to explore the relationships between illness representations, asthma self-management behaviors, gender, and asthma impairment. A significant bivariate relationship was identified between the illness representations of identity, consequences, and treatment control, and the symptom management behavior. A bivariate relationship also was identified between identity illness representation and the environmental control behavior. In the multiple regression model, treatment control and consequences illness representations contributed to variances in symptom management. However, for symptom management, no other illness representations, gender nor asthma impairment were statistically significant. In the final models, the illness representations, gender, and asthma impairment variables did not contribute to variances in medication management or environmental control. The findings indicated among all of the research questions, the treatment control, and consequences cognitive representations were identified as significant for differences in means by asthma impairment, correlations between treatment control, consequences, and symptom management, and associations between symptom management and treatment control as well as consequences.

Noteworthy Anecdotal Findings

The PI identified four major areas of noteworthy anecdotal findings during the analyses of data for this study. The findings were related to: (1) reliability and validity of the ACT; (2) discrepancies in subjective asthma control test and objective PFTs in high risk asthma participants; (3) participants' asthma exposure to formal asthma education; and (4) asthma self-management behaviors exhibited by the participants. Those findings will be discussed in the following sections.

Reliability and Validity of the ACT

Thirteen participants were recruited from the Children's Hospital High Risk Asthma Clinic. The asthma clinic participants had PFT results available on medical records, and the investigator used those results in determining the reliability and validity of the ACT. The reliability and validity of the ACT were assessed using three of the same methods used by Nathan et al. (2004) in the development of the instrument. Those three methods included determining the internal consistency reliability of the ACT for the total sample, correlations between the ACT and PFTs, criterion-related validity of ACT scores, and percent predicted of FEV_1 values. Tables 23–27 are included to depict the results of the reliability and validity assessments. Table 23 reflects the descriptive statistics and reliability for the ACT and PFTs. The ACT scale has only five items; therefore, the Cronbach's alpha and mean inter-item correlations were included as indicators of the reliability of the ACT. Table 24 provides the descriptive for the PFTs. Table 25 examines the correlations between ACTs and PFTs. The validity of ACT scores and percent predicted of FEV_1 values are presented in Table 26. All of the PFTs depicted in the tables were obtained prior to bronchodilator treatments, and the patients' efforts during the PFTs were good. The measure of volume of air the person can force out in the first second of exhalation from a position of maximum inhalation is denoted as FEV_1 (National Asthma Educator Certification Board, 2011). The NHBLI (2007) "Practical Guide for the Diagnosis and Management of Asthma: Expert Panel 3 Report" on the management of asthma report the FEV_1 ranges associated with asthma impairment are $FEV_1 \geq 80\%$ (well controlled), $FEV_1 > 60\%$ but $< 80\%$ of predicted (not well controlled), and $FEV_1 < 60\%$ of predicted (very poorly controlled). The FEV_1/FVC ratio should be greater than 70% (National Asthma Educator Certification Board, 2011). Forced Expiratory Flow ($FEV_{25\text{-}75}$) is the forced expiratory flow rate in the middle 50% of the FVC maneuver that measures the airflow in the small airways. A normal $FEV_{25\text{-}75}$ level is considered as 55% or greater.

Reliability of ACT. In the current study, Cronbach's alpha coefficient for the total sample was 0.78, compared to Nathan et al.'s (2004) reported .84. The value of .78 is within the .70 to .80 range considered by DeVellis to be "respectable" (2003, p. 95) The mean inter-item correlation is .44, which meets the advocated range of .15 to .50 across constructs and .40 to .50 for narrowly defined constructs (Netermeyer et al., 2003). The inter-item correlations ranged from .27 to .68. See Table 23.

Table 23

Reliability of ACT

ACT	*n*	*M* (*SD*)	*Mdn*	Range	Cronbach's α
Reliability instrument	13	16.77 (3.85)	18.00	10–21	.78

PFT results for sample. The descriptive statistics for the PFTs are presented in Table 24. The mean FEV_1 was 80.77. The FEV_1 ranges associated with asthma impairment are $FEV_1 \geq 80\%$ (well controlled) and $FEV_1 > 60\%$ but $< 80\%$ of predicted (not well controlled). Therefore, the mean FEV_1 was on the border of the well controlled and not well controlled asthma impairment level. The recommended FEV_1-FVC value for the age range for the sample is greater than 70 (National Asthma Educator Certification Board, 2011). However, the mean FEV_1–FVC is 66.54. The mean $FEV_{25–75}$ for the Children's Hospital High Risk Asthma Clinic participants was 52. See Table 24.

Table 24

Descriptive Statistics for PFTs (High Risk Asthma Clinic Participants)

Demographics	*n*	*M* (*SD*)	*Mdn*	Range
FEV_1	13	80.77 (21.84)	86.00	29–106
FEV_1/FVC	13	66.54 (13.40)	62.00	45–90
$FEV_{25–75}$	13	52 (33.43)	48	10–120

Correlations between ACT and PFTs. The highest ACT–PFT correlation was between the ACT and FEV_1 and not significant at $r = .458$, $p = .05$ (see Table 25).

Table 25

Correlations between ACT Score and PFTs

Measure	1	2	3	4
1. ACT Total	-	.458	.282	.125
2. FEV_1		-	.713**	.778**
3. FEV_1FVC			-	.894**
4. $FEV_{25–75}$				-

** $p < .01$.

In comparison, in Nathan et al.'s (2004) study the correlation between the FEV_1 and ACT was low ($r = 0.19$, $p = .0001$). In the development of the ACT the highest correlation coefficient was observed between the specialist's rating and ACT scores (r = 0.45, p = .0001).

Discrepancies in ACT and PFTs in High Risk Asthma Clinic Participants (Subjective vs. Objective)

The discussion of discrepancies in the ACT and PFTs for the Children's Hospital High Risk Asthma Clinic participants is provided in two sections. First, the validity of ACT scores and percent predicted of FEV_1 values are compared. The second section includes case analyses of five participants with discrepancies in ACTs and PFTs.

Validity of ACT scores and percent predicted of FEV_1 values. The final method used to determine the validity of the ACT was the comparison of ACT scores with the percent predicted of FEV_1. Nathan et al.'s study (2004) categorized ACT scores by percent predicted FEV_1 levels in order to determine validity of the ACT instrument. The investigator used the same FEV_1 levels to analyze the ACT scores for High Risk Asthma Clinic participants in the current study. Table 26 reflects the results of the participants' ACT and FEV_1 values. The mean scores for all of the groups except 80%–100% of predicted FEV_1 were lower than Nathan et al.'s (2004) comparison values. It is noted that the sample for Nathan et al.'s study (2004) was comprised of 407 participants aged 12 to 94 years, with an average age of 45.2 years. Therefore, the ages of those participants could have impacted their lung values as well as their perception of symptoms on the ACT. However, there is value in comparing this study's results with Nathan et al.'s (2004) reports. First, the values reflect how the ACT scores of some participants corresponded closely with their FEV_1 values. Second, the comparison of

ACT scores and FEV_1 values in this study provide opportunities for further validation of the ACT instrument. See Table 26.

Table 26

Validity of ACT Scores and Percent Predicted of FEV_1 Values

% Predicted FEV_1 Values	29%–59% *n* = 2	60%–79% *n* = 3	80%–100% *n* = 6	101%–106% *n* = 2
ACT Scores[a]	12, 20[b]	10[b], 12[b], 18[b]	17,18,19,19,21,21	12[b],19
ACT Mean	16	13.3	19.2	15.5
Nathan[g] Mean	18.3	19.0	19.9	20.9

[a]For individual participants. [b]Scores varied from the expected ACT scores that would coincide with the listed FEV_1 values. [g]Nathan et al. (2004).

In order to further analyze the high and low scores, the PI ran correlations between the five items on the ACT and PFTs. Those correlations identified ACT items that correlated higher with specific PFTs than the total ACT score. As noted in Table 27, the participant's frequency of shortness of breath (r = .721, p = 0.01) was significantly correlated with the FEV_1. That item analysis depicted the contribution of the subjective description of shortness of breath towards evaluation of asthma control and the association of that subjective item on the ACT with the objective PFT FEV_1 result. The shortness of breath item was also the first item selected for the stepwise regression model in the development of the ACT.

Table 27

Correlations between the ACT Items and PFT Results

Measure	1	2	3	4	5	6	7	8	9
ACT									
Item 1[a]	-	.634*	.354	.277	.470	.693**	.432	.440	.282
Item 2[b]		-	.285	.680*	.271	.783**	.721**	.502	.485
Item 3[c]			-	.303	.603*	.696**	-.071	-.152	-.318
Item 4[d]				-	.561*	.781**	.543	.404	.317
Item 5[e]					-	.763**	.065	-.125	-.307
ACT Total						-	.458	.282	.125
PFTs									
7. FEV_1							-	.713**	.778**
8. FEV_1FVC								-	.894**
9. $FEV_{25\text{-}75}$									-

[a]School and home activities. [b]Shortness of breath. [c]Waking up because of asthma symptoms. [d]Using inhaler or nebulized medicine. [e]Rating of asthma control.
*p < .05. **p < .01.

Case analyses of the ACT-PFTs results. The investigator performed a case analysis with the ACT–PFT results for the five participants who had lower or higher than expected ACT scores for their corresponding FEV1 levels (see Table 28). The analysis was conducted in order to better understand the impact that the outliers might have had on the ACT's reliability and validity and why. However, the participants' ACT scores were retained in the sample because the case analysis and PFT were not assessments considered for the total sample nor was the ACT–PFT analysis one of the aims of the study. The results related to the ACT and PFTs were noteworthy anecdotal findings of the study. Table 28 presents data for the analysis of participant's self-reported perceptions of asthma (through the ACT items) and their concurrent objective PFTs.

Table 28

High Risk Asthma Participants with Varied ACT Scores and PFTs

Case	ACT Scores and PFT
1	Male–ACT 20 score (well controlled), ACT use of inhaler or nebulizer 3, ACT perception of asthma control 4, FEV_1 59%, FEV_1/FVC 53%, $FEV_{25–75}$ 11%
2	Female–ACT 10 score (not well controlled), ACT shortness of breath 1, ACT use of inhaler or nebulizer 2, ACT perception of asthma control 3, FEV_1 61%, FEV_1/FVC 52%, $FEV_{25–75}$17%
3	Male–ACT–12 score (not well controlled), ACT home or school activities 4, ACT asthma symptoms 2, ACT shortness of breath 3, ACT use of inhaler or nebulizer 1, ACT perception of asthma control 2, FEV 1, $FEV_1$70%, FEV_1/FVC 62%, FEV_{25-75} 35%
4	Male–ACT–18 score (not well controlled), ACT asthma symptoms 5, ACT use of inhaler or nebulizer 3, ACT perception of asthma control 3, FEV_1 72%, FEV_1/FVC 61%, $FEV_{25–75}$ 23%
5	Female–ACT 12 score (not well controlled), ACT use of inhaler or nebulizer 2, ACT symptoms 2, ACT shortness of breath 4, ACT perception of asthma 1, FEV_1 101%, FEV_1/FVC 80%, $FEV_{25–75}$ 120%

Note. Cases do not include all itemized scores that form the ACT total score; selected scores are depicted in the table.

Case 1 is the participant whose ACT was 20 but the FEV_1 was in the 29%–59% range. The participant identified using the inhaler two or three times a week (score of 3) and his perception of his asthma was that it was well controlled (score of 4). However, the participant's PFTs were in the low range with the FEV_1 of 59% portraying the very poorly controlled category and FEV_{25-75} 11% reflecting very narrowly opened small airways.

Case 2 had an ACT total score of 10, which was reflective of shortness of breath more than once per day (score of 1), symptoms deterring school and home activities most of the day (score of 2), symptoms 2–3 nights/week (score of 2), and use of inhaler one to two times/day (score of 2), yet she rated her asthma as somewhat controlled. The FEV_1 of

59% was in the very poorly controlled category as was the FEV_1–FVC of 52% and narrowed small airways indicated by the $FEV_{25–75}$ of 17.

Case 3 was a male participant whose ACT total score was low at 12 (not well controlled). His FEV_1 was 70 (in Nathan et al.'s [2004] 60%–79% range), the FEV_1/FVC was 62, and FEV_{25-75} was 35. The low ACT total of 12 was a result of the participant identifying his symptoms as present two to three nights per week (score of 2) and using asthma medication three or more times per day (score of 1). Shortness of breath was described as occurring three to six times per week (score of 3). However, asthma was described as keeping the participant from getting work done at school and home only a little of the time (score of 4). The range for that response was *most of the time* to *none of the time*. Interestingly, this participant rated his asthma during the previous four weeks as poorly controlled (score of 2), but he perceived no difficulty in continuing his activities at school or home.

Case 4's ACT total was 18 but his FEV_1 was in the 60%–79% range. The high ACT total was a result of the participant's varied responses of not having any nighttime or early morning asthma symptoms (score of 5), shortness of breath (once or twice per week (score of 4), use of inhaler two to three times per week (score of 3) but identifying his asthma rating as somewhat controlled (score of 3). That participant's FEV_1 (72%), FEV_1/FVC (61%), and $FEV_{25–75}$ (23%) were low for the limited identification of asthma symptoms including shortness of breath.

Case 5 was the female who had an ACT total score of 12 but had a FEV_1 within the 101%–106% range. As depicted in Table 28, the participant reported symptoms two to three nights per week, use of medication one to two times per day, shortness of breath once or twice per week and rated her asthma as not controlled at all over the previous four weeks. However, on that clinic day the participant's FEV_1 was 101%, FEV_1/FVC 80%, and $FEV_{25–75}$ 120%. Although asthma symptoms can improve quickly, any improvements in the participant's asthma did not seem to be reflected in rating her asthma as not being controlled at all. In summary, this participant's case analysis supports the recommendation that when evaluating the reliability and validity of the ACT it is sometimes necessary to examine participants' itemized and total ACT scores for further interpretation (Ko et al., 2009; Nathan et al. 2004).

Asthma Self-management Behaviors

Noteworthy anecdotal findings related to asthma education and adolescents' management of asthma were identified through the demographics form and the ASCPI. Those findings are presented in the Asthma education, Asthma self-management plan, Symptom management, and Medication management sections.

Asthma education. The study investigator asked a series of questions about the asthma education of the sample. That information is presented in Table 29. The formal asthma education experienced by the sample was very limited; 80.5% of the participants in the study had not had *formal* asthma education. Therefore, only 26 (19.5%) of the 133 participants reported having attended a program. Those participants responded that they attended classes during the timeframe of 2001–2011; however, some participants said "about" the year identified. The length of the asthma education sessions ranged from 1 hour to 16 hours with the mean being 1.02 hours. The sites of the asthma education varied but the top two locations were hospitals (11.2%) and asthma camps (3.8%).

Table 29

Asthma Education

Demographics	*n* (%)
Formal asthma education completed	107 (80.5)
No	26 (19.5)
Yes	
Year attended asthma education	
2001–2011	26 (19.5)
None	107 (80.5)
Length[a]	
1	6 (4.5)
2	6 (4.5)
4	1 (0.8)
5	1 (0.8)
6	1 (0.8)
7	2 (1.6)
8	4 (3.0)
10	4 (3.0)
16	1 (0.8)
Where classes were held	
Doctor's office	1 (0.8)
Home	1 (0.8)
Clinic	2 (1.6)
School	3 (2.3)
Asthma camp	5 (3.8)
Hospital	14 (11.2)

[a]Length in hours of asthma education program.

The current study assessed the participants' illness representations and self-management behaviors, and asthma education can influence both of those. Therefore, the investigator conducted further analysis of the time between the year that formal asthma education occurred and the date of completion of the study's instruments (see Table 30).

Table 30

Years between Asthma Education and Completion of Study's Instruments

Years	Frequency	Valid %	Cumulative %
0	3	11.5	11.5
1	8	30.8	42.3
2	3	11.5	53.8
3	2	7.7	61.5
4	4	15.4	76.9
5	3	11.5	88.5
8	1	3.8	92.3
9	1	3.8	96.2
10	1	3.8	100.0
Total	26	100.0	

Of the 29.5% of the participants who indicated they had formal asthma education, the average difference between the time of education and data collection was 3.0 years with a standard deviation of 2.742.

Asthma self-management plan. Forty percent of the participants said they never followed an asthma action plan for the self-management of their asthma or they did not have a plan.

Symptom management. The adolescent's self-management of asthma symptoms was measured through the 12-item symptom subscale. The noteworthy symptom management findings included the following: (1) Participants asked physicians and nurses questions about their asthma 0%–30% of the time; (2) Adolescents avoided playing sports when they had trouble breathing 0%–30% of the time; (3) Participants took a break when they had trouble breathing 50%–100% of the time; and

(4) Adolescents let someone know when they were having trouble breathing 70%–100% of the time.

Medication management. There were also noteworthy anecdotal findings associated with medication management behaviors. The ASCPI subscale scores indicated that the adolescents asked physicians and nurses questions about their asthma medication 0%–10% of the time and 60.6% of the sample used a steroid inhaler 0%–30% of the time. The participants used a spacer with their inhaler 0%–10% of the time. Over 60% of the sample (60.6%) used a steroid inhaler 0%–30% of the time. On the other hand, 72 participants responded that they used their rescue inhaler 70%–100% of the time when they first noticed trouble breathing. Finally, 96 of the participants (N = 133) reported giving themselves their own medicine 70%–100% of the time.

Summary

The noteworthy anecdotal findings for this study provided additional information about adolescents' perceptions of their asthma, provided information from adolescents about potential contributors to their poor self-management behaviors, and supported findings in the literature regarding the self-management behaviors of adolescents with asthma.

Chapter IV presented the data analysis of the research questions for the current study. Noteworthy anecdotal findings also were identified for the study. In the final chapter, the findings from this chapter will be discussed more in-depth in relation to current illness representations and self-management literature.

CHAPTER V DISCUSSION

The aims of this study of African American adolescents (aged 14–16 years) with asthma were:

Specific Aim 1: To explore differences in illness representations (cognitive and emotional) and self-management behaviors (symptom management, medication management, and environmental control) by gender, asthma impairment (well controlled and not well controlled), and gender by asthma impairment among African American adolescents (aged 14–16 years) with asthma.

Specific Aim 2: To explore relationships between illness representations (cognitive and emotional), asthma self-management behaviors (symptom management, medication management, and environmental control), gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma.

The purpose of this chapter is to: (1) present the research findings and relate the findings to the literature reviewed; (2) describe the sample in terms of generalizability; (3) identify the strengths and limitations of the study; (4) describe the implications for nursing and health care; and (5) discuss the implications of the study for future research.

Research Findings

Aim 1 Research Question 1

The first research question was: What are the differences in the means of cognitive representations of identity, timeline, consequences, cause, and control by gender, asthma impairment (well controlled and not well controlled), and gender by asthma impairment for African American adolescents (aged 14–16 years) with asthma? The findings for this research question are presented for each illness representation and the associated variables of gender, asthma impairment, and gender by asthma impairment interaction.

Identity illness representation by gender, asthma impairment, and gender by asthma impairment. Identity illness representations reflect the individual's beliefs about the number of symptoms attributed to the illness (Moss-Morris et al., 2002). There were no significant effects for identity by gender, identity by asthma impairment, or identity and gender by asthma impairment.

Although there were no significant associations, identity illness representations for this sample were similar to findings in study of adults with asthma. In the current study, the top six responses to symptoms related to asthma were: wheezeness (90.6%), breathlessness (88.8%), pain (69.9%), sleep difficulties (51.1%), loss of strength (47.4%), and fatigue (40.6%). The description of pain in the identity subscale for the current study was related to pain associated with chest tightness. The top six symptoms related to asthma in this study were consistent with the findings from a previous study by Main, Moss-Morris, Booth, Kaptein, and Kolbe (2003). Although the participants in Main et al.'s study (2003) were adults with asthma and exact percentages were not reported, similar percentages of participants in their study identified symptoms as being related to their asthma: wheezeness (90%), breathlessness (80%), tight chest (80%), sleep difficulties (50%), loss of strength (40%), and fatigue (60%). Although the identity illness representations were not significant in the current study, it is important to be able to explore the symptoms adolescents associate with their asthma as a foundation for improving asthma self-management behaviors of adolescents.

Acute/chronic timeline illness representations by gender, asthma impairment, and gender by asthma impairment. Overall, the findings of this study revealed that there were adolescents who had acute representations of their asthma and others with chronic timeline illness representations. A description that takes into account the acute/chronic nature of asthma is that asthma is a chronic illness and the disease is present even when symptoms are controlled and currently not apparent (Yoos et al., 2007). The concept of chronicity is critical to an adolescent's understanding of the need for daily preventive medications (Halm et al., 2006; Handelman, Rich, Bridgemohan, & Schneider, 2004; Yoos et al., 2007). It could be speculated that illness representations of asthma as a chronic illness by adolescents would lead to use of daily preventive medications such as inhaled corticosteroids and potentially better asthma control (Kaptein, Klok, Moss-Morris, & Brand, 2010). However, if asthma is viewed as an acute illness, it is likely that the adolescent will manage the symptoms only with the periodic use of a short acting beta agonist (i.e., a bronchodilator).

In contrast to the findings of the current study, no studies were identified that specifically reported the acute/chronic timeline representation of adolescents with asthma. However, descriptions of acute illness representations found with adults have been consistent with the findings of the current study. Yoos et al. (2007) conducted a study of the parenteral illness representations of asthma. Parents of children with asthma described asthma as episodic, acute, uncontrollable symptoms, or a combination of the descriptions (Yoos et al., 2007). The acute illness representation of asthma also was reported by 53% of adults with asthma in Halm et al.'s study (2006) and 15% of participants in Horne and Weinman's (2002) study. Furthermore, acute/chronic illness representations were identified in adolescents with a chronic illness other than asthma. As identified by the acute representation of adolescents in the current study, adolescents with atopic eczema also had more strongly held beliefs towards the acute representation (Salewski, 2003). In interpreting the findings from her study, Salewski (2003) suggested that the acute belief may protect the adolescent from feeling hopeless about his or her future life. Similar to chronic representations of adolescents in the current asthma study, adolescents with diabetes also perceived their illness as a chronic condition (Law, 2002). However, a larger percentage of the adolescents in Law's study (2002) identified their diabetes as a chronic illness. The difference in their perceptions of chronicity could be because the symptoms and management of diabetes involve more complex daily activities than asthma and require a consistent teaching plan (e.g., diet and insulin) that reminds them daily.

Acute/chronic timeline by gender. There were significant main effects for acute/chronic timeline by gender. In this study, the females' higher score reflected more strongly held beliefs about the chronicity of their asthma than the males held. Although adolescent females in the current study's findings had more strongly held beliefs about the chronicity of their asthma, no comparison illness representations studies of adolescent females with asthma were identified in the literature. Physical as well as psychosocial factors could explain the chronic illness representations of females in this study. Females may see their asthma more chronic; Cydulka et al. (2001) reported that adult females described more distressful asthma symptoms, had more severe activity limitations, used more medication, and had more ED visits than males; this also could be the same for adolescent females. Another researcher speculates an association between chronicity and gender. Osborne et al.'s (1998) interpretation of the gender differences in acute and chronic timeline was that women might perceive the same level of airflow differently than men perceive it and with a greater perception of discomfort. Therefore, women's activities of daily living would be impacted greater by their discomfort. As a result, their asthma could be perceived as more chronic because of the impact on their daily lives. There is the possibility that in the current study, as similar to other adolescent studies, some of the adolescent females' perceptions of their chronicity of asthma were influenced by the impact of their symptoms on their lives (Chhabra & Chhabra, 2011; Naleway et al., 2006; Sundell, Bergstrom, Hedlin, Ygge, & Tunsater, 2011). Cydulka et al. (2001) also suggested that women are more attentive to bodily changes and subsequently report more symptoms, which may lead to perceiving asthma as chronic. Adolescence is not only a time of puberty and bodily transitions, it is also a period when emphasis is on females being in tune with bodily changes (Steinberg, 2008). As a result, the females in the current study of adolescents could be more in tune with their bodily changes including variances in their asthma symptoms, thus viewing their condition as ongoing or chronic. A final explanation for the females' chronic timeline representation is that they were socialized into the chronicity of asthma. Asthma is a hereditary illness and the prevalence is higher among adult women, particularly African American women. Therefore, the adolescents in this study might have grandmothers, mothers, or siblings with asthma. They possibly had older females in their families or community network who experienced daily challenges with asthma or served as caregivers for family members in carrying out asthma management tasks within the adolescent's environment (Sterling & Peterson, 2003). Adolescent females then have more of socialization into the daily roles of having a chronic illness like asthma and/or taking care of children with asthma.

In the current study, the lower score for males meant they thought of their asthma as more acute than chronic. No comparison studies were identified to determine the acute/chronic timeline of other adolescent males with asthma. However, the current study's findings reinforce those of Halm et al. (2006) who also identified the puzzling gender difference that more males than females had acute illness representations of asthma. Halm et al. described the finding as a "no symptoms, no asthma" (2006, p. 576) mental model and acknowledged that the episodes of dramatic, fast onset of severe symptoms with little warning may encourage the acute representation of asthma. More explicitly, Halm et al. noted that the episodes identified as "asthma attack" (2006, p. 678) reinforce the acute asthma concept.

Gender differences during adolescence are attributed to "a complexity of changing and interwoven influence" (Galambos, Berebaum, & McHale, 2009, p. 256). The acute timeline representations of the adolescent males in the current study could have been influenced by their developmental stage. Adolescent males are in a developmental period of increased masculinity, peer acceptance, independence, and socialization to gender behaviors and roles. Therefore, for some males, taking the risk of an asthma attack might have been preferable to being different from their friends. Furthermore, using a steroid inhaler when symptoms were not apparent was not coinciding with their increased masculinity and self-reliance (Hammond, 2010; Kyngas, 1999; Rhee et al., 2009). Additionally, adolescent males in Rydstrom et al.'s (2005) study described "distancing themselves from their disease" (p. 392), which included convincing themselves that their disease was not serious or chronic and not embracing the actions associated with the chronicity of the illness.

Despite age differences, the adult males in Halm et al.'s (2006) study and the 14- to 16-year-old males in the current study had similar acute timeline representations of their asthma. Interestingly, the males in both samples could be influenced by socialization to certain behaviors or roles. In an earlier study on gender disparities, men were described as being "underanxious about their health and or ignoring symptoms or illness until the health problem became acute" (Council on Ethical and Judicial Affairs, 1991, p. 561). Woods, Brown, and Engel's (2010) study revealed that men with asthma were more likely to be admitted as an emergency and to die during a hospitalization. Conversely, Naleway et al. (2006) did not find gender differences in self-reports of asthma severity and in asthma hospitalizations.

The findings of the current study support the need for healthcare providers' awareness of males' *and* females' potential acute representations of asthma. Furthermore, the acute/chronic timeline illness representations identified in the current study support the need for future research on adolescents' acute/chronic illness representations.

Acute/chronic timeline by asthma impairment. There was a significant main effect for acute/chronic timeline by asthma impairment, and higher scores meant strongly held beliefs about the chronicity of the condition (Moss-Morris et al., 2002). Thus, the not well controlled group's higher score reflected strongly held beliefs about the chronicity of its asthma. Because no adolescent or adult comparative studies were identified for acute/chronic timeline by asthma impairment, it is difficult to speculate on the findings. Potentially, for the not well controlled group, increased symptoms, use of more medication, and more frequent healthcare visits influenced the chronic timeline illness representations of their asthma. By contrast, the well controlled group's lower score reflected more acute perception of asthma than chronic representation. It is possible that those well controlled adolescents were characterized by histories of few distressing flares, intermittent use of short-acting beta agonists, and infrequent interruption of activities of daily living because of their asthma. Therefore, it is possible that those experiences have contributed to their acute illness representations of their asthma.

Acute/chronic timeline and gender by asthma impairment interaction. There was an interaction effect for acute/chronic timeline by gender and asthma impairment variables. The high scores for both female asthma impairment groups reflected strongly held beliefs about the chronicity of their asthma. The female not well controlled impairment group's higher mean indicated that they thought of their asthma as a more chronic illness than well controlled females and males of both impairment categories. The not well controlled group had been previously identified as having stronger chronic illness representations; therefore, the investigator anticipated that difference in the means of the asthma impairment groups. What was striking was that *both* asthma impairment groups for males had means more associated with an acute illness representation. This puzzling finding is demonstrated further by the current study finding that males make up 48.9% of the total sample and that 63.6% are well controlled and 38.4% are not well controlled—all associating asthma as an acute illness.

No studies were identified that specifically measured acute/chronic timeline illness representations and the gender by asthma impairment interaction in adolescents. However, other asthma studies provided insight into the acute/chronic timeline and gender by asthma impairment findings. Although asthma affects a larger portion of males in early childhood, it is a disease more prevalent in females beginning with adolescence (Fagan et al., 2001; Sears et al., 2003; Tantisira et al., 2008). Females reported higher asthma symptoms and severity (not well controlled) and more behaviors related to the chronicity of asthma (Fagan et al., 2001; Van De Ven et al., 2007). Worse asthma impairment characteristics (e.g., increased airway responsiveness, worse asthma health status) were reported in studies of females when compared with males (Fagan et al., 2001; Tantisira et al., 2008). However, those studies did not add the measurement of the participant’s illness representations. Future studies are needed to explain why both of the males’ asthma impairment groups have acute illness representations.

The investigator conducted a post hoc analysis in order to further confirm the significant gender by asthma impairment interaction. The analysis indicated that there was a significant difference in the mean scores for females well controlled (M = 18.15) and not well controlled (M = 21.54). Furthermore, the results supported that females whose asthma was not well controlled had more beliefs about the chronicity of their asthma than those who were well controlled. Additionally, the post hoc analysis supported the finding that there was no difference in the means of males who were well controlled and those who were not well controlled. Those findings indicated there were no differences in the acute and chronic timeline beliefs among males whose asthma was not well controlled from those who were well controlled.

Cyclical timeline by gender, asthma impairment and gender by asthma impairment. There was no significant effect for cyclical timeline and gender or for cyclical timeline by gender and asthma impairment. However, there was a significant main effect for cyclical timeline and asthma impairment. The interpretation of the cyclical timeline score is that higher mean scores indicate strongly held beliefs about the cyclical nature of asthma (Moss-Morris et al., 2002). Therefore, the not well controlled group's higher mean scores reflected their strongly held beliefs about the cyclical (i.e., episodic) nature of asthma. Furthermore, the more strongly held beliefs for the not well controlled impairment group would be influenced by the frequent cyclical or episodic asthma attacks that would characterize uncontrolled asthma. It also is likely that the well controlled group perceived their asthma as less cyclical or episodic because they could be experiencing less obvious symptoms of their asthma. The small but significant difference between the two asthma impairment groups emphasizes the importance of adolescents in both impairment groups understanding that the cyclical nature of asthma requires adjustments in their self-management behaviors.

Zebracki and Drotar reported that adolescents in general may hold an "out of sight/out of mind" (2004, p. 144) view and may forget or reframe the experience of their asthma symptoms. The cyclical (i.e., episodic) nature of asthma could mean that adolescents develop a pattern of thinking that coincides with the cycles or episodes. Consequently, their asthma would only be thought of when it flares, and when symptoms are no longer noticeable, asthma is not in their thought process. While some could attribute these thoughts to adolescent cognitive immaturity, a similar thought process also was reported by adults in Halm et al.'s (2006) study. Additionally, Haughney et al. (2008) also reported that patients with asthma often doubt the necessity of taking a daily medication for a condition that they perceived as episodic or cyclical. The findings of the current study are consistent with Zebracki and Drotar (2004), Halm et al. (2006), and

Haughney et al. (2008), which all reinforce the need to educate both well controlled and not well controlled adolescents with asthma about the variability of asthma symptoms and how to self-manage their illness.

Consequences illness representation by gender, asthma impairment, and gender by asthma impairment. There was a significant main effect for consequences and asthma impairment. However, there were no significant interact effects for consequences by gender or for consequences and gender by asthma impairment.

Higher consequences illness representation scores are interpreted as having strongly held beliefs about the negative consequences of asthma (Moss-Morris et al., 2002). The not well controlled asthma impairment group held more beliefs about the negative consequences of having asthma. The not well controlled group's consequences beliefs could be associated with having frequent symptoms and subsequent increased use of medication to control their symptoms and resultant decreased physical activity participation. They could view themselves as different from their peers by experiencing more school absences and, therefore, make-up work, and/or using health services more frequently. Consistent with the findings of the current study, the adolescents in the studies of Rich et al. (2002), Rydstrom et al. (2005), Van De Ven et al. (2007), and Velsor-Friedrich et al. (2004) all reported experiencing the negative consequences of asthma. Wirrell, Cheung, and Spier's (2006) findings provided further support for the consequences representations of the not well controlled group in the current study. Despite healthcare professionals reinforcing that many adolescents can improve their asthma control and live with minimal consequences of asthma, 39% of Wirrell et al.'s (2006) participants rated asthma as commonly causing physical disabilities, and 63%

responded that asthma commonly restricts activities. The participants in Wirrell et al.'s (2006) study were identified as potentially having more severe asthma, but their responses reinforced differences in the perceptions of adolescents and healthcare providers and the need to assess adolescents' consequences illness representations.

The significance of the not well controlled group's negative consequences beliefs reinforces the importance of addressing the negative consequences of having asthma from a developmental standpoint. Adolescence is a time of great peer influence and acceptance as well as establishing more independence. As a result, the adolescent with asthma is trying to fit in with peers while also increasing her or his own management of illness; therefore, the negative consequences of having asthma, such as limiting exposure to friends who smoke or having to use an inhaler before a football game, make the adolescent with asthma feel different from their peers, thereby reinforcing the negative consequence of asthma. Often in clinic situations, healthcare providers discuss physical symptoms of asthma but must also address the psychological aspects of asthma and their impact on functioning and quality of life.

Causes (psychological attributes) by gender, asthma impairment, and gender by asthma impairment. There were no significant effects for the causes (psychological attributes) by gender or the causes (psychological attributes) and gender by asthma impairment. There was a significant main effect for the causes (psychological attributes) by asthma impairment. The causes illness representations reflect the individual's beliefs about the causes of his/her illness. The not well controlled asthma impairment group had more strongly held beliefs or connections with the identified psychological attributes. Hence, adolescents in the not well controlled group viewed causes of their asthma as being associated with such psychological attributes as their emotional state, family problems, and stress or worry. Interestingly, in Moss-Morris et al.'s (2002) sample of chronically ill adults (including those with asthma), psychological attributes also were selected as causes of their illnesses. No comparison studies were identified of adolescents' psychological attributes by asthma impairment.

Similar to the findings in the current study, in Horne and Weinman's (2002) study, stress was identified as a causal agent of asthma. In contrast, a higher percentage of participants endorsed pollution, heredity, and chance or fate as causal agents for their asthma (Horne & Weinman, 2002). In contrast to findings of the current study, Rich et al.'s (2002) study identified hereditary, fate, and contact with a contagious person as causes of asthma. The variations in the findings of the current study and Rich et al.'s (2002) study support the need not only to examine adolescents' perceived causes of their asthma but also as previously suggested, to determine appropriate tailored interventions for the identified beliefs. If adolescents identify psychological attributes as causal agents, as in the current study, the healthcare provider must consider whether those agents are impacting the adolescent's psychological status and also contributing to uncontrolled asthma.

Treatment control by gender, asthma impairment, and gender by asthma impairment. There was no significant effect for treatment control by gender or for treatment control and gender by asthma impairment. There was a significant main effect for treatment control by asthma impairment. Moss-Morris et al. (2002) interpreted the higher mean as being representative of positive beliefs about the treatment's controllability of the illness. In the current study, the well controlled high score reflected more positive beliefs about the treatment's controllability of the asthma. One explanation could be that since individuals are well controlled, they are more positive about the effectiveness of their treatment (i.e., asthma medication). Not well controlled adolescents might have experienced one of four scenarios. First, not well controlled adolescents might have taken medication that was ineffective in controlling their asthma. Second, adolescents might have been less adherent with their medication regimen. That is, either they did not take their medication as ordered, or they used the medication inhaler improperly. Third, improper utilization of health care or decreased access to health care would impact the availability of consistent healthcare providers to improve the adolescent's asthma control. Fourth, for adolescents in the not well controlled group, the treatment's controllability could relate to something as simple but important as improper inhaler techniques. As a result using an incorrect technique, the correct dosage of medication would not obtained to control their asthma.

Consistent with the findings of this study, Hagger and Orbell (2003) reported that the more positive beliefs adolescents had about their treatment's controllability, the better their disease state. In the current study, the well controlled adolescents had a higher mean score, which reflected more positive beliefs about the treatment's controllability of their asthma. In contrast, seven of Buston and Wood's (2000) participants were described as "believing firmly that particular elements of their regimen were having no effect on their symptoms" (p. 136). The responses provided by Buston and Wood's (2000) participants potentially could reflect explanations that would be given by not well controlled adolescents in the current study. The adolescents in the not well controlled group had a lower means reflecting less positive beliefs about their treatment's control of their asthma.

It is the difference in the means of the well controlled and not well controlled groups that reinforces the importance of educating adolescents according to their level of asthma impairment and treatment control illness representations. The differences in the two asthma impairment groups support the fact that a single educational strategy does not work effectively with all individuals. It also is important to bring the adolescent with asthma into the clinical discussion with a parent in order to determine the adolescent's perspective on the effectiveness of the treatment plan, his or her adherence to the plan, and whether the appropriate inhaler techniques are being used. The findings regarding treatment control and asthma impairment for this study lend themselves to further clinical considerations and research.

Personal control illness representation by gender, asthma impairment, and gender by asthma impairment. For the current study, there were no significant effects for personal control by gender, personal control by asthma impairment, or personal control and gender by asthma impairment. Most of the adolescents responded that there was much they could do to control their symptoms (66.9%) and to determine whether their asthma improved or worsened (74.4%). The adolescents also responded that the course of their asthma depended on them (54.1%), that they had the power to influence their asthma (52.6%), and that their actions would affect their asthma (70.6%). The responses of the 14- to 16-year-old adolescents in the current study were similar to responses from Cohen et al.'s (2003) sample of adolescents (mean age 15.6 years). Seventy percent of them reported a high sense of personal control they had over their asthma symptoms (Cohen et al., 2003). Similarly, in Horne and Weinman's (2002) study of adults with asthma, 87% of the participants responded that they could do much to control their asthma. Neither Cohen et al. (2003) nor Horne and Weinman (2002) differentiated their responses by gender or asthma impairment.

Aim 1 Research Question 2

The second research question was: What are the differences in emotional representations by gender, asthma impairment, and gender by asthma impairment for African American adolescents (aged 14–16 years) with asthma? Neither the main effect for emotional representations by gender nor interaction effect for emotional representations and gender by asthma impairment was significant. There was a significant main effect for emotional representations by asthma impairment. Higher means indicated higher levels of emotional responses to asthma (Moss-Morris et al., 2002). In the current study, adolescents in the not well controlled group had the higher mean, reflecting more negative emotional responses to their asthma. The IPQ-R assessed whether the adolescent's asthma made them feel depressed, upset, angry, worried, anxious, or afraid (Moss-Morris et al., 2002). Therefore, those adolescents whose asthma was not well controlled reported more of the identified emotions. Whether it is one of the emotions identified, such as depression, or a combination of emotions, these emotions need to be addressed.

Although few studies have measured the emotional illness representations of individuals with asthma, some studies have been conducted to assess individual emotional representations or a combination of the ones that were measured by this study (Bender & Zhang, 2008; Cohen et al. 2003; Rich et al., 2002). As in the current study, in

Bender and Zhang's (2008) study, depression and anxiety were associated with adolescents whose asthma was not well controlled. Additionally, Cohen et al. (2003) reported that 42% of their adolescent participants had experienced anxiety in relation to their asthma, and 39% had expressed fears of dying. Adolescents in Rich et al.'s (2002) study described feelings of isolation from their peers because of their asthma and fears of dying from asthma. The emotional illness representations reported in the current study as well as those reported in the literature reinforce the need to assess emotional representations and to facilitate appropriate support for adolescents' emotions.

Depression and difficulties in coping with stress, fears, and worry are all heightened during adolescence and particularly for females (Steinberg, 2008). For chronically ill adolescents, it is important to address their emotional representations and provide necessary support and therapies. As noted in Bender and Zhang's (2008) study, depression and anxiety can worsen asthma symptoms; conversely, uncontrolled asthma symptoms and the resulting consequences can contribute to an adolescent's depression. Although emotional representations by gender was not significant, depression has been identified as being more prominent among adolescent females; therefore, it should be addressed in clinical interventions and research.

Aim 1 Research Question 3

The final research question for aim 1 examined the differences in means of self-management behaviors of symptom management, medication management, and environmental control by gender, asthma impairment (well controlled and not well controlled), and gender by asthma impairment. Remarkably, there were no significant differences in the means of the self-management behaviors by gender, asthma impairment, or gender by asthma impairment interaction. It was particularly surprisingly that the self-management behaviors findings were not significant in the current study because adolescents' inadequate asthma self-management is a major problem noted clinically and in the literature (Joseph et al., 2010; Sin et al., 2005). The lack of significant differences could be attributed to the small sample size, unequal *N* size, or type of self-management behavior instrument used. Although Pillai's Trace statistics were used as a backup to the Wilks' Lambda because it is more robust in its measurements (Pallant, 2010; Tabachnick & Fidell, 2007), the Pillai's Trace statistics were not significant either.

Although for the current study the results were not significant, the not well controlled group had slightly higher means of symptom management (62.53 males and 58.33 females) and environmental control management (31.87 males and 30.06 females), and not well controlled males had the highest level of symptom management of the four impairment by gender groups. It could be that having uncontrolled asthma required those adolescents to be more engaged with trying to manage their symptoms and environment than those whose asthma was well controlled. Because of the episodic nature of asthma, another interpretation would be that those with not well controlled asthma or even very poorly controlled asthma were more aware at the time of the need for symptom management and environmental control.

Overall, the current study demonstrates there is room for improvement in self-management among the adolescents. The self-management means were 58.3 for symptom management (range 0–109), 55.8 for medication management (range 7–108), and 29.8 for environmental control (range 2–60) reflecting moderate levels of self-management. The ASCPI that was used to measure self-management behaviors did not provide guidelines for interpretation of self-care practice scores with the greater population. However, the discussion of compliance and adherence in literature provides insight into management. Sin et al. (2005) and Rhee et al. (2011) reported that adolescents missed identification of early symptoms and waited too long before intervening during an exacerbation. Management for asthma varies from 3% to 88% with an average of 50%, and the 50% nonadherence occurs in pediatric patients as well as adults (Bauman et al., 2000). Less than optimal management found in the literature was consistent with the less than optimal management found in the current study. Bauman et al. acknowledged that "since most people are unable or unwilling to accept and adhere to medical advice" (2000, p. 74), there is a need for research to identify strategies to improve compliance or adherence among patients. The responses reported by adolescents in the current study also support the need identified in the literature for further research and intervention development to improve the self-management behaviors of adolescents.

Aim 2 Research Question 1

The first research question for aim 2 was: What are the bivariate relationships between cognitive (identity, timeline, consequences, cause, and control), emotional representations, and asthma self-management behaviors (symptom management, medication management, and environmental control) in African American adolescents (aged 14–16 years) with asthma?

Four significant bivariate relationships were identified between cognitive illness representations and self-management behaviors. From highest strength of correlation to the lowest, those variables are: (1) treatment control and symptom management,

(2) consequences and symptom management, (3) identity and environmental control management, and (4) identity and symptom management.

Treatment control illness representations and symptom management. The relationship between the treatment control variable and symptom management had the highest correlation. However, the strength of that correlation was considered small and represented 6.25% of the shared variance (Cohen 1988; Pallant, 2010). Despite the small strength of the relationship, the correlation is significant from the statistical and clinical perspectives. Treatment control illness representations reflect the adolescents' beliefs about whether their treatments can control their asthma (Moss-Morris et al., 2002). When assessing treatment control illness representations, as in the current study, the major component of treatment control is medication control. On one hand, symptoms may stimulate medication use by acting as a reminder or by reinforcing beliefs about its necessity (Horne, 2011). Conversely, the absence of severe symptoms might cause an adolescent to interpret her/his condition as more benign that it actually is and hence to doubt the need for treatment (Horne, 2011).

Consequences illness representations and symptom management. The second most significant correlation identified was between the consequences illness representations variable and the symptom management variable. Consequences illness representations are based on beliefs about the negative consequences of having asthma (Moss-Morris et al., 2002). Insel, Meek, and Leventhal (2005) further emphasized that the consequences beliefs are based on imagined and felt experiences. In the current study, the small, positive relationship represented 4.41% of the shared variance, but it was still important to take into account when educating adolescents with asthma (Cohen, 1988;

Pallant, 2010). For example, the wheezing adolescent football player who believes that his asthma is keeping him from achieving his top status on the team could deny the symptoms and remain in the game, hence exhibiting poor symptom management.

Cohen et al.'s study (2003) as well as the current study highlight the importance of examining adolescents' views and feelings about the negative aspects of having asthma. In Cohen et al.'s (2003) study, 29% of the adolescents were embarrassed by their asthma, and 32% were embarrassed about taking asthma medication in view of their friends. Furthermore, in that study, participants who had not disclosed their asthma to their friends were more likely to feel embarrassed by their disease ($r = 0.95$, $p < 0.001$).

Identity illness representations and environmental control management. There was a small positive correlation between identity illness representations and environmental control management. The relationship represented 4% of the shared variance. To identify the identity illness representations, the IPQ-R first asks adolescents to rate using a yes/no format whether or not they have experienced each asthma symptom. Then, the adolescents are asked whether or not they believe the symptoms to be specifically related to their asthma. The latter scores are used for the identity subscale. In the current study, the symptoms identified as related to asthma, such as wheezing or shortness of breath, would be used by the adolescent when making environmental control decisions. The adolescent who recognized that wheezing was one of his asthma symptoms would have to determine if he should leave a smoke-filled room when he starts wheezing. An adolescent who identifies shortness of breath as an asthma symptom would have to consider whether she was having shortness of breath while visiting a friend's home because of their cat.

Environmental control is an important aspect of the self-management behaviors. It is particularly a key behavior used to assess with those in the adolescent developmental stage because environmental control management of those adolescents is influenced by wanting to be like their peers. The findings of this study are consistent with Everhardt et al.'s study (2011) where more optimal environmental control was associated with more positive asthma control and lower levels of functional limitations.

Identity illness representations and symptom management. There was a small positive correlation between identity illness representations and symptom management. It is interesting that there was only 3.24% of shared variance because identity illness representations are based on beliefs that symptoms relate to one's asthma and symptom management behaviors is the other variable. Two factors to consider with the current study's sample were the asthma impairment levels of the adolescents and the sample's prior asthma education. The fact that 58.6% of the sample was in the not well controlled group could reflect some deficits in symptom management. The mean for symptom management for the not well controlled group was 59.95 (range 11–109) reflecting moderate levels of symptom management for the study's adolescents. On the other hand, the 41.4% of the sample who were well controlled might have had fewer identity illness representations and the need for symptom management thus impacting the identity–symptom management relationship. The well controlled group's mean was 56.00 (range 0–88) reflecting moderate levels in symptom management. Although that moderate level corresponds with the level of management in the literature of pediatric and adult patients, it is still not adequate symptom management and reflects the need for asthma education and self-management interventions (Bauman, 2000). The sample's limited formal asthma education also could have impacted the adolescents' connection of their symptoms with symptom management. Only 19.5% of the sample had received formal asthma education. However, the investigator acknowledges the informal asthma education that adolescents might have received during office visits.

Unexpectedly, no bivariate relationships were identified between illness representations and medication management. With the number of relationships identified in other studies between illness representations and medication management, it seemed likely that a relationship would be identified in the current study. For example, in Byer and Myers' (2000) study, identity illness representations explained 7.0% of the variance in medication management. Although 7% is still low, that study showed more of a relationship between identity and medication management than the correlation of identity illness representations and symptom management in the current study. Although they were not significant in the current study, additional correlations between illness representations and medication management in the literature were acute/chronic timeline and medication management as well as consequences and medication management (Byer & Meyers, 2000; Horne & Weinman, 2002).

Aim 2 Research Question 2

The second research question under aim 2 was to explore the associations between symptom management and the set of cognitive representations (identity, timeline, consequences, cause, and control), emotional representations, gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma.

The PI conducted multiple regression analysis in order to determine associations between cognitive representations, emotional representations, gender, and asthma impairment. Two of the cognitive illness representations, treatment control and consequences, were statistically significant independent predictors of symptom management. The treatment control subscale contributed 6.25% of the shared variance and 5.4% of a unique contribution to symptom management. The consequences subscale provided 4.41% of the explanation of the shared variance and 3.7% as a unique contributor to symptom management. The application of the findings to the current sample would reflect that adolescents who held more positive beliefs that their treatment could control their asthma and reported more consequences of having asthma were more likely to participate in symptom management. More specifically, those adolescents who thought that their treatment (i.e., medication) could control their asthma were more likely to participate in symptom management. Since consequences was a predictor of symptom management in the current study, adolescents who had more beliefs about the functional, social, psychological, and economic consequences of asthma were more likely to exhibit symptom management behaviors. Treatment control and consequences account for approximately 10% of the explained shared variance in symptom management. Therefore, there is still the potential for the influence of the unaccounted variance.

Although the investigator anticipated that two of the variables, identity and asthma impairment, would be predictors, they were not. The identity illness representations had a small positive correlation with symptom management, but identity was not a predictor of symptom management. Since identity labels the symptoms that the individual relates to his or her asthma, it seemed there would be a greater association between identity and symptom management. The second variable that the investigator anticipated to be a predictor was asthma impairment. The asthma impairment variable was identified with seven out of the eight illness representations that had medium or small effect sizes. Since symptom management has the potential for influencing the level of impairment, it was interesting that it was not a predictor. The asthma impairment variable was identified with seven out of the eight illness representations that had medium or small effect sizes. There are limited studies that focus on symptom management; more prominent in the literature are studies that target several self-management behaviors, including symptom management.

Aim 2 Research Question 3

The third research question under aim 2 addressed the associations between medication management and the set of cognitive representations (identity, timeline, consequences, cause, and control), emotional representations, gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma. Contrary to the expectation, in the final multiple regression model for the current study, none of the illness representations variables or gender or impairment in predicting medication management were statistically significant. Medication management is a major component of asthma self-management; therefore, it was anticipated that at least one of the variables (cognitive representations, emotional representations, gender, or asthma impairment) would be a predictor.

Although none of the variables were significant predictors in the current study, a major focus of recent illness representations studies has been on medication management, particularly adherence to medication. That focus has been influenced by the clinical shift to the use of preventer medication in order to decrease morbidity and mortality rates of asthma. As with the current study, Cohen et al.'s (2003) participants were adolescents with asthma. The study investigated the contributions of illness representations to two self-management behaviors: taking an inhaler to school and use of preventive medication. Personal control and treatment control were associated with increased transport of the inhaler, and emotional representations (particularly embarrassment) decreased carrying and using inhalers (Cohen et al., 2003). Other studies have been conducted with adults with asthma to determine associations between illness representations and adherence. In Byer and Meyer's (2000) study, causes, chronic timeline, and identity were predictors of adherence. In Halm et al.'s (2006) study, participants who had acute, episodic representations of asthma (acute/chronic timeline) had poorer adherence to inhaled corticosteroids and other self-management behaviors. Treatment control and consequences of asthma were associated with the non-adherent medication management behaviors of participants in Horne and Weinman's (2002) study. Jessop and Rutter (2003) identified identity, causes, and cure-control as predictors of current adherence while cure-control and chronic timeline were predictors of future adherence. Despite the nonsignificant findings in the current study, medication management is a key component of asthma control in adolescents. Therefore, it is important to conduct future research to determine if the illness representations in the literature are associated with medication management in other adolescent studies.

Aim 2 Research Question 4

The final research question for the current study was: What are the associations between environmental control and the set of cognitive representations (identity, timeline, consequences, cause, and control), emotional representations, gender, and asthma impairment in African American adolescents (aged 14–16 years) with asthma?

In this multiple regression model, none of the variables (cognitive and emotional illness representations, gender, and asthma impairment) were statistically significant predictors of environmental control. Although identity and environmental control shared a small positive correlation and 4% of variance, identity was not a predictor of environmental control. The multiple regression model was reviewed to determine the illness representation that was closest to a level of significance for environmental control. Emotional representations were identified as the illness representation that was the closest to being statistically significant but that value was .103. It is an interesting consideration that emotional representations would be associated with environmental control management. However, when analyzed, the environmental control questions ask for responses to what percentage of the time the individual avoids triggers of their asthma in certain settings (e.g., home, a friend's house, school, etc.). Examples of triggers such as pets, dust, smoke, and playing sports are provided in the instructions. Perhaps it is the reminders of their triggers—negative experiences in certain settings or environmental control decisions—that would evoke emotional responses to environmental control questions, or, if their emotions, as identified in the IPQ-R (e.g., depressed, anxious, worried, upset, or afraid), potentially served as the impetus for them to engage in environmental control. One example of the emotional concern is the adolescent whose asthma is triggered by cat dander and is afraid of having to go to the emergency room if she stays overnight in the home of a friend who owns a cat. Another example is an adolescent who wants to fit in with his peers but knows that his best friend's cigarette smoke is triggering his asthma. These examples support the value of identifying predictors of environmental control in order to support self-management behaviors that will improve outcomes for adolescents with asthma.

There were no other studies identified that focused on illness representations and environmental control. However, it is an important topic because environmental control (i.e., environmental exposures and strategies to control them) has been identified as a contributor to greater asthma morbidity, especially for minorities living in urban environments (Everhardt et al., 2011). It would be of value to identify the beliefs or perceptions that would promote better environmental control and potentially decrease environmental contributors to the morbidity rates of children and adolescents with asthma.

Summary of Research Findings

The current study addressed a total of seven research questions. Differences in the means of cognitive representations revealed significant effects for the following variables: (1) acute/chronic timeline by gender (main effect), (2) acute/chronic timeline by asthma impairment (main effect), (3) acute/chronic timeline and gender by asthma impairment (interaction effect), (4) cyclical timeline by asthma impairment (main effect), (5) consequences by asthma impairment (main effect), (6) treatment control by asthma impairment (main effect), and (7) causes (psychological attributes) by asthma impairment (main effect). Significant differences in emotional representations by asthma impairment also were identified as a main effect. However, there were no significant differences in the means of self-management behaviors by gender, asthma impairment, or gender by asthma impairment. Significant bivariate relationships determined through their correlations included: (1) treatment control and symptom management, (2) consequences and symptom management, (3) identity and environmental control management, and (4) identity and symptom management. Multiple regression analyses revealed significant associations between treatment control and symptom management as well as consequences and symptom management. No relationships were identified between medication management or environmental control and the set of cognitive representations (identity, timeline, consequences, cause, and control), emotional representations, gender, and asthma impairment. A post hoc analysis of the acute/chronic timeline illness representations gender by asthma impairment interaction confirmed there was a significant difference in the chronic timeline illness representations of the well controlled and not well controlled females. However, there was no significant difference in the means of the well controlled and not well controlled males.

Anecdotal Noteworthy Findings and Potential Impact on Self-management Behaviors

Aim 2, research questions 2, 3, and 4 focused on the self-management behaviors (symptom management, medication management, and environmental control) of adolescents with asthma. There were two anecdotal noteworthy findings that could have impacted the adolescents' reported self-management behaviors. First, the sample had limited asthma education or self-management preparation. The findings of the current study revealed that 80.5% of the adolescents had no *formal* asthma education. The adolescents also indicated that their usual sites of asthma care were general doctor (54.1%), health department (13.5%), specialist (26.3%), and ED (6.0%). What was not identified by this study was the type of *informal* asthma education that might have been provided during visits to their usual sites of care. The lack of asthma education could have influenced the percentage of adolescents who exhibited appropriate self-management behaviors. Asthma education has been identified as an important component of a comprehensive asthma self-management program for adolescents (NHLBI, 2007).

Second, over 70% of the adolescents in this study did not consistently use an action plan on the self-management of their asthma. The percentage of adolescents identified as not consistently using an action plan was based on those who never followed a plan (25.6%), did not have a plan (14.3%), or followed their plans 50% of the time or less (57.2%). The expert panel who developed the “Practical Guide for the Diagnosis and Management of Asthma: Expert Panel Report 3” recommended that “all patients have a written asthma action plan that includes instructions for both daily management and actions to manage worsening symptoms” (NHLBI, 2007, p. 98). The recommendations for asthma action plans and asthma self-management education have been made in order to decrease morbidity rates and improve asthma outcomes.

Sample and Generalizability

This section focuses on specific sample and setting characteristics and relates those characteristics to the potential generalizability of the results. The sample characteristics addressed are: (1) race/ethnicity, (2) developmental stage and ages, (3) parents’ income, (4) location of housing, (5) formal asthma education and action plans, and (6) self-management behaviors.

First, the sample was composed of African Americans, limiting generalizability of the results to this ethnic group. Few studies have been conducted with samples that are comprised only of African Americans with asthma. This study will contribute to the body of literature on African Americans with asthma.

Second, the participants in the current study were adolescents, 14 through 16 years of age. Therefore, the findings are relevant to young people in the developmental stage of middle adolescence. More specifically, the current study contributes to the limited body of literature on African American middle-stage adolescents with asthma. This is an understudied population and Joseph et al. (2007) and Sin et al. (2005) are among the few studies in this area.

Third, the generalizability of the findings often is characterized by the income or socioeconomic status of the parents. In the current study, the parents' income level was not ascertained through the demographics form for the adolescents. Often adolescents are not aware of the specific income range of their parents. Therefore, questions about the number of days that the family went hungry and the family's money for living were asked in order to obtain proxy information about the family's income level. Three of the adolescents reported days when the family went hungry, which potentially indicated a low family income.

The education level of adolescents' parents is an indicator of their socioeconomic status. In the current study, the educational attainment of the father and mother was assessed according to the education level completed. That data was compared with national statistics in order to provide a frame of reference for the generalizability of the sample in terms of parents' income and educational levels. According to 2010 national data, the percentage of African Americans greater than or equal to 25 years of age who had earned at least a high school diploma was 84.2% (U. S. Census Bureau, 2012). For the current study, 78.9% of the parents had finished high school. The educational attainment of at least a bachelor's degree was categorized nationally by race and gender: 17.7 % of African American men and 21.4% of African American women. For the current study, the question asked about completion of a bachelor's degree or higher, and 17.3% of the fathers and 22.6% of the mothers had achieved that status. Therefore, the educational level of the parents of the adolescents was slightly below the national percentage for African Americans with a high school degree. Furthermore, based on the national status of African American men and women with bachelor's degrees or higher, for the current study, the fathers had a slightly lower percentage and the mothers had a relatively higher percentage of bachelor's degrees.

Generalizability of the sample in relation to the income of the parents could be described with poverty levels of the counties of residence of the adolescents. Ten of the eleven counties represented by the adolescents had a greater portion of residents with poverty rates greater than or equal to the national 2009 poverty rate.

Although specific income levels of the parents of the adolescents in the current study could not be determined, the descriptions of the hunger in the family, family's money for living, educational levels of parents, and poverty levels of the adolescents' counties of residence contribute pertinent information to gauge the generalizability of the findings. There is support that there was diversity in the parental income levels of the adolescents.

Fourth, the current study was conducted with adolescents who represented counties throughout a Midwestern state in the U. S. Although a large percentage (74.4%) of the adolescents was from a metropolitan county, other adolescents were from counties ranging from suburban areas to farming communities. Although predominately metropolitan, the generalizability was broadened because of the diversity in populations represented by the sample.

Fifth, adolescents in the current study were reflective of adolescents who have had little formal asthma education and more informal asthma education. Only 19.5% of the sample had attended formal asthma education. The majority of their asthma care was provided by general physicians (54.1%), health department clinics (14.3%), or specialist offices (25.6%). Therefore, the majority of the adolescents were receiving their asthma education during office visits for acute or routine care. It is of note that 6% of the adolescents identified the ED as the site for most of their asthma care.

Finally, the generalizability of this study is considered for the applicability of the results to adolescents who exhibit deficits in their self-management behaviors. Performing symptom management was reported by 58.3% of the sample, while 55.8% indicated that they manage their medication, and 29.8% are involved with environmental control. Reflective of those management behaviors are responses to such questions as the percentage of time they monitor themselves for asthma symptoms (65% monitored symptoms 50% of the time or less), use a bronchodilator inhaler at the first sign of difficulty breathing (38.3% reported waiting 50% of the time or more before using their bronchodilator), or avoided triggers at friends' homes (57.9% indicated they avoided triggers 50% of the time or less). The percentages of symptom management, medication management, and environmental control demonstrated in the current study support that the participants in the study are representative of adolescents who do not exhibit high percentages of self-management behaviors.

Strengths and Limitations

Strengths

The identified strengths of this study are: (1) sample size, (2) male representation, (3) adolescent-only sample, (4) use of primary data, (5) use of a standardized measure of illness representations and asthma control, and (6) lack of missing data.

First, the sample size of this study was 133. The fact that it exceeded 100 increases the internal validity of the research (Halm et al., 2006; Horne & Weinman, 2002; Kaptein et al., 2008). The investigator acknowledges that the sample size also could be viewed as a limitation because of the use of multiple regression analyses and the expectation of sample size and number of variables. To conduct multiple regressions, it was recommended that the total size of the sample should be greater than or equal to 50 + 8m where m equals the number of independent variables (Tabachnick & Fidell, 2007). The current study had 10 variables; therefore, a sample of 130 was recommended—the current study had a sample size of 133. Furthermore, when testing for individual predictors, the recommended sample total was greater than or equal to 104 + m. In order to achieve that recommendation, a sample of 114 was needed for the current sample. The study's total sample of 133 met the criteria. It is still believed that the sample size is a strength given that the study focused on African Americans who are historically underrepresented in participation in research and the adolescents were recruited through a statewide collaborative effort of school, healthcare, and community entities.

Second, the number of males represented in this study proves to be a strength because male participation in research often is limited. The fact that this study included

65 males and 68 females provided valuable data on males' perspectives of their illness, in particularly asthma.

The third strength is that the current study focused particularly on adolescents with asthma. The illness representations and self-management of adolescents are of concern because of their varying levels of asthma impairment (especially their poor control of asthma), inadequate self-management behaviors, and mortality rates. For adolescents with asthma, added to the complexity of asthma self-management are the developmental changes and challenges they are encountering. By targeting the adolescent developmental stage, the current study provides input on their beliefs and perceptions at this stage of maturity and identifies misperceptions to correct so they are not carried into their adult self-management behaviors. The current study is particularly important because the number of studies that focus on adolescents is very limited and illness representations studies of adolescents with asthma are minimal. Therefore, the current study contributes to the specific literature on adolescents with asthma.

Fourth, the use of primary data is to be considered a strength because the researcher was able to design the study, use a comprehensive number of the illness representations variables, assess self-management behaviors, and incorporate other variables such as gender and asthma impairment for evaluation. Additionally, the researcher broadened the assessment of self-management behaviors by expanding the ASCPI to obtain more information on symptom management, medication management, and environmental control.

The fifth strength was the use of a standardized measure of illness representations and asthma control. The IPQ is a long-recognized, valid tool that has been used in a number of studies (Kaptein et al., 2008). The current study used the IPQ-R which is a revised version that was developed to expand the number of cognitive representations and to add the dimension of emotional representation (Moss-Morris et al., 2002). This instrument was especially beneficial given the targeted group of adolescents. It allowed the researcher the opportunity to capture emotional representations that have been found to be significant contributors to asthma outcomes in the adolescent developmental stage (Cohen et al., 2003). More specifically, the asthma version of the IPQ-R was used in the current study and permitted the adolescent to respond to questions that focused on asthma. The ACT was used to determine the asthma impairment groups of adolescents. The ACT has been used in studies and clinical settings with children, adolescents, and adults and has been recommended by the expert panel for the "Practical Guide for the Diagnosis and Management of Asthma" (NHLBI, 2007).

Finally, the lack of missing data was a strength. The few missing items were randomly dispersed and reduced the number of subjects and/or cases that required deletion from the analyses.

Limitations

The identified limitations of this study are: (1) race, (2) number of adolescents in the gender/asthma impairment groups, (3) description of family's income, (4) power, (5) design of the study, and (6) instruments.

First, race is considered a limitation in terms of generalizability of the findings. However, it may be viewed as a strength in terms of contributions to inquiries about health disparities, and especially asthma disparities. Second, the number of adolescents in each gender/asthma impairment group varied. In the well controlled groups, the numbers were 35 males versus 20 females. For the not well controlled groups, males comprised 30 of the 78 adolescents, whereas, females numbered 48.

Third, the lack of specific information about the family's income for each adolescent was identified as a limitation. The family income of each adolescent was gauged by asking the adolescent to respond whether the family did not have enough money, had enough money, or had more than enough money. A better estimate of the family's income would have been to have the adolescent respond to whether he/she received reduced lunch or free lunch.

Fourth, the lack of adequate power impacted the findings of the current study. Although the sample size was 133 and there were significant findings with the study, the researcher conducted a power analysis to determine if the lack of power contributed to the nonsignificant results. The analysis was based on a desired power level of 80% or better (Tabachnick & Fidell, 2007). The power analysis for ANOVA revealed that there were variations in the percentages of power associated with the illness representations and self-management behaviors. The highest percentages of power with symptom management were treatment control (87.1%) and consequences (67.7%); the power for the remaining illness representations, gender, and asthma impairment lowest percentages ranged from 5% to 35% (see Table L1). The power for illness representations, gender, and asthma impairment associated with medication management and environmental control were 5% to 48% (see Table L2 and Table L3). A power analysis also was conducted for the MANOVA statistical analysis. The observed power ranged from 5% to 14% (see Table L4). The limited power for the current study provided explanations for some of the nonsignificant findings and provided support to conduct future studies on illness representations and self-management behaviors with adequate power for the statistical techniques.

Fifth, the study was designed for only a single assessment of adolescents' illness representations and self-management behaviors. Longitudinal assessments of the adolescents' illness representations and self-management behaviors would provide the opportunity for more comprehensive evaluations of the adolescents. Since adolescence is a stage of cognitive maturity and increased decision-making skills, a longitudinal study would provide the opportunity to determine changes in illness representations and self-management behaviors.

Sixth, there were two limitations related to the study's instruments. The Cronbach's alpha for the IPQ-R identity subscale was .394, which was considered inadequate. Such a low Cronbach's alpha value could lead to inaccurate results. The second limitation related to study instruments was associated with the use of the ASCPI. The instrument was selected because of the limited number of tools available to measure self-management behaviors of adolescents and because in studies it had a Cronbach's alpha of 0.86 to 0.89 (Fitzpatrick & Frey, 1993; Velsor-Friedrich et al., 2005; Velsor-Friedrich et al., 2004). The ASCPI has been used successfully to measure self-management practices in studies by Velsor-Friedrich et al. (2005, 2004). However, Velsor-Friedrich (2005, 2004) used the total score for evaluation of findings. The current study focused more specifically on the totals for each of the subscales of self-management behaviors (symptom, medication, and environmental control). Therefore, the investigator had to add questions to the original instrument then pilot the revised instrument. Although the Cronbach's alpha for each of the three subscales was high (symptom .75, medication .72, and environmental control .79) and the subscales had been piloted, the current study was the first use of the subscales to measure self-management behaviors. The intent in using the subscales was to evaluate each of those behaviors in order to target future education or interventions necessary to improve asthma outcomes.

Implications for Nursing and Healthcare

Noteworthy Findings Related to Study Aims

There were several noteworthy findings that have major clinical implications. The first noteworthy finding was related to the research question investigating the acute/chronic illness timeline representation. Statistically, the acute/chronic timeline by gender effect was significant. The overwhelming importance, however, is the clinical implications with African American males with asthma. All of the males in this study perceived their asthma as an acute illness. This could lead to delay in treatment among African American males 14–16 years of age and help to explain the higher asthma mortality rates among African American males in comparison to males of other races and all females (Akimbami et al., 2009; CDC, 2002). The acute illness representation also could lead to increased morbidity and mortality because of the underuse of anti-inflammatory therapy and the overuse of short-acting beta agonists (Fritz et al., 2010; Halm et al., 2006). Indeed, African American adolescent males are more likely to delay treatment than females (Murray et al., 1997; Pawar & Smith, 2006). Potentially, the consequences of males having an acute illness representation are the denial of symptoms, underutilization of health care resulting in less education about the chronic nature of asthma, and decreased socialization to having a chronic illness (Fritz et al., 2010;

Halm et al., 2006, Jarrett, Bellamy, & Adeyemi, 2007; Rhee et al., 2008). It is important to determine any misperceptions that African American males might have regarding their asthma and to provide tailored asthma education to their perceptions before they enter adulthood. Such tailored interventions have the potential of positively impacting mortality, morbidity, and health disparities.

The second noteworthy finding was related to asthma impairment. The episodic nature of asthma creates periods when the adolescent seems to be well controlled, but exposure to an asthma trigger can precipitate acute respiratory problems (Halm et al., 2006). It is crucial that those adolescents who may be well controlled for varying periods of time are not falsely lulled into thinking that they have no asthma disease. It also is critical that not well controlled adolescents recognize how their self-management behaviors can positively or negatively impact their level of asthma control. Additionally, there were significant differences in the means of the acute/chronic timeline, cyclical timeline, consequences, cause, treatment control, and emotional illness representations by asthma impairment. Therefore, it is vital in the clinical setting to address illness representations and beliefs with the awareness of potential differences in representations based on the adolescent's level of asthma impairment. It also is important that both asthma impairment groups are educated about asthma as a chronic illness, variations in levels of asthma control, and appropriate self-management behaviors (Schreck & Williams, 2006; Sin et al., 2005; Zebracki & Drotar, 2004).

Noteworthy Anecdotal Findings

There were other noteworthy anecdotal findings not related to the aims. The first noteworthy point was the sample's limited asthma education or self-management preparation. The findings of the current study revealed that 80.5% of the adolescents had no formal asthma education. What was not identified by this study was the type of informal asthma education that might have been provided during visits to their usual sites of care. However, the lack of asthma education could have impacted the self-management behaviors exhibited by the adolescents in the current study. This noteworthy finding supports efforts to provide comprehensive asthma education for adolescents with asthma in order to improve their asthma outcomes. Furthermore, there are clinical implications not only for providing appropriate asthma education to meet the adolescent's needs but also to routinely reinforce that asthma education with the adolescent (Joseph et al., 2007; Sin et al., 2005).

Second, there was limited use of asthma action plans among the adolescents in the current study. Over 70% of the adolescents in this study did not have the consistent use of an action plan for their asthma. The expert panel who developed the "Practical Guide for the Diagnosis and Management of Asthma" (NHLBI, 2007) not only recommended that all patients have written asthma action plans but also that providers include adolescents in the development of their action plans and to review their adherence and concerns.

The third anecdotal noteworthy aspect of this study was the number of significant findings suggesting that nurses and other healthcare professionals who gain a greater awareness of an adolescent's cognitive and emotional illness representations will be better able to more effectively assist them in self-management behaviors. We know that nurses and other healthcare professionals play a vital role in improving self-management skills and changing perceptions of illness and the treatment of asthma. As depicted by the significant emotional representations and psychological attributes identified as causes of asthma, it also is important that healthcare providers address psychological concerns of adolescents with asthma. Furthermore, the need to be cognizant of differences in illness representations by gender and asthma impairment is reinforced.

Lastly, the findings of this study also could provide a guide for improving patient-provider communication. Communication with patients is enhanced when healthcare professionals show interest in the patient's beliefs and emotions regarding their illness (Kaptein et al., 2008; Sawyer & Aroni, 2005; Sidora-Arcoleo, Yoos, Kitzman, McMullen, & Anson, 2008). This is particularly important when treating adolescents who can be reluctant to engage in such conversations. The illness representations framework could be a guide to explore adolescents' perceptions of asthma. According to de Ridder, Theunissen, and van Dulmen (2007), explicit conversations about illness representations during consultations results in more attention to patient concerns and lifestyle issues and an overall improvement in patient-healthcare professional communication. Their findings showed that after a brief training, healthcare professionals were able to change their communication style in a way that allowed for a more thorough consideration of patient self-management (de Ridder et al., 2007). Thus translating illness representations and self-management behaviors research into clinical practice can enhance patient-provider communication and improve asthma outcomes (Sidora-Arcoleo, Feldman, Serebrisky, & Spray, 2010). Furthermore, incorporating such illness representations and self-management training in our nursing and health provider education programs will prove only to be beneficial in more effective disease management, and in particular, asthma.

Of particular note is the way in which the development of more effective asthma action plans for treatment and daily self-management plans can be impacted by illness representations communication. By making the adolescent part of the conversation at the outset, the nurse or other healthcare professional is able to identify and correct misperceptions in illness representations (McAndrew et al., 2008). Furthermore, the nurse or other healthcare professional will be able to accurately tailor asthma education to the specific needs of the individual (McAndrew et al., 2008). Two examples of how this can be implemented using the findings of the current study follow.

Our first patient is “Robert.” He is a 16-year-old whose asthma is not well controlled, and he has an acute, episodic illness representation of his asthma (*acute/chronic*, *cyclical timelines*). Robert also reports “my asthma keeps me from playing soccer (*consequences*) and I get anxious when I think about my illness (*emotional representations*).” Based upon Robert’s illness representations evaluation, expressed beliefs, and level of asthma impairment, the healthcare professional can ascertain that Robert has inadequate self-management behaviors.

Our second patient is “Joan,” a 14-year-old female, whose asthma is well controlled. She has a chronic illness perception of her asthma (*acute/chronic timeline*) and is confident that her bronchodilator and inhaled steroid can control her asthma (*treatment control*). However, she feels depressed at times (*emotional representations*) because her asthma sets her apart from her peers.

The implication is that the healthcare professional can be proactive in eliciting Robert’s misperceptions of his asthma and Joan’s emotional response to her asthma then develop specific asthma self-management (including treatment) plans for each and provide a tailored asthma education plan.

Implications of the Study for Future Research

Findings from this study can guide future research. First, illness representations and relationships with various asthma outcomes is an emerging area of research (Kaptein et al., 2008). A unique finding of this study was the differences in illness representations by asthma impairment. Future studies could continue to evaluate differences in illness representation by asthma impairment in order to further identify beliefs and perceptions specific to certain impairment groups. Additional research will assist in determining whether illness representations “drive” asthma impairment levels and self-management behaviors. In the current study, the adolescents were grouped into two categories, well controlled and not well controlled. Future studies will provide the opportunity to determine associations between illness representations and more specific asthma impairment groups (well controlled, not well controlled, and very poorly controlled). In the current study, there was an association between only one self-management behavior (symptom management) and illness representations. Studies have identified the lack of adequate asthma self-management among adolescents, including the descriptive findings of the current study. Future research is needed to determine relationships between such variables as illness representations, gender, asthma impairment, self-management behaviors, and self-efficacy as a basis for improving asthma outcomes. Self-efficacy has been identified in other adolescent studies as an important contributor to improved self-management behaviors among adolescents (Clark et al., 2010; Sawyer, Drew, & Duncan, 2007; Velsor-Friedrich et al., 2005).

Second, the current findings indicate the need for continuing research which will lead to the development of an intervention that will incorporate illness representations and assess their impact on asthma outcomes. There are illness representations and self-management behaviors intervention studies that have been conducted with adults with various illnesses such as diabetes, arthritis, lupus, myocardial infarctions, cystic fibrosis, and asthma; however, the literature reflects that there is a particular need for the development of such an intervention specific to adolescents with asthma.

Third, in the current study, a surprising finding was that the variables treatment control and consequences illness representations were significant findings in three of the seven research questions. Further research with a larger sample could provide more of an explanation of the impact those two illness representations have on asthma impairment and symptom management.

Fourth, data analysis was not conducted in this study for two of the illness representations (illness coherence and self-reported causes of asthma). Illness coherence was not analyzed in the current study because it was not in the earlier developed self-regulation model used as the framework for this study. The data were collected for future research because illness coherence is a component of the IPQ-R but the model selected had not been updated to include all components of the IPQ-R. It is important to analyze this illness representation because it has been highly significant and had strong associations with self-management behaviors. Based upon self-reported causes of asthma by adolescents in this study, the researcher believes that future research should be conducted. That analyses will require a qualitative analyses of the responses, and an overview of the adolescents' responses revealed causes identified by this sample that were not in Moss-Morris et al.'s (2002) original list. Thus, the analyses of self-reported causes have the potential to contribute to the literature.

Fifth, one significant finding of this study was that males in *both* asthma impairment groups had acute illness representations of their asthma. This warrants further study because of the potential impact on medication management, morbidity rates, and health disparities among African American males. What future studies need to determine is if this was particular to African American males or indicative of males in general.

Sixth, the differences in the Children's Hospital High Risk Asthma Clinic adolescents' asthma control test and pulmonary function results provided valuable insight into the lung functions, asthma management, and illness perceptions among adolescents with asthma. This will be helpful because the lung functions and illness perceptions of some of the adolescents revealed critical information that would explain some of their poor asthma self-management behaviors. Extending the investigation of the relationships between asthma control test scores, PFTs, illness representations of the adolescents and their parents, and self-management behaviors of high risk asthma adolescents will greatly contribute to the literature.

Finally, the findings of the current study reflect the benefit of replicating the study using additional illness representations and self-management behaviors instrument. Technologically advanced instruments that are developmentally appropriate will be considered for use in future research. A large percentage of the variance was not explained by the multiple regression models for the self-management behaviors. Replication of the current study to capture more of the unexplained variance and narrow to specific aspects of self-management will be a consideration for future research.

Additionally, a more comprehensive longitudinal study will provide additional useful information about beliefs as they develop. The opportunity to use instruments that can better capture, in greater detail, the self-management behaviors exhibited by adolescents could enhance the research that is conducted. For example, using additional self-efficacy instruments would enhance knowledge of adolescents' perspectives. A further consideration or future research is to target specific races/ethnicities and developmental stages. The current study was conducted with African American adolescents and a future study should be replicated with that population as well as with Puerto Rican adolescents since they also have a high prevalence of asthma and morbidity rates. A comparative analysis should be done with a broad spectrum of adolescents and ethnic groups to determine if the findings could be applicable to any individuals with asthma in the adolescent development stage.

This study provided an opportunity to explore illness representations and self-management behaviors of African American adolescents with asthma. The acute/chronic timeline, consequences, and treatment control representations show the most promise for tailored interventions. However, in the current study illness representations only contributed a small amount of variance; therefore, it is important to continue with research to determine other variables influencing the self-management behaviors of adolescents with asthma.

APPENDIX A PERMISSION TO USE ILLNESS REPRESENTATIONS–ASTHMA SELF-MANAGEMENT FRAMEWORK

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APPENDIX B REVIEW OF THE LITERATURE

Table B1

Asthma Self-management Descriptive Literature Table

Source	Sample & Design	Variables & Instruments	Findings and Comments
Boudreaux et al., 2003	*N* = 1095 African American (62%), Hispanic (23%), White (15%) Aged 2–17 yrs Analysis of two prospective cohort studies	1) Subjective and objective measures of asthma severity 2) Asthma medication use (including oral corticosteroids, rescue inhalers, & inhaled corticosteroids) 3) Healthcare utilization as assessment of asthma severity and management Instrument: Multicenter Airway Research Collaboration (MARC) Survey	African American participants (73%)–inadequate symptom mgmt & poor med mgmt (delayed or no use of inhaled steroids, increased β_2 agonist); Hispanic children & adolescents–highest (77%) in reporting inadequate inhaler use; White participants (71%) lowest level of inadequate symptom & medication management Asthma impairment: African American & Hispanic participants–greater lifetime histories (63%, 64%, respectively) & previous yr (34%, 31%, respectively) hospitalizations, more ED visits in the past year (*Mdn*–2 for African Americans, 3 for Hispanics) Asthma severity at ED presentation, ED mgmt & course, hospitalization during index visit, discharge Rx, & post-discharge outcomes equivalent among all race/ethnic groups; no gender differences reported

continued

Bruzzese et al., 2002	*N* = 334 9th grade students Descriptive design	Asthma symptoms, medications, cigarette smoking, environmental allergies Instrument: Asthma survey (developed for study)	Asthma impairment: 8% of students wheezing severe enough to limit speech; 6% ≥ 4 attacks of wheeze in previous 12 months Only mild persistent (3%), moderate persistent (11%), & severe asthma (36%) taking daily medications 8% of those with mild intermittent asthma smoked cigarettes, 26% (mild persistent asthma), 17% (moderate persistent), & 5% (severe) ($p < .01$); some students with asthma aware of allergies; many did not know if allergic to dust (22%), mold (22%), or roaches (15%)
Bryant-Stephens, & Li, 2008	*N* = 396 Aged 2–16 yrs Males = 46% African American: 99% RCT	Environmental triggers, environmental control measures in the home Instrument: Symptom dairies, observations during home visits of triggers, and environmental control measures	Baseline for two intervention and control groups: Passive smoking: 55%–60% of homes had ≥ 1 adult who smoked Cockroaches: 40%–45% of homes; rodents: 45%–55% of homes Pillow covers: 7%–12% of homes; mattress covers: 12%–16% of homes Beta agonists: 42%–44%, anti-inflammatory medication: 88%–96% Asthma impairment: determined by number of ED visits and regular sick visits 12months prior to study; participants averaged 2 ED visits and 1.3 regular sick visits related to asthma.

continued

Buston & Wood, 2000	*N* = 49 Adolescents, aged 14–20 yrs Females (*n* = 29) Males (*n* = 20) No races identified; Greater Glasgow, United Kingdom Asthma impairment: not specifically identified, inferred as not well controlled, 28 participants had oral steroids prescribed at last visit, 20 hospitalized in the previous year Qualitative study: In-depth interviews, focus groups	Non-compliance in adolescents with asthma Interview, focus groups	Most participants had not always complied with self-care regimens; reasons given for past, present non-compliance with prescribed medication: forgetfulness (*n* = 24), belief that the medication ineffective (*n* = 7), denial of being an asthmatic (*n* = 4); other categories—difficulty using inhalers, inconvenience, fear of side effects, embarrassment, and laziness Participants believed that compliance with prescribed medication was extremely important; this belief following a negative experience that they attributed to their non-compliance; other descriptions: (1) denials of asthma symptoms and not taking medication, hoping that it would go away, (2) fears about side effects of the medication and their fear of dying from asthma
Cloutier et al., 2008	*N* = 2,724 Aged: 6 mos–18 yrs Males: 44.7% Hispanic (*n* = 1,883) African American (*n* = 583) White (*n* = 43) Asthma impairment: mild persistent: 30%; moderate persistent: 18%; severe persistent: 2%	Asthma impairment Instruments: Easy Breathing Survey (developed for study)	All three categories (mild persistent, moderate persistent, severe persistent): African American children less likely than Hispanics to get their inhaled steroid prescription filled 25% of African American children with severe persistent asthma did not have medication 12 months after receiving the prescription—another aspect of inadequate medication management

continued

Cydulka et al., 2001	*N* = 1,291 Females: 62% African American: 56% males, 49% females White: 19% males, 24% females Hispanic: 23% males, 25% females Asthma impairment identified through objectively measured level of airway obstruction Males had more severe airway obstruction than women Combined study from 4 prospective cohort studies	Gender differences in asthma symptoms Instruments: Multicenter Airway Research Collaboration Survey (developed for study)	Females more likely than males to report severe complaints of symptom frequency, symptom intensity, and resulting activity limitations; females with moderate exacerbations more likely to describe their exacerbations as severe Male participants had more severe airway obstruction than women Men had an initial peak expiratory flow rate of 41 ± 15 vs 47± 16; $p < .001$ for women Despite severe obstructions, male participants reported less frequent, less distressful asthma symptoms, and less severe activity limitations than females
Forero et al., 1992	*N* = 1,313 Aged 12–21 yrs Study conducted in Australia Impairment: presence of wheeze symptoms in previous 12 months Public school students: 18%–20% reported symptoms Physician patients: 40% reported symptoms w/in previous 12 mos. Design: surveys from 3 community populations that were a part of a large asthma education program	Asthma symptoms, adherence, self-management behaviors, cigarette smoking	Although 90% of both male and female adolescents with asthma reported using short-acting bronchodilators as regular medications, only 44% used inhaled corticosteroids and cromolyn as regular asthma control medication 10% of the adolescents used theophylline; 7% of the participants used nonasthma medications such as antibiotics, nasal sprays, decongestants 22% of participants smoked

continued

Fritz et al., 1990	*N* = 37 children 7–15 yrs Males (*n* = 27) Females (*n* = 10) Race/ethnicity not identified Asthma impairment: Moderate to severe asthma, required daily medication.	Subjective assessment of symptoms, accuracy of symptom perception Instrument: A 10 cm visual analogue scale used for subjective ratings (Scale was not identified by name)	Investigators used 0.60 and above for high accuracy, 0.30–0.59 for moderate accuracy, below 0.30 for low accuracy Subjects (*n* = 7) highly accurate when subjective ratings of symptoms compared with objective peak flow readings. Moderately accurate (*n* = 17), and inaccurate (*n* = 13) in subjective ratings of asthma symptoms No differences were noted in the subjective assessment of symptoms of males (M = 13.50, SD = 10.91) and females (M = 13.16, SD = 7.88) [$t(35)$ = - 0.09, *NS*]
Guendelman et al., 2002	*N* = 134 8–16 yrs Males: intervention group 61%, control group 54% African Americans: intervention 79%, control 74% White: intervention 8%, control 12% Mild: intervention 23%, control 29% Moderate: intervention 66%, control 69% Severe: intervention 11%, control 12% RCT	Asthma diagnosis, limitation in activity, asthma symptoms, absence from school, peak flow reading in yellow or green zone, use of health services Health Buddy Device and asthma diary (developed for study)	At baseline, 46%–47% of the 2 groups seldom or never took asthma medication without a reminder

continued

Joseph et al., 2007	*N* = 314 Aged 15–19 yrs Females: 63.4% African American: 100% Design: RCT-Web-based tailored multimedia (intervention) vs access to generic asthma websites (control)	Self-management behaviors: adherence to medication, environmental control Instruments: Baseline, online questionnaire; medication module (developed for study)	Inadequate medication management documented through lack of adherence to medication: adherent to use of controller medication in previous 7 days (8.6%), not adherent with controller medication (25.0%) Lack of environmental control identified through the participants' smoking habits or exposure to smoke: exposed to household tobacco smoke (59.2%), smoked $\geq$ 1–2 cigarettes on days smoked in previous 30 days, (5.2%)
Kyngas, 1999	*N* = 266 Females (n = 133) Males (n = 133) Finnish study, race/ethnicity not specified Aged 3–17 yrs	Compliance with health regimens (asthma mgmt & avoidance of asthma triggers) Analyzed association between compliance & age, asthma severity, & smoking Instrument: Compliance questionnaire (developed for study)	Participant reported results: (1) complied fully with health regimens (42%), satisfactory compliance (42%), poor compliance (18%) 90% with poor compliance said it was too difficult to fit self-care schedule into their lives Poorest compliance: avoiding foods, animals, and pollens that cause asthma attacks; highest compliance was for medication and controlling visits to medical staff Variables such as age, smoking, alcohol intake, and severity of disease were significantly associated with compliance
McQuaid et al., 2003	*N* = 106 Aged 8–16 yrs Males: 58% Caucasian: 68% African Americans: 23% Hispanic: 5% Biracial: 5%	Adherence, self-management behaviors Electronic adherence monitor Adherence questionnaire (developed for study)	Adherence measured by MDILog electronic asthma med. monitor Mean level of adherence to prescribed medication was 46% for both males and females and no matter what level of asthma impairment Older (12–16 years) had lower levels of adherence (r = -.21, p < .05) than younger (8–11 yrs) children and adolescents African American, Hispanic, and Biracial participants were grouped into a general minority category for comparison of adherence with Caucasian participants Sig. differences in adherence between Caucasian (M =.53, SD =.29, mdn =.57) and nonCaucasian participants (M = .37, SD = .26, mdn = .38) were found, $F(1,98)$ = 7.55, p < .01)

continued

Morgan et al., 2004	*N* = 937 Aged 5–11 yrs Males: 60% African American & Hispanic: 70% Asthma impairment: described in terms of maximal number of days with symptoms (intervention and control group 6.0), baseline lung functions (88% intervention, 87% control), and unscheduled ED visits in 2 months before baseline (intervention 49%, control 53%) Design: RCT of environmental intervention	Home environmental exposures Asthma mgmt questionnaire (developed for study); home environmental control evaluation tool (developed for study) Allergy control (MultiTest)	Baseline characteristics intervention and control groups: depicted a high prevalence of allergic sensitization to cockroach and dust mite allergens Detectable levels of cockroach allergen found in 68.4 % of bedrooms and dust mites in 84.1% of the bedrooms Smokers in 16%–18% of homes, dogs in 22%, cats in 16%–18% High rate of symptoms and medication for control within 2 wks of baseline indicated by 84% were using a beta$_2$ agonist but only 45%–46% were using an anti-inflammatory medication Within 2 months of baseline, 49%–53% of the sample had $\geq$ 1 ED visit and 13%–14% had $\geq$ 1 hospitalization
Motlow & Ozuah, 2003	*N* = 200 Aged 13–18 yrs Hispanic: 68% African American: 26% White: 6%	Asthma severity and medication management: use of anti-inflammatory medication compared to use of bronchodilator	72% of adolescents had symptoms once per month (comparable to being well controlled), 33% had wkly symptoms (compared to being not well controlled), 14% had daily symptoms (comparable to being poorly controlled) 73% of adolescents with daily symptoms reported using a beta$_2$ agonist Only 33% with daily symptoms reported using inhaled corticosteroids

continued

Murray et al., 1997	*N* = 1,739 Aged 5–34 yrs African Americans (*n* = 1,155) White (*n* = 633) Females (*n* = 931) Males (*n* = 837)	Self-management behaviors (medication management) and health care utilization Asthma self-management questionnaire (developed for study)	African American males (64%) had significantly ($p < 0.0001$) higher use of oral adrenergic agonists followed by White males (51%), African American females (44%) and White females (34%) White females had highest use of inhaled glucocorticoid therapy (14%), followed by White males (9%) African American males (8%) and females (7%) Oral corticosteroids were used most often by African American males (48%); use among the other groups ranged from 36%–40% ($p = 0.002$) African American males had sig. greater use of cromolyn inhalation (27%), followed by White males (2l%), African American females (14%) & White females (10%)
Naleway et al., 2006	*N* = 1,191 Caucasian: 92% Ages: Adults Males (*n* = 574) Females (*n* = 617)	Differences in self-management behaviors of adult males and adult females Asthma Survey(developed for study)	Females (9% vs 6% of males) reported higher medication management in terms of their use of peak flow meters Males reported more use of OTC medication to control asthma than females (29% vs16%, $p < 0.0001$)

continued

Pawar & Smith, 2006	*N* = 635 African Americans: 100% Ages: $\leq$ 64 (66% of *n*: children & adolescents up to 21 yrs of age) Females: 53.7% Males: 45.8% (males < 21 yrs of age comprised a majority of the total sample (38.6%) Design: Computerized WV Medicaid paid claims records for medical services & Rx meds delivered through a fee-for-service system	Medication management Computerized WV Medicaid claims records	African American recipients were under-using controller medication, including inhaled corticosteroids African American participants filled their short-acting beta agonist more frequently (3.2 mean claims per recipient) than inhaled corticosteroid prescriptions (2.3 mean claims per recipient) Incidence of ED visits and hospitalizations were higher among African Americans Males 21 yrs and older accounted for the lowest proportion of age–gender groups, these recipients had the highest rates of hospitalizations and ED visits for asthma
Raherison et al., 2000	*N* = 6,507 total group; *n* = 359 with asthma Children 6–7 yrs, (78 boys, 76 girls) Adolescents 13–14 yrs (109 boys, 96 girls) Race/ethnicity: Not specifically identified; authors stated questionnaires translated into French; assumuption: all participants read French Design: Cross-sectional study population enrolled in the ISAAC, Bordeaux, France	Asthma symptoms, medication compliance, utilization of health services ISAAC Questionnaire (ISAAC Steering Committee, 1998) Additional questionnaires (self-evaluation of exacerbation severity, and home management)–developed for study	During mild exacerbation, 38.7% (adolescents) & 9.3% (children) waited until end of exacerbation without taking any medication Although most patients used were taking β_2-agonist, 21%–43% of children/adolescents did not receive appropriate meds in event of exacerbation Adolescents: (1) 19.6% did not take med for an exacerbation at all; (2) 19% w/severe asthma exacerbations used med other than prescribed beta agonist or corticosteroids, but parents of children adhered to the prescribed med; (3) 38.9% with moderate asthma took their med at the onset followed in percentage by those with mild asthma (32.3%) & severe asthma (20.2%); (4) Adolescent participants who took med if the exacerbation of symptoms was long-lasting: participants with moderate asthma (31.8%) were the highest category again followed by those with mild asthma (20.7%) and only 4.8% of participants with severe asthma

continued

Rhodes et al., 2005	*N* = 31, 618 Males (*n* = 12, 803) Females (*n* = 18,815) Race/ethnicity-specific races/ethnicities were not identified; broad statement that respondents were predominately Caucasian Asthma impairment: current asthma prevalence for the 8 states combined was 7.7% Design: 8-state telephone survey of chronic illnesses (including study of gender differences in asthma)	Gender differences in asthma control Behavioral Risk Factor Surveillance System (BRFSS) Survey (CDC, 1999)	Females in the study were more likely to report taking medication in the previous 30 days (medication management), use the ED for asthma exacerbations, and schedule a doctor's visit for worsening symptoms Males had a higher mean number of days of activity limitation (55.5 compared to 31.8 days for females)
Scarfone et al., 2001	*N* = 433 Children 2–18 yrs Males: 60% African Americans: 93% Asthma impairment: mild intermittent 36%; persistent asthma: 64% 66% of the participants did not use peak flow meters 74% had been hospitalized for asthma in their lifetime	Asthma impairment and medication management Asthma Exacerbation Response Questionnaire (developed for study)	38% took daily anti-inflammatory therapy, 18% received a daily inhaled corticosteroid 48% did not use a holding chamber with their metered-dose inhalers, and 66% did not use peak flow meters Exacerbation response: 71% did not have written action plan, and 89% did not maintain a symptom diary

continued

Sin et al., 2005 Social Cognitive Theory	*N* = 53 Ages: 15–17 yrs Male: 55% (*n* = 29) African American adolescents: 100% Asthma impairment: whether individual had asthma since childhood (68%), # of hospitalizations w/in previous 3 months (*n* = 1), occasional use of a bronchodilator (52 students) Design: Descriptive correlational design	Self-mgmt behaviors: usual behaviors to minimize symptoms & attack frequency Overall study measured relationship between asthma knowledge, social support, & self-mgmt behaviors Questionnaires: Parcel Knowledge Asthma Questionnaire (Carson et al., 1991); Norbeck Social Support Questionnaire (Norbeck et al., 1983) Asthma Behavioral Assessment Questionnaire (NHLBI, 1984)	Findings for the self-management component: (1) Never seeking help at the first sign of an asthma exacerbation (23%); (2) Always stopping playing and taking it easy (49%) Note: There were sig. relationships between asthma knowledge and self-management behaviors as well as social support and self-management behaviors
Tollefsen et al., 2007	*N* = 160 Aged 13–15 yrs Females (*n* = 94) Males (*n* = 66) Race/ethnicity: conducted in Norway, no specifics provided Design: Descriptive, correlational design Nord-Tondelag Health Study (HUNT-Youth Component; (Norway); Secondary analysis from HUNT study)	Associations between symptom management, environmental control, and gender International Study of Asthma and Allergy in Childhood Questionnaire (ISAAC, 1993)	Findings: (1) Females (*n* = 94) were more symptomatic than males (*n* = 66), reported more current asthma, especially wheezing at baseline; (2) 12% of the females were involved with daily or occasional smoking as opposed to 7.6% among males; (3) Lack of inadequate environmental control as exhibited by 49.7% of females' high exposure to 2nd hand smoke in the home environment; exposure to smoke in the home was a result of a parent or sibling who smoked

continued

Turyk et al., 2006	*N* = 61 Aged 3–13 yrs Males: 63% African American or Puerto Rican: 55% Asthma impairment reported through # and frequency of asthma symptoms in the month before sampling: 36% had 0–1 symptoms, 16% had 6–7 symptoms;42% had no asthma symptoms, 27% had symptoms during the day and at night Design: RCT	Environmental Control Asthma Questionnaire (developed for study) Dust sample, air sample tests (authors and University of Illinois at Chicago Labs)	42% had smokers in their homes and 54% used anti-inflammatory asthma control medication Cockroaches had high presence in 38 of 61 homes and were found to be significantly related to the participants' asthma symptoms

Table B2

Illness Representations (Perceptions and Beliefs) Descriptive Literature Table

Source	Sample & Design	Variables & Instruments	Findings and Comments
Ayala et al., 2006	*N* = 50 Female: 56% (*n* = 28) African American: 48% (*n* = 24) Caucasian/White: 40% (*n* = 20) Others: 12% (*n* = 6) 6th grade: 42% (*n* = 21) 7th grade: 26% (*n* = 13) 8th grade: 32% (*n* = 16) Asthma impairment: Percentage of students on controller medication—42% (*n* = 21); Percentage of students on long-acting beta-agonist: 4% (*n* = 2) Design: Qualitative study-Focus groups for 7 weeks	Developmental differences in asthma management Themes related to asthma self-management Participants completed 2 surveys on asthma self-management behaviors Focus group topics: asthma management and barriers, developmental issues	Mean perceived asthma control: 72.80 (*SD* 24.44, range: 5–97) suggesting that the students felt their asthma was mostly under control Barriers to successful management (developmental differences): (1) Across all 3 grade levels, students reported that managing asthma was “time consuming” and “annoying”; (2) 6th graders: scared about asthma and not wanting to be different or teased by peers; (3) 7th and 8th graders reported that management behaviors were “not needed” because they had outgrown their asthma or it was not severe enough to warrant attention Perceptions of asthma severity consistent across all 3 grade levels; students believed their asthma was not severe enough to need medication; exposure to cigarette smoke was unavoidable; and asthma was not as severe as attention deficit disorder or diabetes No differences reported by gender or race

continued

Buston & Wood, 2000	*N* = 49 Adolescents, aged 14–20 yrs Females & Males Race and ethnicity not reported Asthma impairment: generally described as 28 respondents had been prescribed oral steroids at their last visit; 20 had been hospitalized in the last year	Compliance with asthma self-care regimens Instrument: In-depth interviews for focus group	Most participants admitted that they had not always complied with their self-care regimens Reasons given for non-compliance with prescribed medication in the past or at present were: forgetfulness, belief that the medication is ineffective, denial that one is asthmatic, difficulty using inhalers, inconvenience, fear of side effects, embarrassment, and laziness Of the 49 adolescents interviewed, only 4 reported that they had always and continued to take their medication as prescribed; of the 45 who admitted to be non-compliant, most reported compliance with one aspect of their regimen the majority of the time
Cohen et al., 2003	*N* = 160 Mean age: 15.7 (only reported age) High school students Females: 63% African Americans: 26% Hispanics: 68% Immigrants: 24% Design: Multi-staged, stratified sample survey	Perceptions and attitudes of asthma Teen Asthma Questionnaire	Feeling in control over their asthma symptom: 70% Fear of death reported by 39% Feeling anxiety in relation to their asthma: 42%

continued

Halm et al., 2006 Leventhal Common Sense Self-Regulation Model	*N* = 198 Female: 78% Hispanic: 62% African American: 28% White, non-Hispanic: 3% Other: 6% Asthma severity described through patients' asthma history: 64% had asthma ≤ 20 yrs (64%), 23% had prior intubation, 88% had prior oral steroid use, 31% had used oral steroids all or most of the previous year Design: Prospective, longitudinal, observational, cohort study	Beliefs about asthma and treatment Interviewer administered questionnaire	Only 53% said they only had asthma when they were having symptoms (acute episodic model); 40% felt they had asthma all of the time (chronic model); 6% were in the middle saying they had asthma most or some of the time Males > 65 yrs of age were more likely than females to endorse asthma as an acute episodic disease
Horner, 1999	*N* = 25 Children age 11–14 yrs Males (*n* = 14) Females (*n* = 11) Middle school students White: 100%	Focus group interviews	Males had comments that centered on the theme of "toughing it out" Instead of using medication during asthma exacerbations, male participants described ignoring their symptoms and pushing to finish physical activities

continued

Joseph et al., 2007	*N* = 314 Aged 15–19 yrs Males: 52% African American: 98.6% RCT	Medication management & environmental control Instrument: (1) Lung Health Survey (developed for study); (2) Puff City Web-based disease management program (developed for study)	Baseline data for the 314 participants reflected inadequate med mgmt & environmental control Inadequate med mgmt documented through lack of adherence to med: adherent to use of controller med in previous 7 days (8.6%), not adherent with controller med (25.0%) Lack of environmental control identified through participant's smoking habits or exposure to smoke: exposed to household tobacco smoke (59.2%), smoked $\geq$ to 2 cigarettes on days smoked in previous 30 days, (5.2%)
Knight, 2005	*N* = 10 Aged 13–18 yrs Race/ethnicity not described Study conducted in Hawaii Asthma severity described as mild (*n* = 4), moderate (n = 5) & severe (*n* = 1) Design: Qualitative Study	Beliefs about asthma; asthma self-care practices Semi-structured interview guide (developed for study)	No students used preventive medicines regularly, while 70% of students used preventive medications occasionally, including all of those in the moderate severity group Themes relevant to current study: (1) Medication regimens [worries] . . . "If I forget to take it [inhaler] and then I have asthma, that's when I'm scared of an asthma attack . . . it limits your activities when you have it, 'cause I'm in track and when I have it, I can't run. Nope, can't run, gonna die. It's kinda bad, but, I cope" (14-year-old male) "If you need it, you have it with you—you don't need to rely on anyone else, just yourself. I feel safe with that" (13-year-old male) . . . "if you're having a hard time breathing, jus' use your inhaler and if it doesn't work, then tell someone" (16-year-old male) "I don't feel secure without it—the puffer—I have it in my hand, running" (13-yr-old male) cell continues

continued

			(2) Trigger avoidance: “I get sick every time I go home. The weather changes, the dampness, the smoke and vog [volcano smog]. . . . At home, the vog, I kinda feel tired, I don’t feel as good, and then most times [at home] I have a lot of mucous” (13-year-old male) “When the weather’s cold, when it’s dusty; when there’s lots of fires—a lot of smoke [sugar cane fires on Maui]. Those are triggers for me” (16-year old female) (3) Acceptance of diagnosis: (a) Participants were not fatalistic about their chronic illness, and all but two did not feel limited by it. (b) They accepted the challenges presented by being prepared with their albuterol inhalers, the needing for trigger-avoidance measures, and recognizing the need to stay in shape. (c) They were not ashamed of having to take medicine for a chronic illness, and not especially anxious, even though away from home
Kyngas, 1999	*N* = 266 Children aged 13–17 yrs Males (*n* = 133) Females (*n* = 133) Race/ethnicity not identified but participants were from a Finnish study Asthma impairment: Asthma was categorized as mild (34%), moderate (60%), and severe (6%) Design: Descriptive study	Compliance with asthma regimens Compliance with asthma questionnaire (developed for study)	45% had fears of asthma attacks; the fear of asthma attacks did not have statistically sig. relations to compliance Fears of complications were also very common—74% had fears of complications; a statistically sig. association to compliance ($p < 0.001$)

continued

Naimi et al., 2009	*N* = 40 Aged 15–18 yrs Females: 48% African American: 75% Asthma impairment: FEV_1: mean of 98% (ranging from 68%–127%) of predicted value, indicates that participants airways were open to not well-opened Design: Qualitative and quantitative design	Beliefs and attitudes about asthma	Median adherence was 48% (range 25%– 62%) 38 out of the 40 participants admitted to not adhering to fluticasone/salmeterol, a frequently prescribed controller med 16 adolescents expressed beliefs that they control their asthma & did not see the benefit of taking the medication
Paterson et al., 1999	*N* = 182 overall study; *N* = 35 asthma secondary study Aged 7–14 yrs Races/ethnicities: European/Pakeha (72.5%), Maori (11.5%), Pacific Islands 6.6%, Other (9.3%) Asthma impairment reported as relatively mild (*n* = 15), moderately severe (*n* = 10), & severe (*n* = 10)	Cognitive illness representations questionnaires to measure the effect of the illness experience Instrument: Illness experience questionnaire (developed for study)	The illness representations cause, timeline, and control were most prominent representations among the participants with asthma.

continued

Peterson et al., 2002	*N* = 20 Caregivers of children grades 4–8 African American Asthma impairment: Half of children's asthma rated as moderately severe, 30% as not severe, 20% as severe Design: Descriptive Study with explanatory models (ethnographic study)	Beliefs about asthma Kleinman's Explanatory Model Questionnaire (1980)	7 of caregivers gave responses that authors labeled as medical protocol that included βagonist and if it was too bad to go to ED or physician's office 5 of caregivers identified family regimens they would initiate without following the medical protocol or seeing a physician
Rhee et al., 2009	*N* = 126 Aged 13–20 yrs White (*n* = 62); African American (*n* = 40); Hispanic (*n* = 14) Females (*n* = 75); Males (*n* = 51) Asthma impairment: Diagnosed with asthma $\geq$ 1 year & either used controller medication or had persistent asthma Design: Descriptive Study	Barriers to asthma self-management Instruments: Illness Management Survey 2 (developed for study); Asthma Knowledge Questionnaire (adapted for study); Attitude Towards Illness; Asthma Self-Efficacy; Asthma Control Questions	Most frequently endorsed barrier to asthma self-management: adolescents' unwillingness to give up things physicians had identified Many adolescents had discrepancy between symptom perception and symptom reports, particularly in those adolescents who were not well controlled Adolescents had perceptions that "nothing bad would happen to them if they did not follow their regimen"

continued

Rhee et al., 2008		Asthma control perception	Participants were categorized into 1 of 4 groups: well controlled accurate (perceive symptoms to be well controlled & they are), inaccurate group 1 (perception that daytime symptoms are better than they are), inaccurate group 2 (perception of symptoms was poor & nighttime symptoms are poor), & poorly controlled accurate (perception of asthma is poor & symptoms are not well controlled) Most concerning: participants who had high levels of inaccuracy, even over 31% of inaccuracy Non-Whites (African American, Hispanic, Biracial) were 4 times more likely to be grouped in inaccurate 2 group compared to well controlled accurate group; inaccurate 2 group comprised of highest number (specific number not reported) of Non-White adolescents; Inaccurate 2 group with its poor perception of symptoms and increased nighttime symptoms meant that participants' asthma was not well controlled or was poorly controlled.
Rydstrom et al., 2005	*N* = 23 Aged 13–18 yrs Males (*n* = 11); Females (*n* = 12) Moderate to severe asthma Race/ethnicity not identified: study conducted in Sweden Design: Grounded theory research	Perceptions of asthma Participant interviews	Participants' core concern was not to let the disease get the upper hand over life Adolescents found mgmt strategies: keeping a distance to disease (boys), challenging disease & taking disease into consideration (girls) Specific concerns: (a) not being able to run around due to asthma; (b) wanting to ignore symptoms; (c) feeling reduced in society due to inability to manage asthma; (d) females' reports of pre-medicating before challenging asthma during sports; (e) males' comments about ignoring symptoms.

continued

van der Meer, Rikkers-Mutsaerts, Sterk, Assendelft, & Sont, 2006	*N* =35 Aged 12–17 yrs Males (*n* = 17) Females (*n* = 18) Asthma impairment: Well controlled or poorly controlled Design: Qualitative (Focus groups) and quantitative (Web-based monitoring of symptoms)	Barriers and benefits to traditional and Web-based asthma management Instruments: Focus Groups	None of the participants perceived asthma as a serious disease "It's [asthma] just something you've got. Medications do help but you just have these symptoms" Participants with well controlled asthma expressed laziness in taking medication and unwillingness to take the medication
Velsor-Friedrich et al., 2004	*N* = 24 Aged 14–18 yrs Males (*n* = 11) Females (*n* = 13) Race/ethnicity: Identified as Caucasian, African American, Hispanic but no numbers reported Design: Qualitative Study	Management of asthma Focus Groups	4 themes emerged related to teens' management of asthma: wanting to be normal, unpredictability of disease, credibility of teen with asthma, and self-management issues Pertinent comments: "Asthma comes and goes" and "Desire to be equal to his friends, not below them" Adolescent's description of passing out as a result of hanging on during a soccer game and the coach not allowing him to leave the game

continued

Williams, 2000	*N* = 20 Aged 15–18 yrs Males (*n* = 10) Females (*n* = 10) Race/ethnicity: No specifics reported; study conducted in London Design: Qualitative	Interaction of gender and asthma In-depth interviews	Males described denying symptoms and holding out or delaying seeking health care for their exacerbation in asthma symptoms Adolescent boys were more likely than girls to say they could control their condition with their minds "Asthma creeps up on you, …a lot of the time I know I'm having an attack, but if I'm playing football I'll say, now I'll ignore it and I'll play on, yes, and I'll fight through it. I'll say, look, I know what's happening and I'll take it slower, but you've just got to keep breathing and it goes away, it just goes because of my mental strength" (male) *Participant had to be rushed to the hospital after this scenario "You've just got to have it [asthma] there at the back of your mind, all the time" (female) "Because asthma just tends to be so episodic and you get lulled into a false sense of security when you don't display any symptoms." (female)
Woodgate, 1998	*N* = 23 (*n* = 5 with asthma) Aged 13–16 yrs Males: 11 Females: 12 Race/ethnicity Caucasian (*n* = 19) Asian (*n* = 2) Canadian Aboriginal (*n* = 1)	Beliefs about the development and duration of their asthma	Descriptions: "Not as many people have the chronic asthma but a lot of people have bits and pieces of it" (14-yr-old male) "Getting used to it but continuing to want to get rid of it and hope that it would go away" (14-yr-old male)

continued

Yoos & McMullen, 1996	*N* = 28 Aged 6–18 yrs Males and females: numbers not reported Caucasian (*n* = 10) African American (*n* = 13) Hispanic (*n* = 5) Design: Mixed, qualitative and descriptive quantitative	Perceptions of asthma Interviews Visual analogue scale (Kieckheter, 1987) Hollingshead Two Factor Index of Social Position (Hollingshead, 1957)	5 themes: (a) “I can’t”—a listing of activities that participants thought they could not do, (b) restrictions others imposed, (c) descriptions of asthma symptoms and treatment, (d) fears of death, (e) descriptions of adaptation to asthma, increasing self-management of the illness and the impact of asthma on their daily lives
Zebracki & Drotar, 2004	*N* = 77 Aged 11–17 yrs Males (*n* = 40) Females (*n* = 37) White (*n* = 46) African (*n* = 26) Other (*n* = 5) Asthma as mild intermittent (16.9%), mild persistent (16.9%), moderate persistent (27.3%) and severe persistent (39.0%).	Asthma self-management, adherence to medication Children’s Health Survey for Asthma (American Academy of Pediatrics, 2000) Family Adherence to Medical Regimen (National Cooperative Inner City Asthma Study (1994) Asthma scenarios (Kolbe et al., 1996)	Adolescents tended to focus on the immediate consequences of their behaviors rather than the long term effects of adherence to their medication.

Table B3

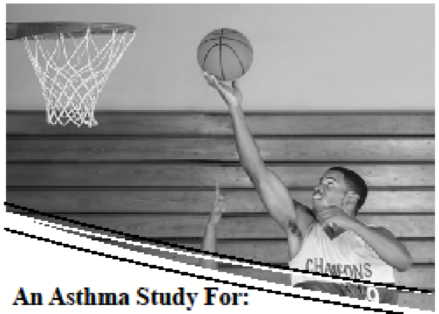
Relationship between Illness Representations and Asthma Self-management Descriptive Literature Table

Source	Sample & Design	Variables & Instruments	Findings and Comments
Jessop & Rutter, 2003	*N* = 330 adults Aged 17–87 yrs Females: 61.8% Race/ethnicity not reported; study conducted in England Design: Descriptive study	Illness representations and association with adherence to medication Beliefs About Asthma Questionnaire (developed for study)	Identity, cause, and control were illness representations that significantly predicted adherence to medication; therefore, participants who believed they had asthma and thought it could be controlled or cured were more likely to adhere to medication than those who attributed the cause of their asthma to an external factor Study also revealed that in their study age (older individuals) and gender (females) were predictors of adherence
Le et al., 2008	*N* = 86 Aged $\geq$ 19 Female: 71.2% African American (*n* = 61); Hispanic (*n* = 1); Other (*n* = 4); White (*n* = 20) Active prescription to use an inhaled corticosteroid indicating not well or very poorly controlled asthma Design: Descriptive	Relationship of African American's illness representations (beliefs) & adherence to med Surveys (developed for study) Electronic monitoring of inhaler use (MedTrac Technologies)	Negative beliefs were held by many African American participants: they did not need as much medication as had been prescribed; they might develop a tolerance to their medications African Americans did not endorse statement that inhaled corticosteroid therapy was safe Adherence was lower among participants who agreed with one or more negative beliefs or disagreed with positive belief about inhaled corticosteroids (24% adherence in African Americans vs 40% for those who had no problematic beliefs, p = .002). The odds of a high negative beliefs index score ($\geq$ 3) in minority patients was nearly 7 times higher as compared to Caucasian participants

continued

Wells et al., 2008	*N* = 950 African American (*n* = 336) White (*n* = 614) Females: 71% Participants had been diagnosed with asthma for at least a year Design: Descriptive	Beliefs influencing medication adherence; internal & external factors influencing adherence Surveys (developed for study) Asthma Control Test (QualityMetric, Inc.) Electronic prescriptions (DrFirst, Inc)	Internal factors (beliefs about asthma and asthma controller medication, readiness to take medication, perceived control over medication, trust in physicians) were more influential than external factors Among White participants, 23% of variance in inhaled steroid adherence was accounted for by perceived necessity of med, doctors perceived source of control, readiness to take inhaled steroids, and knowledge about asthma. Among African American participants, readiness to take inhaled steroids was found to be significantly associated with inhaled corticosteroid adherence Readiness to take inhaled steroids, reflective of control illness representation, accounted for 5.6% of the variance in inhaled steroid adherence

Figure C1. Study recruiting flyer.



An Asthma Study For:

*African Americans
*14, 15, and 16- year-olds (young men and young women)
*Asthma treatment in last 12 months
*Teens in a regular classroom (regular, advanced, and gifted classes)

What will I have to do to be in the study?

- Complete four (4) questionnaires that include questions on what you think about your asthma. There are also questions on how you take care of your asthma.
- It will take about 30 minutes to complete all four questionnaires.

Contact information

INDIANA UNIVERSITY
SCHOOL OF NURSING

Who is conducting this study? Meet the researcher:

My name is Sharron Crowder, and I am a registered nurse with a specialty in adolescent asthma care and teaching nursing students. As part of my graduate program, I am conducting a study on African American adolescents between the ages of 14 – 16 with asthma. The focus of the study is how they view their asthma and how they manage it. This study was approved by a special review board at Indiana University Purdue University at Indianapolis.

If you are interested in being in this study, discuss it with your parents or guardians. Then call me if you are willing to participate. Please contact me directly with any questions you may have about the study. This study is designed to make a difference in the treatment of asthma and participants will be compensated upon completion of the questionnaires.

Contact information:
Telephone (317) 946-2002
E-mail: asthma10@sbcglobal.net

Funded by: National Institutes of Health #F31NR010985-02
Approved by IUPUI IRB

INDIANA UNIVERSITY
SCHOOL OF NURSING

Illness Representations and Self Management Behaviors of African American Adolescents with Asthma

Indiana University School of Nursing
1111 Middle Drive, Suite 345
Indianapolis, Indiana 46202

(317) 946-2002
Email: asthma10@sbcglobal.net

Sharron Crowder, MN, RN

continued

<u>We Need Your Opinion! Make a Difference and Receive a $20.00 Gift Card!</u>

You are invited to be in this study to help us learn more about asthma because….

- Some teens manage their asthma symptoms well; others have more frequent asthma episodes and emergency room visits. What influences those differences?
- Very few studies have been conducted with African American teens with asthma. Your answers to the questions are extremely valuable.

Complete all of the questionnaires and get a Wal-Mart or Target gift card!

<u>If you received this flyer from a relative, friend, or a place in the community</u>, you will be able to complete the questions at a public location.

- Contact Sharron Crowder, forms will be mailed to you and your parent(s)/guardian(s) to sign.
- A public location such as a library, community center or other site will be identified with you and your parent(s)/guardian(s). You will complete the questions at that location.

INDIANA UNIVERSITY
SCHOOL OF NURSING

THIS STUDY IS ABOUT:

- Your thoughts about asthma
- How you take care of your asthma

How do I know if I might be able to be a part of the study?

- You are an African American
- You are 14, 15, or 16 years old
- You have been treated for asthma within the last 12 months
- You are in a regular classroom (includes regular, advanced, and gifted classes)
- You and your parent(s)/guardian(s) sign the forms for you to be in the study.

Illness Representations and Self-management Behaviors of African American Adolescents with Asthma. An asthma study for African Americans 14, 15, and 16 years old. We need the responses to questions from young men and young women.

Call: Sharron Crowder at (317)946-2002 or e-mail: asthma10@sbcglobal.net.

Figure C2. Study recruiting flyer.

APPENDIX D CONSENT AND ASSENT FORMS

INDIANA UNIVERSITY INFORMED CONSENT STATEMENT FOR

Illness Representations and Self-management Behaviors of African American Adolescents with Asthma

Your son or daughter is invited to be part of a research study of what young people think about asthma. The study will also look what your son or daughter does to take care of his or her asthma. Your son or daughter was selected as possibly being in the study because he or she is an African American, 14, 15, or 16 years of age, had asthma treatment in the last year, and is in a regular classroom at school. Please read this form and ask any questions you may have before agreeing to allow your son or daughter to be in the study.

The Primary Investigator for the study is Dr. Kathleen Hanna, an associate professor at Indiana University School of Nursing. The researcher conducting the study is Sharron Johnson Crowder, a nurse and graduate student at Indiana University School of Nursing. The study is being funded by the National Institutes of Health.

STUDY PURPOSE

The purpose of this study is to look at how African Americans who are 14 to 16 year olds take care of their asthma and their thoughts about asthma.

NUMBER OF PEOPLE TAKING PART IN THE STUDY:

If you agree, your son or daughter will be one of about 120 young people with asthma living throughout the state of Indiana.

PROCEDURES FOR THE STUDY:

If you agree, your son or daughter will answer questions about his/her thoughts about asthma, things he or she does to take care of asthma, and the frequency of asthma symptoms. Your son or daughter will also be asked some general background questions such as birth date, grade in school, type of practice (doctor) where they get their asthma care, relatives they live with, and if they smoke. Other questions are about the parent(s) or guardians(s) in terms of the highest grade finished in school, if smoking is allowed in the home or car, and if the family has enough money for food or housing. This question is asked so a question on how much the family makes does not have to be asked. We will also get your zip code so that we can describe the neighborhood where you live. None of the answers will be associated with your name or your address. The questions will take about 25 to 30 minutes to answer. Your son or daughter will circle or check their answers. The study will end upon completion of the questions.

The location for answering the questions for the study will depend on where your son or daughter heard about the study. If he or she heard about the study through the schools, completion of the questionnaires will occur at your son or daughter's school. If your son or daughter is a patient at the Marion County ACTION Center or High Risk Asthma Clinic at Riley, answering the questions would be the center or clinic when there is an appointment to see the doctor. If your son or daughter heard about the study through flyers in the community, the completion of the questions will occur at a public facility such as a library or community center that the parent and researcher agree to.

If your son or daughter is a patient at the High Risk Asthma Clinic at Riley, information from the chart related to the lung function tests will be obtained. These tests are a part of the usual appointment.

RISKS OF TAKING PART IN THE STUDY:

While in the study, there are some minor risks: Your son or daughter may feel a little anxious or uncomfortable as he or she answers questions about asthma. He or she might feel slightly uneasy if it takes a long time to read the questions. Your son or daughter might have a concern of whether the answers provided will remain private.

continued

The researcher will do the following things to minimize the risks: 1) thoroughly explain everything to each subject; 2) emphasize voluntary participation; 3) conduct the interview in a respectful, nonjudgmental manner; and 4) repeat or explain information when necessary. There is also a risk for loss of confidentiality. The consent forms will be kept separate from the questionnaires. The questionnaires will not have names attached.

BENEFITS OF TAKING PART IN THE STUDY:

One potential benefit of your son or daughter being in the study would be helping doctors and nurses who work with African Americans who are 14 to 16 years of age. Doctors and nurses will be better able to help these young people if they know more about what they think and do about asthma. Your son or daughter will be asked questions about their thoughts about their asthma, as well as what they do to care for their asthma. These questions may increase their awareness about their asthma and help them take care of their asthma.

ALTERNATIVES TO TAKING PART IN THE STUDY:

You and your son or daughter can choose not to be in the study.

CONFIDENTIALITY

Efforts will be made to keep your son or daughter's personal information confidential. We cannot guarantee absolute confidentiality. Your son or daughter's personal information may be disclosed if required by law. Your son or daughter's identity will be held in confidence in reports in which the study may be published and databases in which results may be stored. Storage of confidential information, consent/assent forms, and HIPPA information will be kept in locked files. Identification numbers will be used on instruments rather than names, data will be handled only by the researcher and not school or clinic personnel, and collected data will be transported immediately to locked files.

Organizations that may inspect and/or copy your son or daughter's research records for quality assurance and data analysis include groups such as the study investigator and his/her co-investigators and research associates, the Indiana University Institutional Review Board or its designees, and (as allowed by law) state or federal agencies, specifically the Office for Human Research Protections (OHRP) and the National Institutes of Health (NIH) may need to access your son or daughter's medical and/or research records.

COSTS

No costs are anticipated as a result of your son or daughter being in the study. You will not be responsible for these study specific costs: questionnaires or scoring the responses to the questions.

PAYMENT

Your son or daughter will receive a $20.00 gift card for answering all four sets of questions. Gift cards will be available from Wal-Mart and Target and he or she can choose which one he/she wants after answering all sets of questions.

COMPENSATION FOR INJURY

We do not anticipate any type of injury related to completing the questionnaires for the study. However, in the event of physical injury to your son or daughter resulting from being in the study, necessary medical treatment will be provided to your son or daughter and billed as part of your son or daughter's medical expenses. Costs not covered by your son or daughter's health care insurer will be your responsibility. Also, it is your responsibility to determine the extent of your son or daughter's health care coverage. There is no program in place for other monetary compensation for such injuries. However, your son or daughter are not giving up any legal rights or benefits to which your son or daughter are otherwise entitled.

continued

CONTACTS FOR QUESTIONS OR PROBLEMS

For questions about the study or a research-related injury, contact the researcher Sharron Crowder at (317) 946-2002 or e-mail asthma10@sbcglobal.net. You may contact Mrs. Crowder during the day, evening, or weekends. If you are unable to contact Mrs. Crowder, you may contact Dr. Kathleen Hanna, the principal investigator, Monday-Friday, during business hours at (317) 274-1494. If you cannot reach the researcher during regular business hours (i.e. 8:00AM-5:00PM), please call the IU Human Subjects Office at (317) 278-3458 or (800) 696-2949. After business hours, please call Sharron Crowder at (317) 946-2002. In the event of an emergency related to the study, you may contact Sharron Crowder at (317) 946-2002.

For questions about your son or daughter's rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (317) 278-3458 or (800) 696-2949.

VOLUNTARY NATURE OF STUDY

Taking part in this study is voluntary. You may choose for your son or daughter not to take part or your son or daughter may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which your son or daughter are entitled. Your decision whether or not to allow your son or daughter to participate in this study will not affect your son or daughter's current or future relations with where your son or daughter found out about the study.

PARENT/GUARDIAN'S CONSENT

In consideration of all of the above, I give my consent for my son or daughter to participate in this research study.

I will be given a copy of this informed consent document to keep for my records. I agree for my son or daughter to take part in this study.

Printed Name of Participant (son or daughter): ______________________

Printed Name of Parent: ______________________

Signature of Parent: ______________________ **Date:** ____________

Printed Name of Person Obtaining Consent: ______________________

Signature of Person Obtaining Consent: ______________________ **Date:** ____________

IRB Approval Date: April 28, 2011

Expiration Date: April 27, 2012

Version Date (03/25/11) 3 v06/01/2010

Figure D1. Parental consent form.

Indiana University Assent to Participate in Research

Illness Representations and Self-management Behaviors of African American Adolescents with Asthma

We are doing a study. A study is a special way to learn about something. We are doing this study to find out more about African American young people with asthma: we want to know about their thoughts about asthma and things they do to take care of asthma. We would like to ask you to be in this study.

Why am I being asked to be in this research study?

You are being asked to be in this study because you are African American, are 14, 15, or 16 years of age, have had treatment for asthma within the last year, and you are in a regular classroom (includes taking regular, advanced or gifted classes) at school. You will be one of about 120 young people in the study.

What will happen during this research study?

We want to tell you about some things that might happen if you are in the study. This study will take place where you heard about the study; this would be at your school, at the ACTION Center, or the High Risk Asthma Clinic at Riley Hospital. If you received the flyer from a place in the community, your parent(s) or guardian(s) and the researcher will select a public place in the community so you can answer the sets of questions. We will meet with you only one time.

If you want to be in this study, here are the things that we will ask you to do. You will be asked to answer four sets of questions by making a check or circling an answer. Questions will be asked about your asthma symptoms, your thoughts about your asthma, and things you do to care for your asthma. You will also be asked questions such as birth date, grade in school, type of practice (doctor) where you get your asthma care, relatives you live with, and if they smoke. Other questions are about your parent(s) or guardian(s) in terms of the highest grade finished in school, if smoking is allowed in the home or car, and if the family has enough money for food and housing. This last question is so a question on how much the family makes does not have to be asked. We will also get your zip code so that we can describe the neighborhood where you live. None of the answers will be associated with your name or your address. Answering all of the questions takes about 30 minutes.

When you start answering the questions you will be given an i.d. number. That number will be placed on all of your questionnaires instead of your name in order to keep your name private. The person conducting the study will sit in the room with you as you complete the forms. She will be available to explain any unclear questions.

Are there any bad things that might happen during the research study?

Sometimes bad things happen to people who are in studies. These bad things are called "risks." The risks of being in this study might be feeling anxious or uncomfortable as you answer the questions about your asthma. You might feel slightly uneasy if it takes you take a long time to read the questions. Or you might be concerned that others will know you are in the study or the answer is yours. Many things will be done to decrease these risks. You will be placed in a private place to answer the questions. You will be reading and marking the answers so it can be done without others being aware that you are in a study. You will be accompanied to the private place without others knowing you are in the study. Only the person who is accompanying you will know that you are in a study.

Your name will not be identified with your answers, only the people doing the study will have access to the questions.

Not all of these things may happen to you. None of them may happen. Things may happen that the people doing the study don't know about yet. If they do, we will make sure that you get help to deal with anything bad that might happen.

continued

Are there any good things that might happen during the research study?

Sometimes good things happen to people who are in studies. These good things are called "benefits." The benefits of being in this study might be that you will think about your asthma and ways you can better take care of your asthma. We don't know for sure if you will have any benefits. We hope to learn something that will help other young people with asthma some day.

Will I get money or payment for being in this research study?

You will get a gift card after completing all four of the questionnaires. You will get it for your time and effort it takes to answer all of the questions. You can choose to have a $20.00 gift card from Wal mart or Target.

Who can I ask if I have any questions?

If you have any questions about this study, you can ask your parents or guardians or the researcher. Also, if you have any questions that you didn't think of now, you can ask later. You may call the researcher, Sharron Crowder at (317) 946-2002. You may also e-mail Sharron Crowder at asthma10@sbcglobal.net. You may contact Mrs. Crowder during the day, evening, or weekends. Another person to contact if Mrs. Crowder is not available is Dr. Kathleen Hanna. She can be contacted Monday-Friday during the day at 274-1494. You may also contact the IU Human Subjects Office if neither Mrs. Crowder nor Dr. Hanna is available. Their number is at (317) 278-3458 or (800) 696-2949.

What if I don't want to be in the study?

If you don't want to be in this study, you don't have to. It's up to you. If you say you want to be in it and then change your mind, that's OK. All you have to do is tell us that you don't want to be in it anymore. No one will be upset with you if you don't want to be in it. Both you and your parent or guardian need to agree about being in the study.

My choice:

If I write my name on the line below, it means that I agree to be in this research study.

__________________________ ______________
Subject's Signature Date

____
Subject's Name

__________________________ ______________
Signature of person obtaining assent Date

____
Name of person obtaining assent

For IU Human Subjects Office Use ONLY

IRB Approval Date: April 28, 2011

Continuing Review Date: Apr. 27, 2011

Version Date (03/25/11) 2 IRB Template v09/01/2010

Figure D2. Participant assent form.

APPENDIX E IRB APPROVAL

IUPUI-CLARIAN INSTITUTIONAL REVIEW BOARD (IRB) REVIEW

DOCUMENTATION OF REVIEW AND APPROVAL (DRA)

02

IRB STUDY NUMBER: 1003-61
(IRB Office will assign)

Please type only in the gray boxes. To mark a box as checked, double-click the box, select "checked", and click "OK".

SECTION I: INVESTIGATOR INFORMATION

Principal Investigator: Hanna, Kathleen, M. **Department:** IU School of Nursing
(Last, First, Middle Initial)

Building/Room No.: NU-Rm 451C Phone: (317) 274-1494 E-Mail: kathanna@iupui.edu

Contact Information:

Name: Sharron J. Crowder Address: 13202 Duval Drive Fishers, IN 46037
Phone: (317) 849-6163
Fax: None E-Mail: sjcrowde@iupui.edu

If this is a Student Protocol, Last Name of the Student: Sharron J. Crowder Phone: (317) 849-6163

Protocol Title: Illness Representations and Self-management Behaviors of African American Adolescents with Asthma

Sponsor/Funding Agency: NIH-National Institute of Nursing Research PI on Grant: Kathleen Hanna, PhD, RN

Sponsor Protocol #/Grant #: T31NR010985-02 Period: From: 2008 to 2011

Sponsor Type: ☒ Federal ☐ State ☐ Industry ☐ Not-for-Profit ☐ Unfunded ☐ Internally Funded

Grant Title (if different from project title):

SECTION II: TYPE OF REVIEW

☒ Expedited Review
☐ Full Board Review (*Choose One*) → ☐ Behavioral or Social Sciences (IRB-01)
☐ Biomedical (*Choose One*) → ☐ IRB-02 ☐ IRB-03 ☐ IRB-04 ☐ IRB-05

SECTION III: SPECIAL SUBJECT POPULATIONS INVOLVED IN THE RESEARCH

☒ Children
☐ Cognitively Impaired
☐ Economically/ Educationally Disadvantaged
☐ Human Fetuses (or Fetal Tissue) or Neonates
☐ Pregnant Women
☐ Prisoners

SECTION IV: DOCUMENTS INCLUDED WITH RESEARCH SUBMISSION

☒ Informed Consent Document(s), dated: 3/16/10
# of consent documents: 1
☒ Expedited Research Checklist, dated: 3/16/10
☒ Recruitment Checklist, dated: 3/16/10
☒ Advertisement(s), dated: 3/16/10
(# of documents: Flyer, Brochure)

☐ Drug Brochure/Packet Insert, dated:

☒ Assent Document(s), dated: 3/16/10
# of assent documents: 1
☒ Summary Safeguard Statement (SSS), dated: 3/16/10
☒ Authorization(s), dated: 3/16/10
☒ Protocol, dated: 3/16/10
(PhD Dissertation Proposal, includes instruments and performance site commitment letters)
☒ Other, description:
1. Documentation of Review and Approval 3/16/10
2. Request Form for the Inclusion of Children in Research 3/16/10
3. Telephone Scripts 3/16/10
4. E-mail to Dr. Hanna regarding Sharron Crowder's role as co-investigator for the study 3/16/10

You only need to list document dates if they are required by the investigator or sponsor.

Recorded in the Minutes of: JUN 08 2010

v05/01/09

continued

SECTION V: INVESTIGATOR STATEMENT OF COMPLIANCE

By submitting this form, the Principal Investigator assures the Board that all procedures performed under the project will be conducted in strict accordance with those federal regulations, University and Clarian Health Partners policies that govern research involving human subjects. He/she acknowledges that he/she have the resources required to conduct research in a way that will protect the rights and welfare of participants. He/she agrees to submit *any* deviation from the project (e.g. change in principal investigator, research methodology, subject recruitment procedures, etc.) to the Board in the form of an amendment for IRB approval prior to implementation.

SECTION VI: IRB APPROVAL

This research project, including all documents included with the submission (e.g., informed consent statement, authorization, and/or waiver of authorization) has been reviewed and approved by the Indiana University-Purdue University Indianapolis Institutional Review Board or the Clarian Institutional Review Board for a maximum of a one year period beyond the final approval date unless otherwise indicated as follows: ____________________

Authorized IRB Signature: ____________________ IRB Approval Date: 5-4-2010

Recorded in the Minutes of: JUN 0 8 2010

2

v05/01/09

Figure E1. Institutional Review Board approval.

Asthma Control Test™

This survey was designed to help you describe your asthma and how your asthma affects how you feel and what you are able to do. To complete it, please mark an ☒ in the one box that best describes your answer.

1. In the past 4 weeks, how much of the time did your asthma keep you from getting as much done at work, school or at home?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

2. During the past 4 weeks, how often have you had shortness of breath?

More than once a day	Once a day	3 to 6 times a week	Once or twice a week	Not at all
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

3. During the past 4 weeks, how often did your asthma symptoms (wheezing, coughing, shortness of breath, chest tightness or pain) wake you up at night or earlier than usual in the morning?

4 or more nights a week	2 to 3 nights a week	Once a week	Once or Twice	Not at all
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

4. During the past 4 weeks, how often have you used your rescue inhaler or nebulizer medication (such as Albuterol, Ventolin®, Proventil®, Maxair® or Primatene Mist®)?

3 or more times per day	1 or 2 times per day	2 or 3 times per week	Once a week or less	Not at all
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

5. How would you rate your asthma control during the past 4 weeks?

Not Controlled at all	Poorly Controlled	Somewhat Controlled	Well Controlled	Completely Controlled
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Asthma Control Test™ copyright, QualityMetric Incorporated 2002, 2004. All Rights Reserved.
Asthma Control Test™ is a trademark of QualityMetric Incorporated.

Figure F1. ACT instrument.

APPENDIX B

OPTUMInsight™ **LICENSE AGREEMENT - DETAILS**

Licensee: Indiana University
Sharron Crowder
13202 Duval Drive
Fishers, IN 46037
United States

License Number: QM014614
Amendment to: N/A
License Term: 08/14/10 to 08/13/11
Master License Term: N/A

Approved Purpose
Illness Representations and Self-management Behaviors of African American Adolescents with Asthma

Study Name:
Protocol:
Govt. ID:
Study Type: thesis/dissertation
Clients Reference:

Licensed Surveys (Modes) and Services:

Item	**Description**	**Mode of Admin**	**Quantity**
PROJ01	License Fee	Paper	1
ES0010	ACT, Standard Recall	Paper	1

Approved Languages:
United States (English)

ADM012	Patients Enrolled		133
ADMINS	Administrations (133 participants x 1 admin)		133
SS075	Scoring Software v4.5		1
SS082	ACT: scoring credits v4.5		133
EM037	Quick Start Guide: ACT		1

Approved Languages:
United States (English)

OGSR Unfunded Student Program

Quote expires 8/6/12

Figure F2. Permission to use ACT.

APPENDIX G ASCPI

AsSCPT 1

ASTHMA SELF-CARE PRACTICE INSTRUMENT (AsSCPT)

Note: The original questions are numbers 1-21. The additional questions are numbers 22-31.

INSTRUCTIONS

A. Please answer the questions by writing in the number that best answers the question for you. **Think about the past year when answering these questions.**

B. There are no right or wrong answers. Some questions may seem alike. Please answer all the questions.

C. You may write comments or explain your answers next to the questions.

D. When there is a question about your health, take it to mean whatever health means to you.

For each question circle in the percent (%) from 0 to 100 that best answers the question for you. 0% would mean "none of the time or never," 50% would mean half of the time, and 100% would mean "all of the time" or "always." Numbers in between would mean amounts between never and always. You might want to think about it as a line with 0% at one end 100% at the other end, and the other numbers in between like this:

0% 10% 20% 30% 4%0 50% 60% 70% 80% 90% 100%

Never Always

THINGS YOU DO FOR YOUR ASTHMA

1. What percent of the time do you watch yourself for signs of asthma such as wheezing, coughing, or trouble breathing?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

2. What percentage of the time do you know when as asthma episode is "coming on" or starting?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

continued

3. What percentage of the time do you ask your doctor or nurse questions when you do not know something about your asthma?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

4. What percentage of the time do you let someone know when you are having trouble breathing because of your asthma?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

5. What percentage of the time do you talk about your feelings when you are having trouble breathing because of your asthma?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

6. What percentage of the time do you ask someone (your mom, dad, or teacher) to call the doctor when an asthma episode is getting worse?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

7. What percentage of the time do you take a break from what you are doing when you are having trouble with your breathing?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

continued

8. What percentage of the time do you take sips of water when you know you are having trouble with your breathing?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

9. What percentage of the time do you drink extra fluids when you are having breathing problems from your asthma?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

10. What percentage of the time do you stay calm when you are having an asthma attack?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

11. What percent of the time do you avoid playing in sports during recess or gym class because you think it might make you have trouble breathing?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

12. What percentage of the time do you know what is bringing on your asthma?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

continued

13. What percentage of the time do you stay away from things that you know bring on your asthma?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Never Always

14. What percentage of the time do you stay from people who are sick or have colds?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Never Always

15. What percentage of the time do you ask your doctor or nurse questions when you don't know something about your asthma medicines?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Never Always

16. What percentage of the time do you give your self your own asthma medicine?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Never Always

17. What percentage of the time do you remember to take your asthma medicines?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Never Always

continued

18. What percentage of the time do you use your inhaler/"puffer" when you first notice that you are having trouble breathing because of your asthma?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Never Always

19. What percentage of the time do you decide that you need to use your inhaler/"puffer" to help you with your breathing?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Never Always

20. What percentage of the time do you use your inhaler/"puffer" before exercise or playing sports?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Never Always

21. What percentage of your total asthma care (the things you do to take care of your asthma) are you yourself responsible for?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Never Always

22. What percentage of the time do you use any asthma medication on a daily basis?

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Never Always

continued

23. What percentage of the time do you use an inhaled steroid to control your asthma?

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Never										Always

24. What percentage of the time do you skip taking your asthma medicine?

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Never										Always

25. What percentage of the time do you strictly follow the asthma medications as instructed by your doctor?

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Never										Always

26. What percentage of the time do you follow an asthma management plan?

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Never										Always

27. What percentage of the time do you use your spacer when you use an inhaler?

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Never										Always

continued

AsSCP1 7

Some people with asthma are triggered by such things as pets, smoke, dust, weather, and playing sports.
Please answer the questions 28 to 31 according to those things that trigger **your** asthma.

28. What percentage of the time do you avoid your asthma triggers **in your home?**

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

29. What percentage of the time do you avoid your asthma triggers **at school?**

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

30. What percentage of the time do you avoid your asthma triggers **at a friend's house?**

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

31. What percentage of the time do you avoid your asthma triggers **during after school activities?**

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Never Always

Figure G1. ASCP instrument.

From: Maureen Frey [xxx@gmail.com]
Sent: Sunday, July 08, 2012 7:09 PM
To: Crowder, Sharron Johnson
Subject:

Dear Sharron,
Congratulations on your progress on your dissertation. I am glad to give you permission to use the Asthma Self Care Instrument for your study and to include the questionnaire in the dissertation. I understand that the dissertation will be available through bound copies as well as electronically. When completed, please send me an abstract. My address is

.

Sincerely,
Maureen A. Frey, Rn, PhD

Figure G2. Permission to use ASCPI.

APPENDIX H IPQ-R

YOUR VIEWS ABOUT YOUR ASTHMA

Listed below are a number of symptoms that you may or may not have experienced since your asthma. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your asthma, and whether you believe that these symptoms are related to your asthma.

	I have experienced this symptom *since my asthma*			This symptom is *related to my asthma*	
Pain	Yes	No	__________	Yes	No
Sore Throat	Yes	No	__________	Yes	No
Nausea	Yes	No	__________	Yes	No
Breathlessness	Yes	No	__________	Yes	No
Weight Loss	Yes	No	__________	Yes	No
Fatigue	Yes	No	__________	Yes	No
Stiff Joints	Yes	No	__________	Yes	No
Sore Eyes	Yes	No	__________	Yes	No
Wheeziness	Yes	No	__________	Yes	No
Headaches	Yes	No	__________	Yes	No
Upset Stomach	Yes	No	__________	Yes	No
Sleep Difficulties	Yes	No	__________	Yes	No
Dizziness	Yes	No	__________	Yes	No
Loss of Strength	Yes	No	__________	Yes	No

We are interested in your own personal views of how you now see your current asthma.

Please indicate how much you agree or disagree with the following statements about your asthma by ticking the appropriate box.

	VIEWS ABOUT YOUR ASTHMA	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	My asthma will last a short time					
IP2	My asthma is likely to be permanent rather than temporary					
IP3	My asthma will last for a long time					

continued

	VIEWS ABOUT YOUR ASTHMA	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP4*	This asthma will pass quickly					
IP5*	I expect to have this asthma for the rest of my life					
IP6	My asthma is a serious condition					
IP7	My asthma has major consequences on my life					
IP8*	My asthma does not have much effect on my life					
IP9	My asthma strongly affects the way others see me					
IP10	My asthma has serious financial consequences					
IP11	My asthma causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my asthma gets better or worse					
IP14	The course of my asthma depends on me					
IP15*	Nothing I do will affect my asthma					
IP16	I have the power to influence my asthma					
IP17*	My actions will have no affect on the outcome of my asthma					
IP18*	My asthma will improve in time					
IP19*	There is very little that can be done to improve my asthma					
IP20	My treatment will be effective in curing my asthma					
IP21	The negative effects of my asthma can be prevented (avoided) by my treatment					
IP22	My treatment can control my asthma					
IP23*	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My asthma is a mystery to me					
IP26	I don≠understand my asthma					

continued

IP27	My asthma doesn't make any sense to me					
IP28*	I have a clear picture or understanding of my condition					
IP29	The symptoms of my asthma change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My asthma is very unpredictable					
IP32	I go through cycles in which my asthma gets better and worse.					
IP33	I get depressed when I think about my asthma					
IP34	When I think about my asthma I get upset					
IP35	My asthma makes me feel angry					
IP36*	My asthma does not worry me					
IP37	Having this asthma makes me feel anxious					
IP38	My asthma makes me feel afraid					

continued

CAUSES OF MY ASTHMA

We are interested in what you consider may have been the cause of your asthma. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your asthma rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your asthma. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries					
C11*	Overwork					
C12*	My emotional state e.g. feeling down, lonely, anxious, empty					
C13*	Ageing					
C14*	Alcohol					
C15*	Smoking					
C16*	Accident or injury					
C17*	My personality					
C18*	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR asthma. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:

1. ______________________

2. ______________________

3. ______________________

Figure H1. IPQ-R instrument.

From: Moss-Morris, Rona
Sent: Sunday, July 01, 2012 9:42 AM
To: Crowder, Sharron Johnson
Subject: RE: Illness Representations Questionnaire-Revised

Dear Sharon

The IPQ-R can be included in your thesis as long as it is fully referenced.

Best

Professor of Psychology as Applied to Medicine
Health Psychology Section, Psychology Dept.,
Institute of Psychiatry, KCL,
5th floor Bermondsey Wing
Guy's Hospital Campus
London Bridge
London SE1 9RT

Phone:
Fax:
Email:

wishes

Rona

From: Crowder, Sharron Johnson [mailto:]
Sent: 29 June 2012 16:21
To: Moss-Morris, Rona
Subject: Illness Representations Questionnaire-Revised

Dear Dr. Moss-Morris:

I am Sharron Crowder, a doctoral student at Indiana University School of Nursing. I contacted you several years ago regarding the Illness Representations Questionnaire-Revised. I am completing the requirements for my dissertation on the "Illness Representations and Self-management Behaviors of African American Adolescents with Asthma." I used the asthma format for the IPQ-R as the questionnaire in order to assess the participants' illness representations.

I am writing to request permission to publish a copy of the IPQ-R as one of the instruments used for my study. At this time, the request is for use in the dissertation which will be published for our library and available as a published dissertation online. I would appreciate your guidance on the permission process so I can complete the necessary requirements as soon as possible.

Thank you for your consideration of my request. My doctoral program has been enhanced because I had the opportunity to delve into the illness representations of adolescents with asthma. I am looking forward to future opportunities to increase my

continued

knowledge and research on illness representations. Therefore, I am also looking forward to future communication with you. However, at this time, as you can image, I want to complete the first step and that is completion of the dissertation and the PhD in Nursing Science.

Sharron Johnson Crowder, MN, RN
Doctoral Student, PhD Program
Indiana University School of Nursing
xxx@iupui.edu

Figure H2. Permission to use IPQ-R.

APPENDIX I DEMOGRAPHICS FORM

I.D. #
____
Date:
____
Locator Code:
____

Study: Illness Representations and Self-Management Behaviors of African American Adolescents with Asthma

1. Gender: (Please Check)
   ______ Male
   ______ Female

2. What is you birthdate? ______________________________________

3. Grade in School: (Please check)
_______ 8th grade
_______ 9th grade
_______ 10th grade
_______ 11th grade
_______ 12th grade

4. The year that I was diagnosed with asthma: ______________________

5. Where do you go most of the time to take care of your asthma? (Please check)
______ general doctor's office
______ health department clinic
______ specialist's office
______ emergency department

6. Have you completed a formal asthma education program?
______ No
______ Yes
   If yes, complete the additional questions:
   When did you attend the program: Year _______
   Where was the program held?
____
   How long did it last? (Provide number of hours if in one day, or number of days, or weeks)
____

7. How often do you smoke?
______ Never
______ Occasionally
______ Daily

continued

8. Number of smokers in your home?
______ 0
______ 1
______ 2
______ 3
______ ≥ 4
9. Which option best describes smoking in your home?
______ Smoking is allowed in any common room of the home
______ Smoking is permitted in a part of the house where I rarely go
______ There is no smoking at all

10. Which option best describes smoking in your family's car?
______ Smoking is allowed in the car
______ Smoking is allowed in the car if the windows are down
______ There is no smoking at all

11. In the past month was there any day when you or anyone in your family went hungry because you did not have enough money for food?
______ Yes
______ No

12. My parents are
______ Married
______ Divorced
______ Never Married
______ Separated
______ One or both parents have died

13. Who do you live with?
____ Mother ____ Father ____Both Mother and Father
____Guardians ____ Other ____________________________________ (who)

14. Check the highest education your mother/female or guardian has completed?
_________ 8^{th} grade
_________ 9^{th} grade
_________ 10^{th} grade
_________ 11^{th} grade
_________ High school diploma
_________ Associate degree
_________ Vocational degree
_________ Bachelor's degree
_________ Master's degree
_________ Ph.D., JD, MD
_________ I don't know

continued

15. Check the highest education your father/male guardian has completed?
_________ 8^{th} grade
_________ 9^{th} grade
_________ 10^{th} grade
_________ 11^{th} grade
_________ High school diploma
_________ Associate degree
_________ Vocational degree
_________ Bachelor's degree
_________ Master's degree
_________ Ph.D., JD, MD
_________ I don't know

16. Think of the money your family has for living (housing, food, etc.). Which of the following best describes how much money you and your family has:
_________ We don't have enough
_________ We have just enough
_________ We have more than we need

17. Do you consider yourself to be Latino, that is Mexican, Puerto Rican, Cuban, Caribbean, or Latin American Descent? _____ yes _______no

APPENDIX J COUNTY CHARACTERISTICS OF SAMPLE

Table J1

Representation of Sample by County and County's Characteristics (Counties 1–6 of 11)

Demographic	County 1[a]	County 2[b]	County 3[c]	County 4[d]	County 5[e]	County 6[f]
Recruitment Site City	A	B	C	D	E	F
Population						
Total Population	115,548	197,851	69,203	261,328	83,685	491,203
Highest Proportion of Population By Gender	M = 4,516 F = 3,831	M = 8,610 F = 8,336	M = 2,622 F = 2,673	M = 12,302 F = 12,417	M = 3,178 F = 3,321	M = 19,568 F = 20,014
Age Range of Gender Proportion Specified	M = 22–24 yrs F = 45–49 yrs	M = under 5 yrs F = under 5 yrs	M = 10–14 yrs F = 45–49 yrs	M = 40–44 yrs F = 40–44 yrs	M = 10–14 yrs F = 45–49 yrs	M = 10–14 yrs F = 45–49 yrs
Housing Units						
Total	*n* = 107,332	*n* = 195,302	*n* = 64,544	*n* = 260,225	*n* = 80,533	*n* = 484,599
Owner Occupied	*n* = 72,804 (67.8%)	*n* = 144,796 (74.1%)	*n* = 47,275 (73.2%)	*n* = 214,810 (82.5%)	*n* = 58,294 (72.3%)	*n* = 352,964 (72.8%)
Renter Occupied	*n* = 34,528 (32.2%)	*n* = 50,506 (25.9%)	*n* = 17,269 (26.7%)	*n* = 45,415 (17.4%)	*n* = 22,239 (27.6%)	*n* = 131,635 (27.2%)
Household Income						
Total Households	*n* = 46,561	*n* = 71,093	*n* = 27,689	*n* = 91,837	*n* = 34,334	*n* = 184,343
Income level with Highest Number of Residents	$60,000–$74,999 *n* = 4,359 (9.36%)	$75,000–$99,999 *n* = 8,811 (12.39%)	$60,00–$74,999 *n* = 2,855 (10.3%)	$75,000–$99,999 *n* = 14,436 (15.7%)	$75,000–$99,999 *n* = 4,328 (12.6%)	$75,000–$99,999 *n* = 24,642 (13.4%)
Persons below Poverty[g] County% / State 14.4%	20.7%	14.4%	18.1%	5.6%	15.1%	16.4%

continued

Education						
High School Graduates Age 25+	83.6%	78.7%	83.0%	95.9%	85.5%	85.2%
Bachelor's Degree or Higher Age 25+	21.5%	17.6%	15.8%	52.6%	18.8%	18.3%
Employment[h]						
Farm vs. Nonfarm County	Nonfarm	Nonfarm	Farm	Nonfarm	Farm	Nonfarm
Air Quality Index (AQI)[i]						
Days with AQI	215	220	Unavailable	184	88	335
Good Rating	182 (84.6%)	167 (75.9%)	Unavailable	146 (79.3%)	71 (80.6%)	228 (68.0%)
Moderate Rating	33 (15.3%)	52 (23.6%)	Unavailable	35 (19.0%)	17 (19.3%)	105 (31.3%)
Unhealthy for Sensitive Group Rating	0	1	Unavailable	3 (1.63%)	0	2 (.59%)

Note. Data retrieved from U.S. Census Bureau, 2005–2009 American Community Survey, http://factfinder.census.gov.
[a]*n* = 2. [b]*n* = 4. [c]*n* = 3. [d]*n* = 4. [e]*n* = 5. [f]*n* = 3. [g]2009 poverty rate. [h]2002 Employment data. [i]Data retrieved from U.S. Environmental Protection Agency, 2008 Air Quality Index, http://iaspub.epa.gov/airsdata.

Table J2

Representation of Sample by County and County's Characteristics (Counties 7–11 of 11)

Demographic Recruitment Site City	County 7[a] F	County 8[b] G	County 9[c] H	County 10[d] I	County11[e] J
Population					
Total Population	131,015	878,881	144,544	105,343	68,151
Highest Proportion of Population By Gender	M = 4,977 F = 4,620	M = 36,903 F = 41,683	M = 6,877 F = 7,974	M = 3,681 F = 3,600	M = 2,338 F = 2,491
Age Range of Gender Proportion Specified	M = 40–44 yrs F = 45–49 yrs	M = under 5 yrs F = 25–29	M = 25–29 yrs F = 25–29 yrs	M = 40–44 yrs F = 45–49 yrs	M = 5–9 yrs F = 45–49 yrs
Housing Units					
Total	*n* = 125,857	*n* = 859,164	*n* = 168,222	*n* = 96,517	*n* = 65,909
Owner Occupied	*n* = 95,050 (75.5%)	*n* = 536,329 (62.4%)	*n* = 116,599 (69.3%)	*n* = 66,668 (69.1%)	*n* = 47,411 (71.9%)
Renter Occupied	*n* = 30,807 (24.4%)	*n* = 322,835 (37.5%)	*n* = 51,623 (30.6%)	*n* = 29,849 (30.9%)	*n* = 18,498 (28.1%)
Household Income					
Total Households	*n* = 51,732	*n* = 358,284	*n* = 72,843	*n* = 41,932	*n* = 27,699
Income level with Highest Number of Residents	$75,000–$99,999 *n* = 6,049 (11.7%)	$75,000–$99,999 *n* = 38,414 (9.3%)	$75,00–$99,999 *n* = 8,123 (11.6%)	$75,000–$99,999 *n* = 4,194 (10.0%)	$60,000–$74,999 *n* = 2,942 (10.6%)
Persons below Poverty[f] County% / State 14.4%	14.7%	19.7%	15.2%	20.9%	15.4%

continued

Education					
High School Graduates Age 25+	85.5%	84.1%	86.5%	85.2%	81.8%
Bachelor's Degree or Higher Age 25+	16.5%	27.7%	21.3%	20.9%	15.4%
Employment[g]					
Farm vs. Nonfarm County	Nonfarm	Nonfarm	Nonfarm	Nonfarm	Nonfarm
Air Quality Index (AQI)[h]					
Days with AQI	305	365	305	305	181
Good Rating	220 (72.1%)	213 (58.3%)	201 (65.9%)	208 (71.4%)	181 (100.0%)
Moderate Rating	85 (27.8%)	151 (41.3%)	101 (33.1%)	87 (28.5%)	0
Unhealthy for Sensitive Group Rating	0	2 (0.54%)	3 (0.09%)	0	0

[a]*n* = 7. [b]*n* = 99. [c]*n* = 1. [d]*n* = 2. [e]*n* = 3. [f]2009 poverty rate. [g]2002 Employment data. [h]Data retrieved from U.S. Environmental Protection Agency, 2008 Air Quality Index, http://iaspub.epa.gov/airsdata.

APPENDIX K DATA ANALYSES

Table K1

ACT Items

Description of Items	*N*	*M* (*SD*)	*Mdn*	Range
Disruption in school/home activities	133	3.95 (.964)	4.00	1–5
Shortness of breath	133	3.55 (1.23)	4.00	1–5
Nighttime/morning waking to symptoms	133	3.51 (1.36)	4.00	1–5
Use of inhaler	133	3.72 (1.31)	4.00	1–5
Overall rating of asthma control	133	3.74 (.951)	4.00	1–5

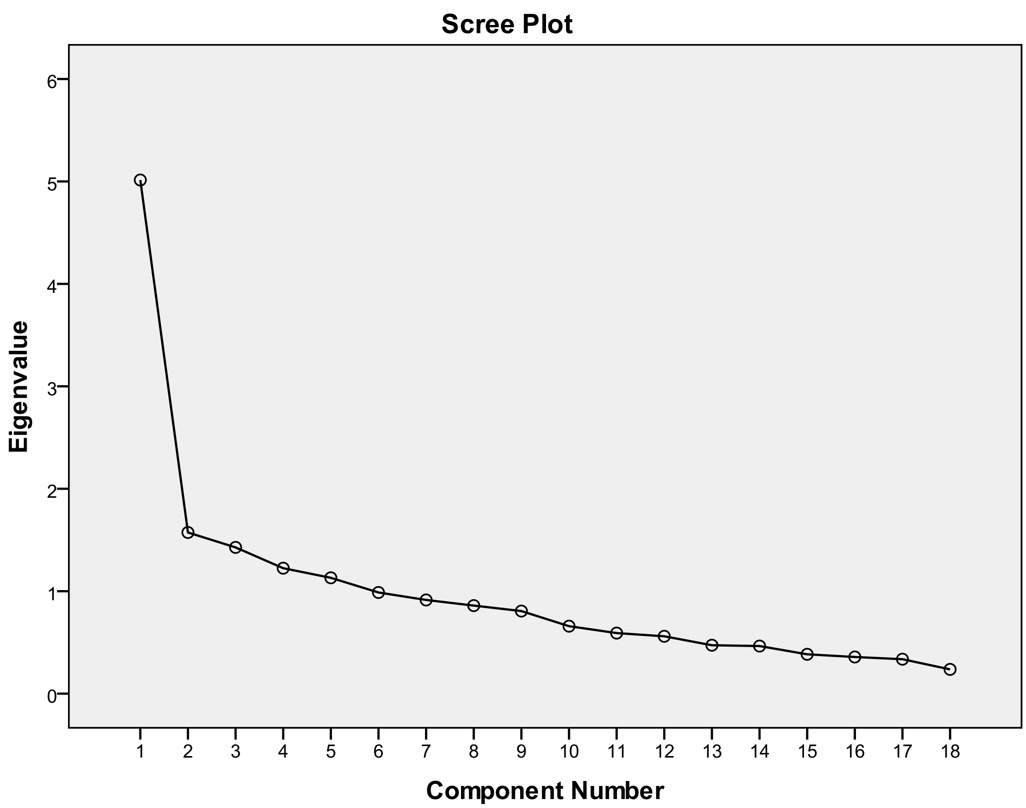


Figure K1. Scree plot for causes principal components analysis.

Table K2

Causes Subscale-Factor Analysis and Parallel Analysis Values

	Initial Eigenvalues			Extraction Sums of Squared Loadings		
Component	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	5.014	27.854	27.854	5.014	27.854	27.854
2	1.573	8.741	36.595	1.573	8.741	36.595
3	1.428	7.931	44.526	1.428	7.931	44.526
4	1.225	6.803	51.329	1.225	6.803	51.329
5	1.131	6.282	57.611	1.131	6.282	57.611
6	.988	5.486	63.098			
7	.915	5.081	68.179			
8	.860	4.776	72.955			
9	.806	4.479	77.434			
10	.659	3.659	81.093			
11	.591	3.284	84.377			
12	.560	3.111	87.488			
13	.473	2.626	90.114			
14	.465	2.581	92.695			
15	.384	2.134	94.829			
16	.358	1.988	96.816			
17	.336	1.868	98.684			
18	.237	1.316	100.000			

Note. Total variance explained. Extraction method is the principal component analysis.

Table K3

Rotation Matrix for Principal Component Analysis of Causes

Causes	Component[a]				
	1	2	3	4	5
Emotional state cause asthma	.808				
My attitude caused my asthma	.765				
Family problems or worries cause asthma	.738				.321
Stress or worry cause asthma	.570				.499
Overwork cause asthma	.493				
Ageing caused asthma	.346	.327			
Accident or injury caused asthma		.765			
Smoking caused asthma		.758			
Alcohol caused asthma		.641	.378		
Altered immunity caused asthma		.486			.451
My behavior caused my asthma			.815		
Diet or germs cause asthma			.674		
Poor medical care cause asthma	.413	.436	.440		
Hereditary caused asthma				-.794	
Chance or bad luck	.311			.611	
My personality caused asthma	.461			.462	
Pollution caused asthma					.648
Germs or viruses cause asthma		.337			.596

Note. Extraction method is principal component analysis. Rotation method is Varimax with Kaiser Normalization.
[a]Rotation converged in 7 iterations.

Table K4

Categories for the Responses to Three Most Important Causal Factors

Original Categories	Frequency = *N* (%)
Accident/Injury	0 (0)
Aging	6 (4.5)
Alcohol	3 (2.3)
Altered Immunity	5 (3.8)
Behavior	13 (9.8)
Chance / Bad Luck	13 (9.8)
Diet / Eating Habits	12 (9.0)
Emotional State	2 (1.5)
Family Problems	4 (3.0)
Germ or Virus	18 (13.5)
Heredity	95 (71.4)
Mental Attitude	3 (2.3)
My Personality	2 (1.5)
Overwork	14 (10.5)
Pollution	50 (37.6)
Poor Medical Care in the Past	9 (6.8)
Smoking	41 (30.8)
Stress or Worry	14 (10.5)
Additional Categories	
Activities	32 (24.1)
Allergies	17 (12.8)
Birth Problems	10 (7.8)
Can’t Breath	3 (2.3)
Environment	4 (3.0)
God	6 (4.5)
Less Water	1 (.8)
Mom’s Behavior	4 (3.0)
Nature	6 (4.5)
Respiratory Infection	1 (.8)
Sore Throat	1 (.8)
Tired	1 (.8)
Weather	11 (8.3)

Table K5

Differences in Means of Self-management Behaviors–Levene's Test of Equality of Error Variances

Self-management Behaviors	*F*	*df*1	*df*2	Sig.
Symptom Management ASCPI	.515	3	129	.673
Medication Management ASCPI	2.545	3	129	.059
Environmental Management ASCPI	2.423	3	129	.069

Note. Design is the Intercept + Gender + Asthma Impairment + Gender * Asthma Impairment. Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

APPENDIX L POWER ANALYSES

Table L1

Observed Power for Symptom Management, Cognitive and Emotional Illness Representations, Gender, Asthma Impairment, Gender by Asthma Impairment

Tests of Between-Subjects Effects

Dependent Variable: Symptom Management ASCPI

Source	Type III Sum of Squares	*df*	Mean Square	*F*	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[b]
Corrected Model	9307.085[a]	10	930.708	2.469	.010	.168	24.691	.935
Intercept	154.658	1	154.658	.410	.523	.003	.410	.097
IdentityRCTotal	978.955	1	978.955	2.597	.110	.021	2.597	.359
TimelineACTotalRC	.129	1	.129	.000	.985	.000	.000	.050
ConsequencesTotalRC	2241.925	1	2241.925	5.948	.016	.046	5.948	.677
PersonalControlRCTotal	24.510	1	24.510	.065	.799	.001	.065	.057
TreatmentControlRCTotal	3662.798	1	3662.798	9.717	.002	.074	9.717	.871
TimelineCyclicalRCTotal	720.571	1	720.571	1.912	.169	.015	1.912	.279
EmotionalRCTotal	166.256	1	166.256	.441	.508	.004	.441	.101
Gender	11.282	1	11.282	.030	.863	.000	.030	.053
AsthmaImpairment	741.256	1	741.256	1.966	.163	.016	1.966	.285

continued

Gender * AsthmaImpairment	380.994	1	380.994	1.011	.317	.008	1.011	.169
Error	45987.652	122	376.948					
Total	507592.000	133						
Corrected Total	55294.737	132						

[a]R Squared = .168 (Adjusted R Squared = .100). [b]Computed using alpha = .05.

Table L2

Observed Power for Medication Management, Cognitive and Emotional Illness Representations, Gender, Asthma Impairment, Gender by Asthma Impairment

Tests of Between-Subjects Effects								
Dependent Variable: Medication Management ASCPI								
Source	Type III Sum of Squares	*df*	Mean Square	*F*	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[b]
Corrected Model	5612.959[a]	10	561.296	1.304	.236	.097	13.040	.645
Intercept	425.335	1	425.335	.988	.322	.008	.988	.167
IdentityRCTotal	.005	1	.005	.000	.997	.000	.000	.050
TimelineACTotalRC	662.829	1	662.829	1.540	.217	.012	1.540	.234
ConsequencesTotalRC	1171.465	1	1171.465	2.722	.102	.022	2.722	.373
PersonalControlRCTotal	190.550	1	190.550	.443	.507	.004	.443	.101
TreatmentControlRCTotal	1314.118	1	1314.118	3.053	.083	.024	3.053	.411
TimelineCyclicalRCTotal	1619.224	1	1619.224	3.762	.055	.030	3.762	.486
EmotionalRCTotal	156.174	1	156.174	.363	.548	.003	.363	.092
Gender	3.915	1	3.915	.009	.924	.000	.009	.051
AsthmaImpairment	475.826	1	475.826	1.105	.295	.009	1.105	.181
Gender * AsthmaImpairment	46.291	1	46.291	.108	.744	.001	.108	.062
Error	52513.342	122	430.437					
Total	471638.000	133						
Corrected Total	58126.301	132						

[a]R Squared = .097 (Adjusted R Squared = .023). [b]Computed using alpha = .05.

Table L3

Observed Power for Environmental Control, Cognitive and Emotional Illness Representations, Gender, Asthma Impairment, Gender by Asthma Impairment

Tests of Between-Subjects Effects								
Dependent Variable: Environmental Management ASCPI								
Source	Type III Sum of Squares	*df*	Mean Square	*F*	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[b]
Corrected Model	3011.350[a]	11	273.759	1.430	.168	.115	15.727	.725
Intercept	1.765	1	1.765	.009	.924	.000	.009	.051
IdentityRCTotal	507.151	1	507.151	2.649	.106	.021	2.649	.365
TimelineACTotalRC	38.182	1	38.182	.199	.656	.002	.199	.073
ConsequencesTotalRC	125.967	1	125.967	.658	.419	.005	.658	.127
PersonalControlRCTotal	376.570	1	376.570	1.967	.163	.016	1.967	.285
TreatmentControlRCTotal	246.430	1	246.430	1.287	.259	.011	1.287	.203
TimelineCyclicalRCTotal	237.634	1	237.634	1.241	.267	.010	1.241	.197
EmotionalRCTotal	197.793	1	197.793	1.033	.311	.008	1.033	.172
PsychologicalSubscale	55.727	1	55.727	.291	.591	.002	.291	.083
Gender	132.182	1	132.182	.690	.408	.006	.690	.131
AsthmaImpairment	227.205	1	227.205	1.187	.278	.010	1.187	.191
Gender * AsthmaImpairment	.878	1	.878	.005	.946	.000	.005	.051
Error	23168.756	121	191.477					

continued

Total	144206.000	133						
Corrected Total	26180.105	132						

[a]R Squared = .115 (Adjusted R Squared = .035). [b]Computed using alpha = .05.

Table L4

Observed Power for Symptom Management, Medication Management, Environmental Control, Gender, Asthma Impairment, Gender by Asthma Impairment

MANOVA Parameter Estimates

Dependent Variable	Parameter	B	Std. Error	*t*	Sig.	95% Confidence Interval		Partial Eta Squared	Noncent. Parameter	Observed Power[a]
						Lower Bound	Upper Bound			
Symptom Management ASCPI	Intercept	58.333	2.964	19.680	.000	52.469	64.198	.750	19.680	1.000
	[Gender=0]	4.200	4.780	.879	.381	-5.256	13.656	.006	.879	.141
	[Gender=1]	0[b]	.	.	.	.	.	.	.	.
	[AsthmaImpairment=1]	-.933	5.466	-.171	.865	-11.747	9.881	.000	.171	.053
	[AsthmaImpairment=2]	0[b]	.	.	.	.	.	.	.	.
	[Gender=0] * [AsthmaImpairment=1]	-6.400	7.482	-.855	.394	-21.203	8.403	.006	.855	.136
	[Gender=0] * [AsthmaImpairment=2]	0[b]	.	.	.	.	.	.	.	.
	[Gender=1] * [AsthmaImpairment=1]	0[b]	.	.	.	.	.	.	.	.
	[Gender=1] * [AsthmaImpairment=2]	0[b]	.	.	.	.	.	.	.	.

continued

Medication Management ASCPI	Intercept	56.625	3.057	18.521	.000	50.576	62.674	.727	18.521	1.000
	[Gender=0]	.642	4.930	.130	.897	-9.112	10.396	.000	.130	.052
	[Gender=1]	0[b]	.	.	.	.	.	.	.	.
	[AsthmaImpairment=1]	-2.075	5.638	-.368	.713	-13.229	9.079	.001	.368	.065
	[AsthmaImpairment=2]	0[b]	.	.	.	.	.	.	.	.
	[Gender=0] * [AsthmaImpairment=1]	-1.220	7.717	-.158	.875	-16.489	14.049	.000	.158	.053
	[Gender=0] * [AsthmaImpairment=2]	0[b]	.	.	.	.	.	.	.	.
	[Gender=1] * [AsthmaImpairment=1]	0[b]	.	.	.	.	.	.	.	.
	[Gender=1] * [AsthmaImpairment=2]	0[b]	.	.	.	.	.	.	.	.

continued

Environmental Management ASCPI	Intercept	30.062	2.045	14.699	.000	26.016	34.109	.626	14.699	1.000
	[Gender=0]	1.804	3.298	.547	.585	-4.721	8.329	.002	.547	.084
	[Gender=1]	0[b]	.	.	.	.	.	.	.	.
	[AsthmaImpairment=1]	-2.812	3.771	-.746	.457	-10.274	4.649	.004	.746	.115
	[AsthmaImpairment=2]	0[b]	.	.	.	.	.	.	.	.
	[Gender=0] * [AsthmaImpairment=1]	.032	5.162	.006	.995	-10.183	10.246	.000	.006	.050
	[Gender=0] * [AsthmaImpairment=2]	0[b]	.	.	.	.	.	.	.	.
	[Gender=1] * [AsthmaImpairment=1]	0[b]	.	.	.	.	.	.	.	.
	[Gender=1] * [AsthmaImpairment=2]	0[b]	.	.	.	.	.	.	.	.

[a]Computed using alpha = .05. [b]This parameter is set to zero because it is redundant.

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Velsor-Friedrich, B., Pigott, T., & Srof, B. (2005). A practitioner based asthma intervention program with African American inner-city school children. *Journal of Pediatric Health Care, 19*(3), 163–171.

Velsor-Friedrich, B., Vlasses, F., Moberley, J., & Coover, L. (2004). Talking with teens about asthma management. *The Journal of School Nursing, 20*(3), 140–148.

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Weinman, J., & Petrie, K. (Eds.). (1997). *Perceptions of health & illness*. Amsterdam, NL: Harwood Academic.

Weinman, J., Petrie, K., Moss-Morris, R., & Horne, R. (1996). The Illness Perception Questionnaire: A new method of assessing the cognitive representation of illness. *Psychology and Health, 11*(3), 431–445.

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Williams, C. (2000). Doing health, doing gender: Teenagers, diabetes and asthma. *Social Science & Medicine, 50*(3), 387–396.

Wirrell, E., Cheung, C., & Spier, S. (2006). How do teens view the physical and social impact of asthma compared to other chronic diseases? *Journal of Asthma*, *43*(2), 155–160.

Woodgate, R. L. (1998). Adolescents' perspective of chronic illness: "It's hard." *Journal of Pediatric Nursing*, *13*(4), 210–223.

Woods, S., Brown, K., & Engel, A. (2010). The influence of gender on adults admitted for asthma. *Gender Medicine, 7*(2), 109–114.

Wright, R., & Subramanian, S. (2007). Advancing a multilevel framework for epidemiologic research on asthma disparities. *Chest, 132*(5S), 757–769.

Yeatts, K., Maier, W., & Shy, C. (2000). Asthma inhaler use and barriers in a population-based sample of African-American and White adolescents. *Annals of Allergy, Asthma, & Immunology, 84*(1), 94–100.

Yoos, H., Kitzman, H., Henderson, C., McMullen, A., Sidora-Arcoleo, K., Halterman, J., & Anson, E. (2007). The impact of the parental illness representation on disease management in childhood asthma. *Nursing Research, 56*(3), 167–174.

Yoos, H., & McMullen, A. (1996). Illness narratives of children with asthma. *Pediatric Nursing, 22(4)*, 285–289.

Zebracki, K., & Drotar, D. (2004). Outcome expectancy and self-efficacy in adolescent asthma self-management. *Children's Health Care, 33*(2), 133–149.

CURRICULUM VITAE

Sharron Johnson Crowder

EDUCATION

Graduate

Date	Place	Degree
2012	Indiana University School of Nursing Indianapolis, IN	Doctor of Philosophy in Nursing Science
1988	Nell Hodgson Woodruff College of Nursing, Emory University Atlanta, GA	Master of Nursing

UNDERGRADUATE

1982	University of Arkansas for Medical Sciences College of Nursing, Little Rock, AR	Bachelor of Science in Nursing

ACADEMIC APPOINTMENTS

Dates	Place	Title/Rank
2004–2007	Indiana University School of Nursing Department of Environments for Health Indianapolis, IN	Visiting Lecturer
2000–2004	University of Oklahoma Health Sciences Center, College of Nursing Lawton, OK	Instructor
1999–2000	Harrisburg Area Community College Practical Nursing/Degree Programs Harrisburg, PA	Associate Instructor
1998–1999	Ivy Tech State College Practical Nursing Program Indianapolis, IN	Instructor
1997–1998	Pikes Peak Community College Associate Degree Program Colorado Springs, CO	Instructor/ Adjunct Faculty
1991–1993	Georgia State University Bachelors Degree Program Atlanta, GA	Adjunct Faculty

CLINICAL APPOINTMENTS

Dates	Place	Title/Rank
1994–1995	Child Development US Army, 414th BSB Hanau, Germany	Child Development Services Nurse

1990–1993	Children's Medical Services Atlanta, GA	Chronic Lung Nurse Coordinator
1988–1990	Children's Medical Services Atlanta, GA	Cardiac/Chronic Lung Nurse
1983–1985	Pediatric Intensive Care Unit, Arkansas Children's Hospital, Little Rock, AR	Assistant Charge Nurse/ Nurse Preceptor
1982–1985	Pediatric Intensive Care Unit, Arkansas Children's Hospital, Little Rock, AR	Staff Nurse

CONSULTATIONS

Dates	Place	Title/Rank
2003–2004	SAMCO Consultants	Health Education Consultant
January 2004 2003	Lawton Ministerial Alliance Education Programs	Developing Community January,

LICENSURE

Registered Nurse: Indiana

PROFESSIONAL ORGANIZATIONS

Inclusive Dates	Full Name
2007–Present	Midwestern Regional Nursing Society
2009–Present	American Thoracic Society
1989–2011	Chi Eta Phi Nursing Sorority
1981–2008, 2012	Sigma Theta Tau Honor Society
2004–2009	Association of Black Nursing Faculty, Leadership Institute Committee
2001–2004	Oklahoma Nurses Association
1991–2000	American Lung Association

HONORS and AWARDS:

Date	Full Name	Granted By
September 2002	OU College of Nursing Fellow	University of Oklahoma Health
May 2004	University of Oklahoma Health Sciences Center	Sciences Center Faculty Leadership Program
May 2004, 2003, 2002	Most Motivational Instructor Lawton Campus University of Oklahoma	Senior Class–College of Nursing
March 2004	OU College of Nursing Nominee for "Good Teaching Award"	University of Oklahoma Faculty Council

March 2003	Outstanding Family of the Year (Professional and Community)	Lawton Community Council
April 2002	Outstanding Clinical Instructor for Distant Sites	College of Nursing, University of Oklahoma

TEACHING ASSIGNMENTS

Indiana University School of Nursing

Course / # cr	Title	Role	Term/Yr	Enrollment
S483 / 3 cr (clin)	Capstone Practicum	Guest Lect/Instr	Spr 07	11
S484 / 1 cr (sem)	Research Utilization	Guest Lect/Instr	Spr 07	11
S483 / 3 cr (clin)	Capstone Practicum	Guest Lect/Instr	Fall 06	13
S484 / 1 cr (sem)	Research Utilization	Guest Lect/Instr	Fall 06	13
S481 / 2 cr (didac)	Nursing Management	Guest Lect/Instr	Spr 06	48
S483 / 3 cr (clin)	Capstone Practicum	Guest Lect/Instr	Spr 06	12
S484 / 1 cr (sem)	Research Utilization	Guest Lect/Instr	Spr 06	12
S481 / 2 cr (didac)	Nursing Management	Guest Lect/Instr	Fall 05	47
S483 / 3 cr (clin)	Capstone Practicum	Guest Lect/Instr	Fall 05	14
S484 / 1 cr (sem)	Research Utilization	Guest Lect/Instr	Fall 05	14
S481 / 2 cr (didac)	Nursing Management	Guest Lect/Instr	Spr 05	36
S483 / 3 cr (clin)	Capstone Practicum	Guest Lect/Instr	Spr 05	36
S484 / 1 cr (sem)	Research Utilization	Guest Lect/Instr	Spr 05	6
S481 / 2 cr (didac)	Nursing Management	Guest Lect/Instr	Fall 04	6
S483 / 3 cr (clin)	Capstone Practicum	Guest Lect/Instr	Fall 04	50
S484 / 1 cr (sem)	Research Utilization	Guest Lect/Instr	Fall 04	14

University of Oklahoma College of Nursing

Course / # cr	Title	Role	Term/Yr	Enrollment
N4134 / 4 cr	The Practice of Leadership	Campus Course Coord/Instr	Spr 04 Spr 03 Spr 02	23 24 26
N4126 / 6 cr	Clinical IV	Course Coord/ Clin Instr	Spr 04 Spr 03 Spr 02	25 26 25
N3034 (didac)	Human Experience	Lawton Campus Course Coord/ Instr	Fall 03 Fall 02	36 34
N3025 (clin)	Clinical I	Lab Instr	Fall 03 Fall 02	36 34

UNIVERSITY COMMITTEE SERVICE

Indiana University–Purdue University Indianapolis

Talent Alliance	Indiana University School of Nursing Representative	2011–Present
Undergraduate Research Opportunities Program	Evaluator	2005

Indiana University School of Nursing

"Connections" Doctoral Support Group	Student Representative	2007–2008
Evidence Based Practice and Innovative Practices Task Force	Member	2005–2006
Admission Criteria Task Force	Member	2005–2006

Community

Baccalaureate Curriculum Advisory Committee	Member	2005–2006
BSN Curriculum Committee	Member	2004–2006
Diversity and Enrichment Committee	Member	2004–Present
Strategic Planning—Innovations Committee	Member	Fall 2004

University of Oklahoma College of Nursing

Historical Committee	Member	2000–2004
Recruitment/Retention Committee—Lawton Campus	Member	2001–2004
NLNAC Sub-Committee on Curriculum and Instruction	Member	2000–2001

PROFESSIONAL SERVICE

State

Indiana Joint Asthma Coalition, Indianapolis, Indiana	2007–Present

Local

Alpha Kappa Alpha Sorority, Inc., Alpha Mu Omega Chapter	2011–Present
Asthma Alliance of Indianapolis, Indianapolis, Indiana	2007–Present
Seminar Coordinator and Lecturer, Oklahoma University College of Nursing–Lawton/Cameron University, Lawton OK	2004
Asthma Program Coordinator, Ft. Sill—Lawton Community Coalition, Lawton, Oklahoma	2003–2004
Oklahoma University College of Nursing, Lawton Campus, Implementation of *A plan to increase passage of the NCLEX exam*	2002–2004
St. John's Missionary Baptist Church, Community Education Committee Lawton, Oklahoma	2002–2004

Lawton Asthma Consortium, Co-Organizer, Nurse Consultant, Lawton, Oklahoma	2000–2004
Union Baptist Christian Academy, Nurse Consultant, Lawton, Oklahoma	2000–2004

PRESENTATIONS

International

*Crowder, S. J. (1995, October). *Asthma management in child development services agencies*. National Association of Education of Younger Children, Mannheim, Germany.

National

*Crowder, S. J. (2006, January). *Gaining a new attitude about leadership*. Chi Eta Phi Nursing Sorority, Inc., Leadership Summit. Indianapolis, IN.

Regional

*Crowder, S. J. (2009, March). *Asthma self-management interventions*. Midwest Nursing Research Society Conference. Minneapolis, MN.

*Crowder, S. J. (2005, March). *Fostering leadership among minority students through mentoring*. Association of National Black Faculty. Kansas City, MO.

Crowder, S. J. (2004, March). *Fostering leadership in a national organization*. Alpha Kappa Alpha Sorority Midwestern Regional Conference, Kansas City, MO.

Hanna, K., Weaver, M., Stump, T., Crowder, S., Miller, A., DiMeglio, L. (2011) *Responsibility for diabetes care among emerging adults with diabetes during transition out of high school and parental home* [poster presentation]. Midwest Nursing Research Society Conference, Columbus, OH.

State

*Crowder, S. J. (2012, February). *Illness perceptions of asthma*. Indiana Public School Nurses Spring Conference. Indianapolis, IN.

*Crowder, S. J. (2011, May). *Integrating the Revised Asthma Guidelines into School Nursing Scope and Standards of Practice*. Indiana Public School Nurses Spring Conference, Indianapolis, IN.

*Crowder, S. J. (2007, October). *Awakening the leader within you*. Oklahoma Public Health Nurses and Immunization Conference, Oklahoma City, OK.

Crowder, S. J. (2006, March). *Cultivating your leadership garden*. Oklahoma Leadership Consortium, Oklahoma City, OK.

Local

Crowder, S. J. (2011, May). *High school to college: Creating a successful transition*. George Washington High School, Indianapolis, IN.

Crowder, S. J. (2011, April). *A career in nursing: Dream to reality*. Northwest High School, Indianapolis, IN.

Crowder, S. J. (2011, March). *A career in nursing: Dream to reality*. Arsenal Tech High School, Indianapolis, IN.

Crowder, S. J. (2011, February). *Asthma disparities*. Ft. Wayne Minority Health Coalition, Ft. Wayne, IN.

Crowder, S. J. (2011, January). *Children and adolescents with asthma*. Martin Luther King Youth Summit, Kokomo, IN.

Crowder, S. J. (2007, September). *African American adolescents with asthma*. Marion County Health Department ACTION Program, Indianapolis, IN.

*Crowder, S. J. (2004, June). *Are you ready for the real world–Is the world ready for you?* Southwestern Medical Center New Graduates Luncheon, Lawton, OK.

Crowder, S. J. (2002–2004). *Developing a plan to increase passage of the NCLEX exam* [Faculty Workshop]. Oklahoma University College of Nursing, Lawton Campus, Lawton, OK.

Crowder, S. J. (2004, April). *Taking energy, passion and a positive attitude into the classroom*. Lawton Elementary School, Lawton, OK.

*Crowder, S. J. (2004, February). *Abstinence–It's worth it*. Phi Delta Kappa Educational Sorority Teen Summit, Lawton, OK.

*Crowder, S. J. (2003, February). *Are you ready for the real world–Is the world ready for you?* Practical Nursing Program, Great Plains Technological Center, Lawton, OK.

*Crowder, S. J. (2001, January). *Asthma management in the school setting*. Lawton Public School Nurses, Lawton, OK.

*Crowder, S. J. (1998, April). *Asthma care and patient education in the pediatric client: The nurse's role*. Colorado Organization for Associate Degree Nursing, Colorado Springs, CO.

*Invited

PUBLICATIONS

Hanna, K., Weaver, M., Stump, T., DiMeglio, L., Miller, A., Crowder, S. (early online access). *Initial findings: Diabetes care responsibility among emerging adults with type I diabetes post high school and move out of parental home*. Child: Care, Health, and Development.

Crowder, S., & Broome, M. (Submitted). *A framework to evaluate the cultural appropriateness of intervention research*.

Crowder, S. (2010). Integrating the Revised Asthma Guidelines into School Nursing Scope and Standards of Practice. *Journal of School Health, 80*, 44–48.

*Johnson, S. (1988). *Children's memories of cardiac surgery and the pediatric intensive care unit environment* [master's thesis]. Atlanta, GA: Nell Hodgson Woodruff College of Nursing-Emory University.

*Maiden name

GRANTS, FELLOWSHIPS, AND AWARDS

Doctoral Scholar Fellowship	Southern Regional Education Board	2010–2012
Educational Enhancement Grant	Graduate Student Organization, Indiana University–Purdue University Indianapolis, $500.00	2010
American Thoracic Society Trainee	American Thoracic Society	2009–2012
National Institute of Nursing Research	(F31) Individual Fellowship	2008–2011
National Research Service Award Award of $93,732.00 (F31NR010985)	Study: Illness Representations and Self-management Behaviors of African American Adolescents with Asthma	
Predoctoral Fellowship	Institutional Research Training Grant (T32) Indiana University School of Nursing	2006–2008
Project: Health/Illness Beliefs of African Americans	Research Incentive Fellowship Indiana University School of Nursing	2009–2010
Project: The Synthesis of Gender and Health	Research Incentive Fellowship Indiana University School of Nursing	2008–2009
Project: Instruments and Methods Used to Measure Illness Representations and Asthma Management	Research Incentive Fellowship Indiana University School of Nursing	2007–2008
Project: Asthma Self-Management Programs	Research Incentive Fellowship Indiana University School of Nursing	2006–2007

RESEARCH

Crowder, S. J. (in progress). *Illness representations and self-management behaviors of African American adolescents with asthma* [doctoral dissertation].

*Johnson, S. (1988). *Children's memories of cardiac surgery and the pediatric intensive care unit environment* [master's thesis]. Nell Hodgson Woodruff College of Nursing-Emory University, Atlanta, GA.

*Johnson, S. (1993). *The impact of a comprehensive asthma management program on children with steroi dependent asthma* [clinical research]. Children's Medical Services Atlanta, GA.

* Maiden name