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THE ASSOCIATION OF PERCIEVED EMOTIONAL SUPPORT SELF-REGULATION AND ASTHMA HEALTH RELATED OUTCOMES

By

Wanda Gibson-Scipio

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ABSTRACT

THE ASSOCIATION OF PERCIEVED EMOTIONAL SUPPORT SELF-REGULATION, DISEASE SELF-MANAGMENT AND ASTHMA HEALTH RELATED OUTCOMES

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The primary purpose of this study was to examine the relationships between Perceived Emotional Support, Phase of Asthma Self-Regulation Development, and Disease Self-Management Behavior among urban adolescents with asthma. Additionally the study sought to determine if Perceived Emotional Support, Phase of Asthma Self-Regulation Development, and Disease Self-Management were directly or indirectly associated with health outcomes(emergency department visits, hospitalizations, symptom days nights awakened and days activity changed due to asthma) and asthma health related quality of life. The sample consisted of 303 urban adolescents in grades 9-12 from 6 high schools in Detroit with a diagnosis of asthma and or nationally accepted respiratory symptom criteria for asthma. Students completed a computerized survey which included demographic data, and measures of all study variables. Phase of Asthma Self-Regulation Development was found to be a significant predictor of Disease Self-Management and Asthma Health Related Quality of Life. Phase of Asthma Self-Regulation Development was also found to moderate the relationship between Perceived Emotional Support and Disease Self Management. Phase of Asthma Self-Regulation Development was found to have a negative association with Asthma Health Related Quality of Life. This relationship was explained by disease severity. PES was not found to have a significant relationship with Health Outcomes or Asthma Health Related Quality of Life. Results of

this investigation indicate that interventions to promote self-regulation among adolescents may positively influence disease self-management behavior and important quality of life outcomes. Further although a relationship was not found between Perceived Emotional Support and any of the outcomes of interest, this does not rule out the potential efficacy for additional investigations to understand the role of disease specific emotional support or other social support functions in disease self-management and asthma health related outcomes.

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Chapter 1

INTRODUCTION

Urban African American youth with asthma experience disproportionate disease severity, morbidity and mortality when compared to Caucasian counterparts (American Lung Association, 2004, McDaniel, Paxson, & Waldfogel, 2006). These disparities exist at a time when scientific knowledge of the disease and the availability of effective treatment options are unprecedented. To date explorations of factors among urban African American adolescents that contribute to these poor health outcomes and quality of life attributed to asthma have failed to explain these disparities or identify effective interventions. However, an emerging focus of research targeting youth with a chronic disease has begun to examine developmentally relevant social contextual variables such as differing functions of social support, intrapersonal factors such as self-regulation and their relationship to disease self-management behavior and health outcomes.

The ability of adolescents affected by asthma to successfully implement a prescribed disease management regimen is a critical element of disease control. Although clinicians are essential in the diagnosis, planning and education of adolescents with asthma, the affected individual's role in the day to day disease management that significantly contributes to health outcomes is unparalleled. Disease self-management behavior includes symptom monitoring, avoidance of known asthma triggers, medication administration and adjustment, attack management and prevention and health evaluation visits. The primary goal of disease self-management behavior is to optimize disease control. According to the National Heart Lung and Blood Institute's Expert Panel Report II (1997) [EPR-II], effective disease self- management behavior would be expected to (a)

prevent asthma symptoms, (b) minimize missed school or work, (c) minimize the need for emergency department visits and hospitalizations, (d) contribute towards maintenance of normal activity levels, (e) contribute towards normal or near normal lung function and (f) to result in minimal or no medication side effects. Effective disease self-management behavior and optimal disease control would allow youth to achieve the goal of living a "normal life" and to achieve clinically significant levels of health related quality of life. Living a normal life is described by youth as being similar to peers and being able to actively participate in routine everyday activities without worry or concern (Rydstrom, Englund, & Sandman, 1999).

The primary responsibilities of disease self-management behavior are transferred from parent to youth beginning in childhood without much forethought or support for the transition of responsibilities (Wade, Islam, Holden Kruszon-Moran, & Mitchell, 1999). The informal and perhaps erratic transfer of disease management responsibility is marked by a decline in adherence rates among adolescents to rates of 50 percent or less when compared to preceding childhood adherence rates (Anderson, Ho, Finkelstein, & Laffel, 1997; Kyngas, & Rissanen, 2001). Disease self-management adherence rates of adolescents are similar to rates found among adult populations. This finding allows for one to conjecture that among persons with a chronic disease, patterns of disease self-management established early in life are continued throughout life. The potential to significantly alter disease self-management behavior that contributes towards effective disease control, minimize related morbidity and mortality and improve health related quality of life has far reaching implications that have yet to be realized.

In addition to the normal developmental impact on emotions, youth with a chronic disease, may experience emotional despair due to disease burden. In fact the relationships with persons most influential in the life of adolescents that are the greatest source of supportive emotional interchange are potentially also the greatest source of emotional upheaval. As parents caregivers and other significant adults in the life of adolescents take on a more distal role in disease management conflict often arises around the emerging adolescent's perspective of disease self-management and the contrast to previously established norms. Although the etiology of some of the parent-child conflict is related to asthma disease self-management, the broader prevailing context that must also be considered is adolescent development and the related developmental tasks.

Peer relationships become increasingly important during adolescence. Youth strive to find greater similarities between themselves and their age matched reference groups. Yet this desire is a source of emotional struggle due to the overt physical symptoms of asthma (wheeze, cough, and shortness of breath), activity limitations, and disease management requirements.

Emotional experiences during adolescence occur in the context of continuous reciprocal interactions with close personal contacts such as parents, peers and significant others. One basic underlying need of adolescents during this period of transition that transcends all interpersonal relationships is the need for emotional support (a sense of feeling loved and valued). Emotional experiences are increasingly being recognized as a common response to disease and illness and are thought to influence health, well-being, and treatment outcomes (DeCoster, 2003). Although emotions are a part of the human

experience that is significantly heightened during adolescence, little is known about how they influence disease self-management behavior.

During adolescence, cognitive processes such as self-regulation (which drive behavior) affect the way youth set goals related to disease self-management and ultimately disease related outcomes. According to Karoly, (1993) self–regulation addresses the process by which the thoughts and behaviors of an individual are adapted over time within a dynamic context. In line with the dynamic adaptation of self-regulation described by Karoly, (1993), Zimmerman, Bonner, Evans, & Mellins (1999) described a model of sequential phases of asthma self-regulation development in which these skills emerge in disease self-management behavior. This model is highly relevant to adolescents and the transitions that youth will undergo as they learn to self-regulate disease self-management behavior. Asthma self-regulation also explores processes that go beyond the automatized task of disease self-management (inhaler use when wheezing) that are characteristic of primitive imitative learning to mechanisms of thought that are goal directed (attack prevention) and that address disease variability and contextual factors that contribute towards disease severity.

Investigations of adolescent populations with chronic diseases often do not take into consideration the developmental transitions that provide an evolving context from which youth function, the central role of the individual towards achieving optimal health outcomes, and the influence of social relationships on thoughts and behavior. Asthma care is prescribed in the clinical setting; however implementation of disease management that contributes significantly to health outcomes takes place in the social environment. In order to gain insight into factors that influence adolescent health outcomes it is critical to

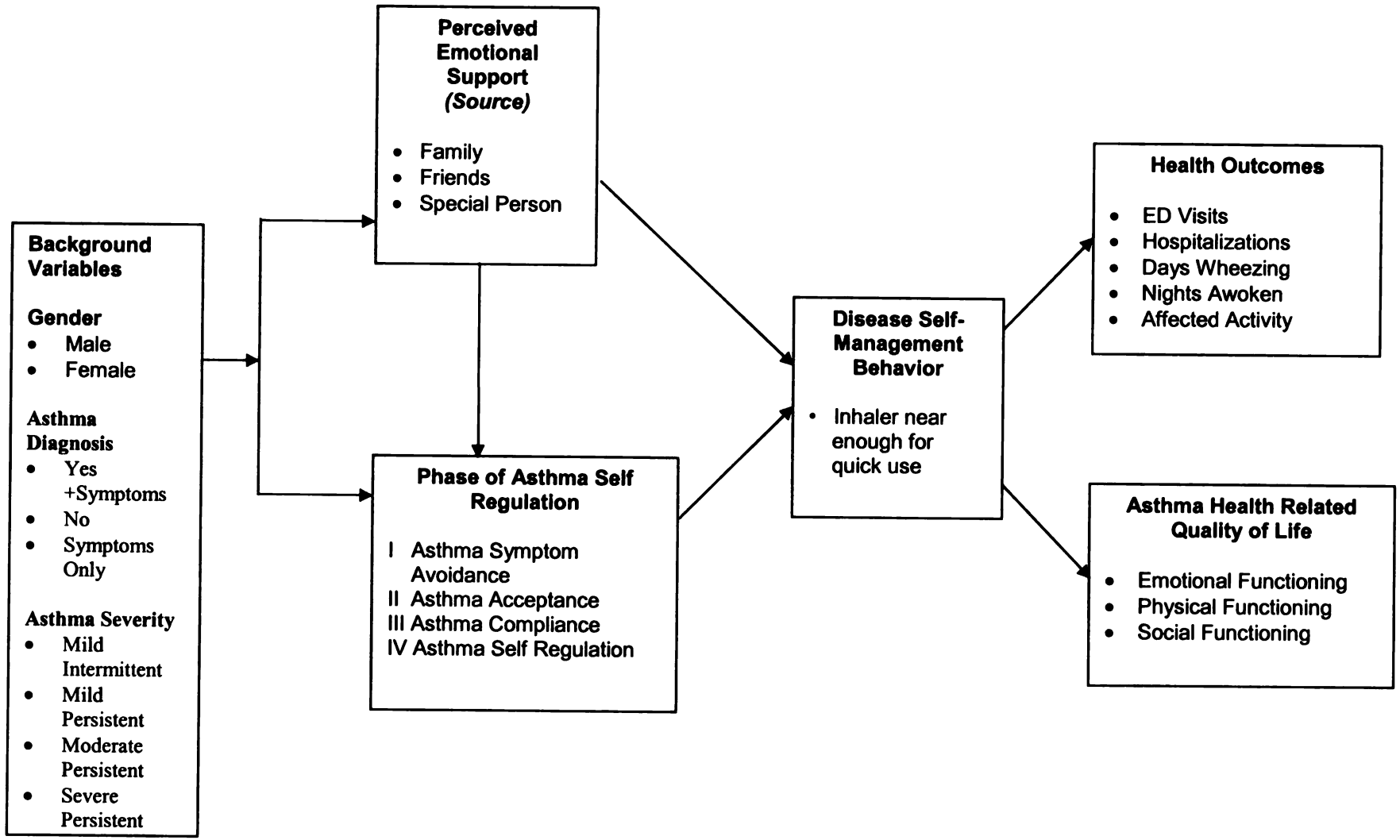
examine factors that are both congruent with normal development and that are relevant to the youth's social contextual environment. Both perceived emotional support and asthma self-regulation are contextual factors that will provide a unique approach to understanding the significance of developmentally relevant influences on adolescent disease self-management behavior.

The overall goal of the proposed project is to determine the perception of emotional support among adolescents with asthma and the relationship with disease self-management behavior. It is hypothesized that this relationship is explained by asthma self-regulation. Therefore phase of asthma self-regulation development will be explored as a mediator of the relationship between perceived emotional support and disease self-management. Finally the association between disease self-management and indicators of morbidity in asthma (hospitalizations and emergency department visits), asthma symptoms and asthma health related quality of life will be tested (Figure 1).

It is critical to understand the determinants of disease self management during adolescence due to the fact that (a) asthma is a leading chronic disease among urban minority adolescents, (b) related morbidity is significant, (c) youth bear the primary responsibilities of implementing a disease self- management plan (d) recognition that implementation of a self-management plan is key to optimizing health outcomes, and (e) adolescence is a period when lifelong behaviors can be established.

Trends of asthma prevalence appear to have recently stabilized after a 1997 redesign of the National Health Interview Survey [NHIS] of asthma prevalence data for the United States, (MMWR, 2000). However asthma continues to be one of the most

Figure 1 Conceptual Model of Hypothesized Influences on Disease Self-Management and Health Related Outcomes



common chronic medical conditions in the United States (Michigan Department of Community Health [MDCH], 2001). More than 30 million Americans reported ever having had a diagnosis of asthma and 20 million persons reported a current diagnosis of asthma National Center for Health Statistics [NCHS], 2002).

Persons affected by asthma are plagued by considerable disease related morbidity and mortality. Although a priority goal of asthma management is attack prevention, in the year 2002, 12 million persons reported having had an asthma attack in the previous 12 months (NCHS, 2002). Attack rates are a key indicator of uncontrolled asthma. Uncontrolled asthma results in greater symptom experiences, hospitalizations, emergency department visits and mortality rates, all of which have continued to increase (Clark et. al, 1999; MMWR, 2000; Strunk, Ford & Taggart, 2002). In the year 2002 there were 1.9 million visits to emergency departments for asthma care (NCHS, 2002). Additionally 484,000 hospitalizations were reported for the same year due to asthma. Of great concern is the fact that persons affected by asthma continue to die despite scientific gains in knowledge of disease pathophysiology and related advancements in effective medical treatment options. Mortality rates for the year 2002 indicated 4,261 persons died from asthma (NCHS, 2002).

Due to hospitalizations, emergency department visits and other factors that contribute to the cost of asthma care, national expenditures for the disease are staggering. Asthma is currently considered an "ambulatory case sensitive condition" which implies that hospitalizations are preventable with adequate outpatient care (Guendelman, Mead, Benson, Chen, & Sameuls, 2002). Despite this designation as a case sensitive condition reports indicate that asthma related direct and indirect health care cost consume 12.7

billion dollars annually. The national expenditure in addition to the high levels of morbidity, mortality and negative impact on quality of life from asthma collectively and independently warrants investigations into strategies that can reduce the burden of asthma and improve health related outcomes.

Asthma in African Americans

Asthma prevalence, morbidity and mortality all demonstrate significant disparities by minority race when compared to non-Hispanic whites. (Litonjua, Carey, Weiss, & Gold, 1999; NCHS, 2002). In the year 2002 asthma prevalence was reported to be 30% higher among non-Hispanic blacks compared to non-Hispanic whites (NCHS, 2002). The asthma attack prevalence rate in 2002 among diagnosed African Americans was also 30% higher than rates found among non-Hispanic whites (NCHS, 2002). African Americans have consistently demonstrated higher emergency department visits and death rates from asthma than any other ethnic group with current available estimates (American Lung Association, 2003; MMWR, 1998). Comparative data indicate that African Americans are 3 times more likely to be hospitalized from asthma and 4 times more likely to die from asthma when compared to Caucasians (Strunk et al., 2002).

Asthma in Adolescents

Asthma is a leading cause of chronic illness among youth which continues throughout the adolescent years. In fact prevalence estimates and asthma attack rates are greater during adolescence when compared to younger ages. Between 1995 and 1996 youth age 11-17 had greater asthma prevalence estimates than younger age groups (MMWR, 2000). In 1997 and 1998 asthma attack prevalence rates among this same age group were also greater than for children age 10 and younger (MMWR, 2000). This pattern of greater

disease morbidity among adolescents is consistent with global trends among youth age 13-14 who report greater symptom experiences (cough, wheeze) than younger age groups within the past 12 month period of assessment (Braun-Fahrlander et al., 1998). In the United States morbidity among adolescents is further evidenced by the over 14 million missed school days annually and reported activity restrictions (Clark et al., 1999; Schleicher, Koziol, & Christiansen, 2000).

Asthma in African American Adolescents

The characteristics of persons considered to be at greatest risk for asthma morbidity and mortality include living in an urban setting, being of non-Caucasian race, having a household income consistent with a lower socioeconomic status, and being young (Schleicher et al, 2000). Asthma in urban African American adolescents is a priority health concern due to the disproportionate health disparities found in this population. National estimates of disease prevalence, mortality and morbidity are sparse in that most reports classify adolescents with children. Collectively data is often reported as children 0-17 years of age. However some state data provides a more detailed record of asthma health statistics among the adolescent population.

In Michigan 29.9% of non-Hispanic black middle (6^{th} -8^{th} grades) and high school (9^{th}-12^{th} grades) students have been told in their lifetime that they had asthma compared to 20.6% of age matched white students (MDCH, 2004). Among this same population current and lifetime asthma is significantly higher for black students than for white students (MDCH, 2004). Nationally, non-Hispanic blacks had an asthma prevalence of 30% higher than non-Hispanic whites. When assessing asthma control as indicated by attack prevalence within the previous 12 months non-Hispanic blacks had Asthma

prevalence, morbidity and mortality are higher among urban African American adolescents than non-Hispanic White age matched peers, (Clark et. al, 1999; Centers of Disease Control [CDC], 1996). Results of the National Health Interview Survey (NHIS), 2001, indicate prevalence rates for Non-Hispanic black youth to be 10% higher than non-Hispanic white and 40% higher than Hispanic youth (combination of all groups of persons identified as Hispanic). The disparities of asthma related mortality are further substantiated in that among persons aged 15-24 with asthma, African Americans were 6 times more likely to die than Caucasians (CDC, 1996). The disparities found among urban African American adolescents are disturbing and indicate that these youth have yet to demonstrate a significant reduction in disease related morbidity, and mortality. This population requires further exploration of personal and environmental factors within the context of normal adolescent development that are central to asthma control and related health outcomes.

Conceptual Model

Self-Regulation: A Social Cognitive Perspective

For years human behavior was thought to be the result of observation based learning experiences. Little or no consideration was given to internal mediating thought processes. However more recently scientists have increasingly begun to recognize the multidimensional mechanisms of human behavior and the previously ignored relationships between external influences and internal processes. Behavior is no longer thought of so simplistically or without significant consideration to intrapersonal and the interpersonal interactions between humans and their environment. In this study an examination of the relationships between external influencing factors and internal cognitive process and the effect on behavior will be conducted guided by self-regulation theory using a Social Cognitive perspective.

Disease self-management behavior informed by Social Cognitive Theory (SCT), is a leading theory that has successfully been used as a guide to explain and predict health behavior among adolescents (Montgomery, 2002). The explanatory focus of the theory provides direction for scientific inquiries such as the current investigation that are attempting to gain insight into the significance of associations of personal influences (cognitive or affective factors) environmental influences (social or physical factors) and behavior (actions and reactions of the individual) (Clark & Zimmerman, 1990). The theory has also demonstrated its predictive qualities that support interventions designed to facilitate behavior change among persons with a chronic disease (Clark, Valerio, 2003). SCT hypothesizes that relationships between personal influences, environmental

influences and behavior constantly interact in a reciprocal deterministic manner (Bandura, 1989). These interactions are significantly influenced by self-regulation processes (Clark, & Zimmerman, 1990). Although the model is triadic and there are several reciprocal influences on behavior, the sources of influence differ in terms of strength of association and the timing of their reciprocity (Bandura, 1986). This can be interpreted as meaning that competing influences are not necessarily equal and the reciprocal nature of influences is not simultaneous (Bandura, 1986).

Zimmerman uses the theory of SCT to formulate a perspective of understanding the theory of self-regulation. Self-regulation takes into account the cognitive sub-processes (self observation, self-judgment and self-evaluation) which guide one's decisions to maintain, modify, or discontinue a behavior. The loop of self-regulation is initiated through the use of behavioral strategies and is subsequently changed based on enacted feedback (Clark & Zimmerman, 1990). Over time and with support, individuals increasingly learn to use the evaluative feedback mechanisms of self regulation as a primary means of regulating behavior. As adolescents mature, evaluative consequences, increasingly are based on ones own personal standards or goals and less influenced by external agents. This change in reliance on external influences is consistent with the changes in disease self-management during adolescence where youth begin to set their own standards as they rely less on the standards of parents. The social cognitive perspective of self-regulation has been found to play a central role in disease self-management (Clark, Gong, & Kaciroti, 2001). There are three sub-processes of self-regulation that are hypothesized as key in the use of disease self management behavior for asthma.

The sub-process of self-observation refers to the active role of monitoring ones own behavior or the behavior of others towards a specific related asthma health goal. An asthmatic perhaps would begin to keep track of the number of times that they have participated in a selected sport without having to stop the activity due to asthma symptoms. The observation serves the purpose of providing information for self-judgment regarding a behavioral strategy (use of a new medication) to goals (uninterrupted sports participation) through the mechanism of conscious awareness. Thus observation is purposeful in self-regulation as described by Langer, (1989), "it signals temporary disengagement from automaticity or a transition from mindlessness to mindfulness". Self-observation is not limited to attentiveness to one's own behavior, but also to the behaviors of others as it applies to one's goal pursuit. For example persons with asthma are advised to limit and or avoid direct and indirect exposure to tobacco smoke. However the adolescent may note the frequency in which their exposure to tobacco smoke results in subsequent asthma symptoms.

Self-judgment is the use of specific criteria to assess a given situation or problem based on ones goals (Clark & Zimmerman, 1990). In the previous example the problem was active participation in sports resulting in frequent interruptions due to asthma symptoms such as cough, wheeze or difficulty breathing. Self-judgment would entail judging the effectiveness of a new medication based on personal standard for acceptable interruptions in sports activities. The youth may set a goal of no interruptions per practice session. By using the information obtained from self-observation, the youth would compare and contrast the difference in sports related activity tolerance prior to and after the initiation of a new medication.

Self-reaction/evaluation is the act of purposefully attempting to detect discrepancies between one's goals and related strategies by reacting to self-observation and self-judgment (Clark & Zimmerman, 1990). As the individual reacts they determine the efficacy for continuing, changing or abandoning a behavior. Continuing with the previous example the youth may determine from self-observations and self-judgment that use of a new medication has no observable effects on their ability to participate in sports activities without frequently occurring asthma symptoms. Their reaction to this finding could result in a change in behavior such as discontinuation of the medication or increasing the dosage or frequency of the medication.

Being self-regulating is key to optimizing disease self-management because ones behavior is goal oriented, inclusive of self observation/monitoring and self reaction within a feedback loop. This is in contrast to behaviors that are driven by habit, tradition, or directives that have little meaning or value to the individual and that have an end point defined by completing a task. Personal and environmental factors serve to influence the sub-processes of self-regulation and the subsequent behavior. What is not known is how the environmental factor of perceived emotional support influences asthma self-regulation. In the current proposal the influence of an environmental factor (perceived emotional support) will be examined for the association with phase of asthma self regulation development and disease self management. Self-regulation is a proactive as well as reactive process of disease self-management that requires more than knowledge or initial commitment (Zimmerman et al., 1999). According to SCT the individual and the context within which they implement a disease self-management regimen is central to understanding related behavior.

Although self-regulation has innate qualities exhibited as early as infancy, throughout life the process is adaptable to dynamic context (i.e. adolescent development and or disease self-management) whereby skills are developed over time in what appears to be a phased sequential path (Zimmerman et. al, 1999). The sequential phase approach of understanding self-regulation is similar to other theories of behavioral change such as the Transtheoretical Model of Behavior Change. A sequential phase of self-regulation accounts for the process of changing underlying beliefs and methods of coping in order to adopt a preventive asthma regimen (Zimmerman et al., 1999). A SCT perspective of self-regulation was selected to guide the understanding of how the interaction of an environmental influence (perceived emotional support) and a personal influence (phase of asthma self-regulation) and behavior (carrying a rescue medication at all times) are related and to determine the direct and indirect effect of these variables on health related outcomes and asthma health related quality of life.

Emotions and cognitions such as the processes of self regulation are thought to be intricately and dynamically linked. Further this interrelationship is also hypothesized as one of the mechanism by which information is processed and actions executed (Bell, & Wolfe, 2004). Social Cognitive theory (SCT) was selected as the guiding framework to examine these relationships because a major thrust of the theory has been to gain an understanding of how social cognitive variables interact with self-regulating processes to achieve desirable health behaviors for disease self-management (Zimmerman, 1999). Further SCT combines the elements of social, cognitive, and developmental psychology which are consistent with the focus of the current study.

Chapter 2

REVIEW OF THE LITERATURE

Disease self-management consists of behaviors that are implemented by persons with a chronic disease such as asthma in an effort to minimize symptoms, control disease and improve health outcomes. Factors that influence disease self-management which contribute to health outcomes among adolescents are not fully understood. Adolescence is an opportune time to optimize disease self-management behavior that may persist throughout life. The influence of social contextual factors hypothesized to influence disease self-management behavior will be discussed using a Social Cognitive view of self–regulation which is the selected theoretical model that will be used to guide this research project. A review of the literature as it applies to the components of the model proposed for this research will follow.

Gender

Gender refers to the behavioral, cultural or psychological traits (Merriam-Webster online) that males and females learn via the socialization process. Through the process of socialization males and females learn interpersonal and interaction skills that are in conformity with the values of ones' society (Dictionary.com/socialization). Socialization usually begins with the family and is further shaped by relatives, friends, and the greater society at large. For example males are socialized to handle problems independently while females are encouraged or allowed to express dependency (Barbee et al., 1993). Female role expectations often emphasize nurturance and emotional expressivity while male roles emphasize achievement success and inexpressiveness. The socialization process begins early in life and provides the bases for differences in how males and

females interact with others in social relationships, how they may seek support (Barbee et al., 1993) and potentially how they think about situations that require self-regulation. These findings suggest that gender should be examined as a covariate for its potential influence on study variables.

Available data for gender also suggest differences in terms of prevalence, morbidity and mortality rates among youth less than 18 years of age. Males have been found to be hospitalized at rates 60% higher than females. Within this same population death rates for males occur at a rate 80% higher that that for females (MDCH, 2005). Among youth within a Medicaid population, persistent asthma is found 40% more often in males than females (MDCH, 2005). Data that focused specifically on adolescents from the Youth Risk Behavior Survey (CDC, 2003) found that among youth attending high school in grades 9-12, significantly more females than males with a current asthma diagnosis reported an asthma episode or attack within the most recent 12 months of being surveyed (CDC, 2005). Specific data on adolescents in terms of gender differences in mortality and morbidity is limited due to the common practice of grouping adolescents with children under the age of 18. This finder further justifies the inclusion of gender as a covariate of interest in the current stud to help determine if there are differences among adolescent youth in the study population.

Diagnosis

Asthma has been reported as an under diagnosed condition among children, adolescents and young adults (Siersted, Boldsen, Hansen, Mostgaard & Hyldebrandt, 1998; Yeats, Shy, Sotir, Music, & Herget, 2003). In a study of Danish adolescents, females were found to be overrepresented among youth without a diagnosis of asthma

when compared to diagnosed teens where females are underrepresented (Siersted et al., 1998). Cough which is a hallmark symptom of bronchitis was found to be a primary presenting symptom among youth with undiagnosed asthma. This symptom may have contributed to a repeated diagnosis of bronchitis among adolescents as opposed to a diagnosis of asthma (Siersted et al., 1998). Further less than one third of adolescents with undiagnosed asthma reported their symptoms to a doctor (Siersted et al., 1998). Undiagnosed youth that report asthma symptoms experience significant health consequences (Yeatts, et al., 2003). In a study of youth ages 12-14 in North Carolina, 20% of undiagnosed youth missed a half day or more of school per month due to wheeze compared to 47% with a diagnosis (Yeatts et al., 2003). Another 25% limited activities because of wheeze once or more per month and 32% reported sleep disturbances because of symptoms of wheeze during a 4 week period (Yeatts et al.,2003). The impact of being undiagnosed is further exemplified in these youth who report 1 or more ED visits for asthma-like symptoms and 5% reporting a symptom related hospitalization in the past year (Yeatts et al., 2003). Persons with asthma-like symptoms have not been well studied among urban high school adolescents. Therefore persons that report symptoms consistent with asthma over the past 12 months will be included in the current study. The study will also exam how the main study variables differ by diagnosis.

Severity

According to the NHLBI Expert Panel Report II (1997) there are 4 severity classifications for asthma. These classifications are based on the individual's subjective report of asthma symptoms and or the objective measurement of airway obstruction. Severity classifications are; mild intermittent, mild persistent, moderate persistent and

severe persistent. In general the greater the frequency of asthma symptom experiences and or the greater the objective measure of airway obstruction, the greater the asthma severity.

Asthma severity is an important predictor of health outcomes and asthma health related quality of life. Among adolescents with mild asthma that participated in high school sports from a suburban school in Western Washington, health related quality of life was found to be significantly lower when compared to their healthy peers (Hallstrand, Curtis, Aitken, & Sullivan, 2003). Similar findings were noted in a study of primarily African American children between the ages of 5-12 from the Atlanta Empowerment Zone. Results from this study found that health related quality of life was negatively correlated with asthma severity, and missed school days.

Although the relationship between asthma severity, and health outcomes has been studied among youth results have not been found to be significant. Munzenberger, & Vinuya (2002) implemented an intervention study of primarily African American children age 7-13. Although they were able to demonstrate significant improvements in asthma severity (measured by symptom experiences) no significant association was found between asthma severity and quality of life. The findings by Munzenberger and Vinuya (2002) are similar to results of a school based intervention developed for inner-city school children ages 8-13. In the school based study results demonstrated significant improvements in self-care measures, however, there were no significant differences between the control and intervention group on the health outcomes urgent visits to the doctor or school absenteeism.

Although the studies discussed did not demonstrate an association between asthma severity and the health outcomes described, none focused on urban teens in high school. It is important to determine if findings among adolescents will be similar to those among younger youth. An understanding of the factors that are associated with health outcomes such as hospitalizations and emergency department visits among adolescents has important implications. If severity is not associated with factors such as health-related quality of life, hospitalizations and emergency department visits, it will be important to study this population further to better understand what aspects of their disease are related to outcomes of interest to the affected individual and to clinicians.

In the studies reviewed, evidence suggests that greater asthma severity is not associated with health related quality of life. Health related quality of life has been described as an important health outcome that has significance to the daily life of the affected individual. Evidence of the magnitude of disease severity among adolescents was demonstrated in the finding that youth classified in the lowest severity rating (mild intermittent) were found to have a significantly poorer health related quality of life than their disease free counterparts. To this end, severity will be used as a covariate to examine differences among youth in the current study. By using severity as a covariate this investigation will be able to examine the significance of how symptom experiences as compared to diagnosis status is related to health outcomes.

Perceived Emotional Support

Perceived emotional support will be operationalized in this study as the individual's perception of being loved and valued by family, friends and special persons in this study. As youth begin to exert greater independence in thought and behavior around disease

self-management, it is critical that close personal contacts of adolescents continue to display love and support despite predictable inadequacies and uncertainties. Taking a developmental perspective to address disease self-management is a key to understanding factors that influence health outcomes, reducing asthma morbidity and mortality and improving health related quality of life.

Much of the evidence relating the social support and disease self-management and or disease control is derived from the correlation of various functions of social support (instrumental, informational, emotional, appraisal) and specific disease self-management behaviors that contribute to health outcomes. Studies that included emotional support in general also included other support functions. The following review will discuss findings related to emotional support and other support functions concluding with the relevance to the current study.

Social support and disease self-management behavior during adolescence has primarily been studied among diabetic populations. The disease self management requirements for adolescents diagnosed with diabetes and asthma are similar in that both require daily medication, self-monitoring, adaptation of a medical regimen to changing levels of physical functioning, and other dynamic individual and social contextual variations. Diabetes is also a common disease among adolescents. The following review of literature related to social support and disease self-management behavior will focus on adolescents with asthma and diabetes that addresses self –management and or disease related health outcomes.

Recently Sin, Kang, & Weaver (2005) examined the relationships between asthma knowledge, self-management and social support among urban African American

adolescents with asthma. The social support functions examined in the study were total functional support (combination of affect, affirmation, and aid), network support (number of person in network, duration of relationships and frequency of contact) and total loss (combination of number of persons lost and amount of support lost reflecting support no longer available). In the above study, asthma knowledge and social support were found to be predictive of self-management behavior. Parents, friends, and school teachers (in this order) were the most commonly identified sources of support for youth with asthma. Parents, when compared to other sources of support most often, provided various forms of aid support (money or a ride to the doctor). Total support was positively correlated with asthma knowledge $r = 0.31$, $p<0.05$ as well as asthma self-management behavior $r = 0.34$, $p< 0.008$. The overall model testing showed that asthma knowledge and social support accounted for 14% of the self-management behavior variability ($F= 4.05$, $p = 0.024$ (Sin et al., 2005).

Findings from the above study provide evidence for the relationship between social support and self-management behavior among African American adolescents. However the support functions tested did not include emotional support which had it been included may have added to the variance explained by the model. Further it is not clear if any specific support function or source of support contributed more to the relationship between social support and self-management behavior. Another concern brought forth in the study was the finding that when adolescents were asked if they sought support during an asthma attack, 23% indicated that they never seek help from other people at the first sign of breathing problems (Sin et al., 2005). This is unfortunate in that management of early asthma symptoms can prevent debilitating exacerbations that result in emergency

department visits and hospitalizations. Of question is the reason that adolescents do not seek support and if provisions of emotional support would influence this critical choice during independent decision-making.

In a study of 266 Finnish adolescents with asthma, Kyngas (1999) studied social support and other factors that predicted compliance with a medical regimen. Only results that pertain to social support will be discussed. Compliance was measured by self report that was later analyzed to form three levels of compliance; good, satisfactory and poor. In this study social support function was not clarified, but source of support was identified as parent, physicians, and nurses. Results indicated that of adolescents with good compliance reported receiving support from parents (93%), physicians, (99%) and nurses (98%). These findings are in contrast to youth that reported satisfactory compliance and received support from their parent (7%), physician (1%) and nurses (2%). Adolescents that rated themselves as having poor compliance did not report receiving support from parents, physicians, or nurses.

Subsequent to the above analysis Kyngas, & Rissanen, (2001) added near equal numbers of adolescents with epilepsy, juvenile rheumatoid arthritis, and insulin-dependent diabetes mellitus to the sample. Each group of youth answered the same questionnaire that was tailored to the specific disease. An additional source of support (friends) was included. The results using odds ratio indicated that social support from nurses when compared to social support from physicians, family, and friends was more predictive of compliance with health regimens by adolescents OR = 7.28, $p < 0.0000$, 3.42 $p = 0.09$, 2.69, $p = 0.07$ 2.11, $p = 0.67$ respectively.

There are several notable limitations in the studies of adolescents with asthma and social support. First only total scale scores for social support were reported. It was not clear if any specific support function contributed more to disease self-management than another. It is also unclear which functions of social support were measured. Although nurses were considered an important source of support, it is not clear which support function provided by nurses contributes most to compliance with a medical regimen. Due to the fact that relationships between support functions and disease self-management vary, it is important to clearly identify the support function under investigation. Clarification of these relationships will allow investigators to determine interventions that target sources and functions of support that contribute most to disease self-management behavior.

Multiple studies have been conducted among adolescents with diabetes to examine the relationship between family and peer support, self-management and serum markers of disease control such as hemoglobin A_{1c}(HbA_{1c}). The type of support functions varied within studies with most measuring several functions such as instrumental, informational, emotional, and appraisal support. In some reports the different functions of support were not always defined making comparisons between studies difficult.

The demographic characteristics of study populations have primarily been adolescents ranging in age from 10-18, Caucasian race, and middle to upper income socioeconomic status (Greco et al., 2001; Hanna & Guthrie, 2001; LaGreca & Bearman, 2002; Schroff Pendley et al., 2002) Skinner & Hampson, 1998). In studies where age varied enough, comparisons were made between older and younger youth. In all studies except one,

older adolescents perceived less support than younger participants (LaGreca & Bearman, 2002; Skinner & Hampson, 1998).

Families consistently provided more instrumental support than friends in the form of giving insulin injections, blood glucose testing, and preparing meals (La Greca et al., 1995; LaGreca & Bearman; Skinner & Hampson, 1998). These tasks are consistent with qualitative findings from focus group interviews of adolescents conducted by Hanna & Guthrie (2001) where youth described assistance with tasks as helpful supportive behavior. Instrumental support for diabetes task were often associated with better compliance and better HbA_{1c} levels which is considered an indicator of metabolic control. It is clear that as youth age they are given less support for the task associated with disease self-management, but what is not known is what type of support is consistent with the transference of responsibilities for disease related tasks including the related cognitive processes of self-observing, self-judging and self-evaluating these events.

Peers are an important source of support for adolescents. As adolescents begin to spend more time with peers and attempt to identify with age matched referents it is unclear how support within the relationship is associated with disease self-management. Peers are often found to provide higher levels of disease specific and global emotional support than families among youth with diabetes, however this support has not been found to correlate with self-management activities (except diet) or metabolic control (La Greca et al., 1995; Shroff- Pendley et al., 2002). Further exploration of this relationship is needed as proposed by the current study to determine if these findings hold true among

urban adolescents with asthma and if other factors such as self-regulation may interact with emotional support and disease self-management.

Based on review of the social support literature, few studies focused on adolescents with asthma and emotional support. In fact urban African American adolescents and youth from lower socioeconomic groups that are at high risk for negative health outcomes related to a chronic disease were a part of only one study population. These findings support the focus of the current study population and the need to describe emotional support from parents', peers and special persons within this understudied population. Also a concern raised from the literature review is the finding that adolescents often report lower levels of emotional support from parents when compared to friends. Parents are critical to successful adolescent development. Youth with a chronic disease may struggle with moving towards autonomy in disease self-management if emotional support is not available.

Finally although each study identified examined relationships between social support and disease self-management tasks, none evaluated the relationship between social support and self-regulation. In the current study self-regulation development is hypothesized to be an important variable that may account for the differences in disease self-management among adolescents. An understanding of the relationship between self-regulation and disease self-management may further explain the variances found in the study by Sin et al. (2005) which only explained 14% of the variability in self-management behaviors.

Self-Regulation

Adolescents diagnosed with asthma rarely focus on long-term disease control. Routine activities of the adolescent are generally associated with an immediate gain such as puffing on an inhaler during an acute asthma attack to relieve symptoms. Although this behavior is consistent with attack management, it does not contribute to disease control. Additionally this action generally takes place when symptoms become severe, and if the inhaler is readily available. Actions that must be taken in advance to prepare for an attack (carrying a rescue inhaler) that may occur outside of the window of immediacy pose a potential disconnect to adolescents. In order to become effective managers of their disease, youth must learn to set short term and long term goals and to implement the related activities in a multitude of settings and social situations. Adolescents who are able to self-regulate disease self-management behaviors are expected to ultimately have better health outcomes than persons who rely on acute severe symptom experiences to drive behavior (Clark, et al. 2001).

Self-regulation offers a means of focusing asthma disease self-management behavior around goals consistent with disease control (Zimmerman et al., 1999). Self-regulation is also consistent with the developing adolescents' desire for autonomy and identity formation as disease manager. The ability to self-regulate however is not fully innate, but is progressively developed through social modeling, support and feedback that are gradually withdrawn over time as the individual becomes adept at goal setting and the process of goal attainment (Clark & Zimmerman, 1990). The increasing ability to self-regulate is consistent with adolescent cognitive development which allows youth to more

rapidly acquire knowledge; process information, problem solve and reflect on outcomes (Bruzzese et al., 2004).

According to Zimmeran et al., (1999), self regulation development is sequential. Among asthmatics four stages of have been identified: (Phase 1) Asthma symptom avoidance; (Phase 2) Asthma acceptance; (Phase 3) Asthma compliance; and (Phase 4) Asthma self-regulation. Among adult caregivers of children with asthma, phase of self-regulation has been found to be related to asthma symptoms such as wheezing, sleep disturbances, activity restrictions and emergency department use. Zimmerman et al. (1999) found that higher phase of self-regulation was associated with fewer days of wheezing, sleep disturbances, home restrictions and emergency department visits. Additionally self-efficacy, management/prevention behaviors and resourcefulness increased with higher phase of self-regulation. The cognitive changes that occur during adolescence may best be represented by a phased approach to describing self-regulation within this population.

The sub-processes of self-regulation have also been examined among caregivers of children with asthma for associations with disease management (Clark , Evans, Zimmerman, Levison, & Mellins. 1994; Clark, et al., 2001). In the first study by Clark et al., (1994) parental asthma self-regulation was found to account for 10% of the variance in mother's asthma management behavior and 12 % of the variance in preventive behavior for asthma. In a second study by Clark et al., (2001) self- regulation was measured over a 22 month period (baseline, 6 months and 1 year, and 2 years) for the associations with outcomes (ED visits, hospitalizations, parental report of the child's quality of life, parental and office visits for follow up asthma episodes. Demographic

variables of age, ethnicity, and income proved non-significant in this study. The self-regulation sub-process of making judgments was found to correlate with parental efforts to observe the child in relevant situations. Making observations consistently correlated with using more asthma management strategies. The higher the parent's baseline score for observing the child in asthma related situations the higher the parental report of the child's quality of life score at 2 years There were also significant associations between judgment and use of management strategies. Judgment at baseline was marginally predictive of physician visits. Management strategies at baseline did not predict outcomes 2 years later.

Findings from the studies described in this review show support for the relevance of self-regulation to disease self-management and health outcomes. Conclusions about self-regulation among adolescent populations cannot be drawn from the above studies however due to the study population being representative of parents and caregivers. Adolescents are expected to differ from caregivers because of their stage of development and experience as the manager of a chronic disease. Evidence is needed to determine the role of self-regulation among adolescents in order to recognize their increasing role in disease self-management. In this study the phase of self-regulation development will be examined with the intent to develop appropriate phase based strategies to support self-regulation in future research endeavors.

According to social cognitive theory, children learn self-regulation through external social means including parental modeling and or assistance (Clark & Zimmerman, 1990). Further when considering the triadic interacting influences of behavior, environmental, and personal factors, each are considered as potentially equally powerful influences on

the development of self-regulation (Clark & Zimmerman, 1990). During adolescence the primary environmental influences are family, peers, and potentially other close personal contacts.

There were no studies found that explored the proposed relationship between any function of social support and self-regulations in disease self-management. During adolescence it is important to determine if perceived emotional support that addresses social contextual developmental needs of youth is associated with self-regulation.

Disease Self-Management Behavior

A primary contributing factor to the negative health outcomes of asthma is ineffective disease self- management (Kyngas, 1999). Factors that influence disease self-management and subsequent morbidity, mortality and quality of life are complex and not well understood. Yet ineffective disease self-management is known to contribute towards underlying physiological mechanisms of asthma that result in airway remodeling, symptom experiences, and ultimately impose functional limitations.

Disease self-management behaviors include the day-to-day activities that youth must implement such as symptom assessment and monitoring, medication administration and adjustment, anticipation and management of environmental triggers that contribute to asthma exacerbations. During the adolescent years self-management behavior is known to significantly decline to rates of fifty percent or less when compared to self-management behavior in childhood (Anderson, et al., 1997; Kyngas, Rissanen, 2001; Wade et. al, 1999). If one were to compare self-management behavior of adults and youth, one could conjecture that based on reported adult adherence rates, that there is relatively no change in self-management behaviors from adolescence through adulthood.

It is critical to understand the determinants of disease self management during adolescence due to the fact that (a) asthma continues to be a highly prevalent disease among adolescents, (b) related morbidity is significant, (c) youth bear the primary responsibilities of implementing a disease related self management plan (d) recognition that implementation of a self-management plan is key to optimizing health outcomes, and (e) adolescence is a period when lifelong health related behaviors can be established (NHIS, 2003; Ozer, et al., 2003; Wade et al., 1999).

Asthma drug therapy is a central treatment strategy for disease self-management among youth. Adolescents also report the desire for complete responsibility for taking their medications despite admitting the need for support (Slack & Brookes, 1995). In this study disease self-management will be operationalized as carrying a rescue inhaler.

The focus on rescue medications as opposed to controller medications in this study was decided upon for several reasons. Although corticosteroids are essential to asthma control, they have been found to be prescribed less in minority inner city socially disadvantaged populations (Adams, Fuhbriggee, Guilbert, Lozano, & Martinez, 2002; Eggleston, et al., 1998). The lack of a controller medication could potentially confound findings due to the fact that there were no questions in the baseline survey that would allow for the interpretation of a negative response regarding following a doctors orders for controller medication use. However, most inner city adolescents with asthma report having a rescue inhaler. Use of a rescue medication requires that youth use self-regulation processes to be prepared for acute attack management and to prevent attack such as those that result from exercise induced asthma. Therefore although use of rescue medications is

not intended for control of disease severity it is an important treatment strategy for disease management.

Use of a rescue medication by adolescents is poor. Cohen, Franco, Motlow, Reznik, & Ozuah., (2004) found that among urban African American and Latino youth only 38% reported taking their "asthma pump" with them when leaving home. This finding is consistent with other researchers who have found that teens thought that carrying an inhaler with them was a bother (Slack & Brooks, 1995) and some reported that using an inhaler in public places was embarrassing (Penza- Clyve, Mansell, & McQuaid, 2004; Slack & Brooks, 1995). Another 29% of adolescents reported feelings of embarrassment by their symptom experiences from asthma and 32% were embarrassed by taking asthma medicine in front of friends (Cohen et al., 2003). The relationship between embarrassment of asthma and taking asthma medication raised even more concern in that youth that were embarrassed about their asthma were less likely to carry their asthma medications at all times ($r=0.98$, $p<0.001$ (Cohen,et al., 2003).

Teens with asthma have identified that a major goal in their life is to be "normal" Velsor-Friedrich, et al., 2004). Because of this overwhelming need for normalcy teens are willing to delay treatment such as taking a rescue medication during an acute attack, even if it means jeopardizing their health (Velsor-Friedrich, Vlasses, Moberley, & Coover, 2004). Youth participating in focus group studies reveal that they often delay taking action at the first sign of an asthma attack. Instead of immediately attempting to mitigate symptoms they often wait until symptoms are severe (van Es et al., 1998; Velsor-Friedrich, 2004) or they just wait out the symptoms until they abate (Raherison, Tunon De Lara, Vernejoux, Taytard, 2000). Sin et al. (2005) reported that only 49% of

adolescents took action when they first note breathing problems. Despite awareness by youth that use of a rescue medication could prevent the onset of symptoms resulting from exercise induced asthma, few reported taking this preventive action (van Es et al., 1998). The above behaviors provide evidence of inadequate self-management behavior that could result in delayed treatment and contribute to hospitalizations and emergency department visits. According to Milgrom et al., (1995) hospitalizations for asthma could virtually be eliminated with effective asthma management.

In a study of African American adolescents in an urban city, researchers examined adolescents self report of disease self-management using the Revised Asthma Problem Behavior Checklist (RAPBC) (Walders, Drotar, & Kercsmar, 2000). The RAPBC is used to identify problematic illness management behaviors such as medication usage, preventive behaviors, and attack intervention strategies (Walders et al., 2000). Findings indicated that youth reported a mean level of nonadherence of 1.79 (SD 1.5) which corresponds with "rarely" engaging in problematic illness management behaviors (Walders, et al., 2000). The findings above are in contrast to younger children ages 11-14. Horner (1999) found that middle school children could describe a sequence of problem-solving steps when faced with an asthma attack. One of the first strategies children used was to self-medicate with an inhaler which they "kept everywhere" such as school, backpack, or in a locker. Next students evaluated the effectiveness of the medication and the need for a subsequent dose or the use of a different medication. Children also described behavioral strategies that included altering their activities during an asthma attack. Some children even reported taking preventive steps prior to exercise by self-medications.

The evidence of ineffective disease self-management in adolescents is astounding. It is unclear however what factors influence disease self-management and why adolescents demonstrate poorer skills than children. Many studies of disease self-management in asthma have focused on the use of controller medications. The current study will focus on the preventive strategy of disease self-management consisting of carrying a rescue inhaler. In this study perceived emotional support mediated by phase of asthma self-regulation is hypothesized to influence disease self-management. Perceived emotional support is also thought to highlight autonomy which is consistent with the transition towards independence in disease self-management during adolescence.

Asthma Health Related Quality of Life

Asthma Health Related Quality of Life has become an increasingly important patient centered outcome measure for persons affected by pulmonary diseases such as asthma (Hallstrand, et al., 2003). For years clinicians considered subjective assessments of asthma symptoms and objective measures of airway obstruction as a comprehensive assessment of the impact of asthma on the individual (Juniper et al., 1996). However, more recently it has become clear that these measures do not consistency correlate with the personal impact of the disease that affects one's day to day functioning (Juniper, et al., 1996). In addition to the symptom experiences of asthma, adolescents are troubled by the disease impact on physical, social, educational and emotional functioning (Juniper, et al., 1996). In this study QOL will be operationalized by questions that address activity limitations, emotional functioning and symptoms related to the impact of asthma on daily functioning.

Few studies have evaluated Asthma Health Related Quality of Life in a consistent manner among adolescents and even fewer have focused on urban dwelling African American adolescents with asthma. The majority of studies have focused on children mean age 10-12, and caregivers of children with asthma from racial and ethnic groups that included few or no African Americans (Graham, Blaiss, Bayliss, Espindle, & Ware., 2000; Sawyer et al. 2001, Williams et al., 2000). Quality of life has also been measured using both disease specific and generic instruments making it difficult to compare outcomes and even more difficult to interpret results. Studies of children 18 years of age and younger with asthma where generic or disease specific quality of life measures have been used will be discussed.

In studies that included children with asthma QOL has been found to be lower when compared to disease free controls (Hallstrand et al., 2003). Health related quality of life has been measured using disease specific instruments (Erickson et al., 2002; Gibson, Shah, & Mamoon, 1998; Munzenberger & Vinuya, 2002; generic instruments (Hallstrand et al., 2003), or in some cases both (Graham,et al., 2000; Sawyer et al., 2001). When generic instruments were used the study sought to compare children affected by asthma with healthy counterparts (Hallstrand et al., 2003) When both generic and disease specific instruments were used researchers were attempting to determine which factors of quality of life correlated most with asthma. The instrument used most often among pediatric population has been the Pediatric Asthma Quality of Life Questionnaire developed by Elizabeth Juniper, (1996) which is the instrument that will be used in the current study.

In an attempt to determine the impact of asthma on the daily functioning of adolescents, investigators have sought to determine what factors are associated with

health related quality of life. Several investigators developed intervention studies that focused on improving asthma knowledge as a means of improving health related quality of life. However, asthma knowledge has not been found to be associated with disease specific quality of life (Gibson et al., 1998; Gibson, Henry, Vimpani, & Halliday, 1995; Munzenberger, & Vinuya, 2002). This finding does not indicate that knowledge is not an important variable to consider among youth with asthma, but that knowledge alone is insufficient to fully understand health related quality of life. Investigators who focused on symptoms as a predictor of health related quality of life produced inconsistent findings among children. Munzenberger & Vinuya, (2002) found no relationship between asthma symptoms and disease specific quality of life. However, for adolescents experiencing dyspnea during exercise, generic quality of life was found to be 4.4 points lower in adolescent athletes affected by asthma than those not affected by asthma ($p=0.02$).

Asthma severity and sociodemographic variables have also been investigated as predictors of health related quality of life. When quality of life was measured using a generic instrument it was found to be significantly lower in children with moderate to severe asthma (Graham et al., 2000; Sawyer et al., 2001). Of sociodemographic variables measured, household income was the strongest most consistent statistically significant predictor of disease specific asthma quality of life (Erickson et al., 2002) Other sociodemographic variables such as number of siblings were related to symptom subscales of quality of life but no other sociodemographic variables were associated with total scale scores (Erickson et al., 2002).

Another focus of QOL research has been on the evaluation of measures of quality of life including integrative reviews, instrument development and psychometric testing

(Eiser & Morse 2001; Rutshauser, Sawyer, & Bowes, 1998; Ruthshauser et al., 2001; Spieth & Harris, 1995). In theses studies instruments have been tested primarily among Caucasian, European, and Australian populations. No instruments were specifically tested among African American adolescents with asthma.

Findings from studies of health related quality of life have yet to demonstrate consistent findings among predictor variables. None were found that sought to determine the association of asthma health related quality of life among urban African American adolescents or disease self-management. In the current model for this study AQOL is considered as an outcome variable of disease self-management. It is hypothesized that better disease self-management will be positively associated with AQOL. This study will add to the scientific literature by describing asthma health related quality of life (AQOL) among urban African American adolescents, and by examining the relationship between AQOL and disease self-management.

Health Outcomes

Three major categories of outcomes targeted in health care research are (a) physiologic changes that indicate improvement or lack of improvement in the medical condition, (b) utilization of resources that incur cost or that negatively affect productivity, and (c) measures of quality of life and satisfaction with medical care (Blaiss, 2001). In the current study the adolescent's report of the frequency of asthma symptoms such as cough, and wheeze and nighttime awakenings over the past 30 days will serve as indicators of health care outcomes that target improvement in the medical condition. Utilization of resources that incur cost will be measured as frequency of hospitalizations,

and emergency department visits over the past year. Quality of life as previously discussed will also be measured as an outcome.

The frequency of symptom experiences by asthmatics serves as a proxy of disease severity and as indicators of the personal impact of the disease. Asthma symptoms are most bothersome to adolescents because they often represent the unpredictability of the disease and they interfere with feeling normal or similar to disease free peers (Callery, Milnes, Verduyn & Couriel, 2003; Velsor-Freidrich, 2004). Because of the overt nature of asthma symptoms youth report embarrassment and a sense of no longer feeling similar to disease free peers (Callery et al., 2003; van Es, et al., 1998). Additionally when adolescents attempt to alert others such as teachers, or coaches of their symptom experiences they are faced with disbelief, by the person from whom they may be seeking help (Velsor-Friedrich, 2004). Youth report feeling that they must prove that the symptoms are indeed occurring, that they are bothersome, and that they warrant a change in or discontinuance of an activity. Because of the significant impact of the symptom experiences of asthma, investigators must seek opportunities to impact this negative health outcome.

Health outcomes identified as evidence of resource utilization include hospitalizations and emergency department visits. Among persons age 15 and younger, asthma is the third ranking cause of hospitalizations (CDC, 2005). In the U. S. the estimated cost of treating asthma in persons less than 18 is $3.2 billion annually (CDC, 2004). A considerable factor in the annual cost of asthma care is due to hospitalizations and emergency department visits (Smith et al.1997; Weiss, Gergen, & Hodgson, 1992) that not only

represent a lack of disease control, but also represent a significant source of controllable health expenditures associated with asthma care.

The economic and personal cost of asthma is astounding when one considers the designation of asthma as a case sensitive condition where hospitalizations could be prevented. Further it is not clear if the frequency of emergency department visits is primarily due to a lack of access to medical care in ambulatory clinics, ineffective asthma care by clinicians, poor self-management skills by the affected individual or due to the highly unpredictable nature of asthma in which acute attacks may be more common in some persons than others. In the current project the focus will be on disease self-management as a predictor of hospitalizations and emergency department visits. Despite the complexity of factors that may contribute to high resource utilization, disease self-management holds promise as a means of changing current trends.

Disease self-management is hypothesized to minimize resource utilization. However it remains unclear as to which disease self-management behavior correlate best with health outcomes. In a quasi experimental study of African American children ages 8-13 (m=10.06 years) Velsor-Friedrich, Pigott, & Srof (2005) examined the effects of a school-based asthma intervention program on self-care practices, and health outcomes. Although their intervention demonstrated significant improvement in self-care practices among youth, no significant changes were noted in urgent care visits or symptom frequency.

The findings in the study by Velsor-Friedrich et al., (2005) differ from those of a randomized control trial conducted by Guendelman et al. (2002). The age range of the study population was slightly older was 8-16, m=12.1. Approximately 50% were African

American, 15% Caucasian and 20% other, in contrast to the previous study sample that was totally African American. The intervention objective was to assess the effectiveness of an interactive internet based asthma monitoring program as compared to the use of a standard asthma diary. At the 6 week follow up, children randomized to the intervention group reported fewer activity limitations and significantly fewer peak flow readings (objective indicator of asthma severity) in the yellow zone (caution) or the red zone (medical alert). At the 12 week follow up, children in the intervention group showed a significant difference in self-care behaviors such as taking asthma medications without reminders $p=0.001$ and these behaviors were significantly correlated with asthma outcomes. During the 90 day trial period the daily compliance rates declined as time progressed for both groups. However control group compliance declined faster than the intervention group.

The two studies reviewed are similar to others where outcomes vary depending on study population, type of study, variables, and timeframes. No studies were found that used the same predictor variables as in the model in the current study. The current study will focus on an age range of adolescents that should capture middle and older adolescents. Middle and older adolescents have rarely been targeted in the study of asthma.

Literature Review Summary

Based on this review of literature of adolescents with asthma, it is apparent that the factors that contribute most to disease self-management among urban African American adolescents are not clear. The current study will help to fill this void in the literature by focusing on the influence of the social contextual variable emotional support from family

friends and special persons. Although social support is often identified as important to adolescents with asthma the specific support function that contributes most to disease self-management and health outcomes among adolescents is not known.

Additionally a higher phase of self-regulation development by parents of children with asthma has been shown to positively affect the health outcomes of the children (Zimmerman et al., 1999). However, evidence is lacking to determine if this holds true among adolescents as they increase their responsibility for their own disease self-management. Based on the literature review, both emotional support and asthma self-regulation development independently have relevance as factors that may positively influence health behavior. The current proposal will describe each construct within the study populations and also examine associations between variables that are hypothesized to predict disease self-management behavior and influence positive health outcomes.

Chapter 3

METHODOLOGY

The aim of this study was to determine if perceived emotional support is associated with disease self-management behavior health outcomes and asthma health related quality of life among urban adolescents with asthma. Self-regulation was considered to be a potential mediating factor to the relationship between perceived emotional support and disease self management and health outcomes. Gender, diagnosis of asthma or symptoms consistent with asthma and asthma severity were considered as covariates within the model. The proposed study is unique in that the focus is on urban adolescents with asthma which is a population that has not been studied widely. Also perceived emotional support and phase of asthma self-regulation development have not been studied independently or together to determine their relationship with disease self-management, health outcomes or asthma health related quality of life.

Research Questions

The following research questions were developed to achieve the objectives of this study: Among urban African American Adolescents with Asthma:

1. What is the perception of emotional support among urban adolescents with asthma?
2. Does PES differ by gender, diagnosis, or asthma severity?
3. Does Phase of Asthma Self-Regulation Development (PASRD) differ by gender, diagnosis or asthma severity?
4. What is the relationship between PES and PASRD?
5. What is the relationship between PES and Disease Self-Management Behavior?

6. What is the relationship between PASRD and Disease Self-Management? Behavior?
7. What is the effect of PASRD on the relationship between PES and Disease Self-Management Behavior?
8. What is the effect of Disease Self-Management Behavior on the relationship between PES and Health Outcomes?
9. What is the effect of Disease Self-Management Behavior on the relationship between PES and Asthma Health Related Quality of Life?
10. What is the effect of Disease Self-Management Behavior on the relationship between PASRD and Health Outcomes?
11. What is the effect of Disease Self-Management Behavior on the relationship between PASRD and Asthma Health Related Quality of Life?

Design

This study is a secondary analysis of a subset of baseline data, from a randomized effectiveness trial to evaluate a tailored computerized asthma education and disease management program (Puff City) for teens. A cross sectional design was used to collect data to describe the study population and the variables of interest as well as to test a model of associations between the selected variables, indicators of morbidity and pediatric asthma health related quality of life.

Sample

Students enrolled in grades nine through eleven attending any of the six participating high schools in Detroit were recruited. Twelfth grade students were not recruited due to

their impending graduation which would impact their availability for the intervention and follow up phase of the parent study. The parent study (Tailored Asthma Management for Urban Teenagers RO1H68971, PI: CLM Joseph, PhD) is a NIH funded randomized effectiveness trial. Students with or without a diagnosis of asthma confirmed by a healthcare provider and or exhibiting persistent asthma symptoms according to EPR- II (1997) were eligible for the study

Students in the selected high schools all reside in an urban area. At least 52% of the student households represented qualify for subsidized lunch programs. Zip codes for the selected high schools are representative of areas with greater socioeconomic disadvantages including fewer health care resources. According to the 2000 census 15-50% of children less than 18 years of age residing in the zip codes of the identified schools meet federal guidelines for poverty. Selected descriptive characteristics of students attending participating schools are shown in Table 1. Estimates of potential affected students was derived from previous field work with similar schools in the Detroit area that yielded a rate of 11% of the student population as having uncontrolled asthma and approximately 9% having symptoms consistent with asthma without a diagnosis.

Setting

The study took place in six Detroit area public high schools, Cody, Redford, Mackenzie, Mumford, Northwestern, and Ford. All students completed the screening survey in a regularly scheduled class (English) and subsequently the baseline survey on a school computer. The locations of the computers were pre-determined during collaboration with school staff at each respective school. Factors taken into consideration regarding placement of the computers included, availability of network connections,

Table 1

Characteristics of Collaborating High Schools

School	*Zip Code*	*% Black*	*Fed Lunch*	*# 9th-12th*	*Eligible Students*
Cody	48228	90%	65%	1051	116
Redford	48219	73%	30%	1521	167
Mackenzie	48204	100%	80%	1056	116
Mumford	48221	95%	35%	1115	123
Northwestern	48208	99%	60%	824	91
Ford	48219	99%	45%	1187	130
Total/mean	*******	92%	52.5%	6754	743

established computer labs, minimizing disruption to other students in the classroom, school preference and best opportunity to provide privacy.

Procedure

This study was approved by the Michigan State University Committee for Research Involving Human Subjects (UCRIHS) as well as the Institutional Review Board of Henry Ford Health System.

Initial contact was made with the Office of Research, Evaluation and Assessment through an outside research request for the Detroit Public School System. After the proposal was reviewed by this office and approved, a memo that briefly described the study was developed and sent to selected school principals within the targeted area. The Principal of each school had the opportunity to review the proposed study and to determine whether or not they would be willing or able to participate in the project. Six principals signed a letter of agreement to participate in the project and returned it to the school systems research office. Once the notification was received by the research office the project manager of the Puff City program was notified, and meetings were scheduled with Principals and designated staff to present the study purpose, and to discuss and collaborate on implementation strategies for each school. As a result of the meetings Principals identified one staff member from each school that would operate as the day to day champion and contact person for the project. Principals also identified community leaders, parent representatives and students who could assist with implementation. Plans were developed to educate school staff such as counselors, and teachers on the epidemiology of asthma, the related morbidity, mortality, the goals of the project, and relevant implementation strategies.

Each participating school received 3 desktop computers that met specifications according to the district protocols. The computers were installed in the designated locations by Puff City staff. During the study the computers were to be used primarily by students participating in the project. This was to allow participants full access to the program while minimizing the use of existing school computers that were not accessible at all times.

A screening survey (The Lung Health Survey [LHS], Appendix A) was developed for the project using selected questions from validated standardized instruments including the Youth Risk Behavior Surveillance Survey [YRBSS], the International Study of Asthma and Allergies in Childhood [ISAAC] survey and the Fagerstrom Test for Nicotine Dependence questionnaire. The survey included questions to determine an established asthma diagnosis, asthma symptoms, health care utilization for symptoms, and school days missed due to symptoms for any reason. Other items include the student's height, weight, smoking behavior and exposure to environmental tobacco smoke at home.

The LHS was delivered to each school for distribution and administration by English teachers. Passive consent was obtained from parents of all students in 9^{th} -11^{th} grades. English teachers agreed that they would administer the survey during regularly scheduled classes within a week's time. An extension of an additional week was needed due to factors such as teacher absences, pre-scheduled classroom activities, and teacher discretion.

After the scannable response sheets were returned by teachers, they were forwarded to a district vendor, Computer Management Technology (CMT) selected by the Detroit

Public Schools (DPS) for data processing. This step was to assure student confidentiality and anonymity prior to consent and assent to participate in the study. Using a predetermined algorithm developed by the PI on the project, scan sheets were analyzed to identify adolescents with a diagnosis of asthma and current symptoms (diagnosed) undiagnosed but current asthma symptoms.

Persons in the diagnosed and undiagnosed categories were eligible for the study. As students in the current diagnosed and undiagnosed categories were identified, a packet of information containing a pamphlet that explained the study and the rights of research participants, consent and assent forms, were mailed by CMS to each family. In each packet families were given two options to return assent and consent forms. The families could either send the forms to the schools where sealed drop boxes were located or directly mail the forms to the PI. After students returned assent and consent forms, demographic information and links to the LHS results were released to the PI. Students were subsequently contacted to schedule a time for orientation to the computer, the program and to take the baseline questionnaire.

Sample Size

There were 5,963 students in grades 9-11 of the six participating high schools that completed the Lung Health Survey. Of the students completing the Lung Health Survey 599 students (10.1% of 5963) met the study criteria. Of the 599 students that were eligible to participate in the study 350 (58% of 599) returned both assent and consent forms. Therefore the number 350 will be used for purposes of power calculations.

The power and effect size tables developed by Cohen (1987) can be used to approximate the number of subjects required to use a two tailed t-test, One-Way Analysis

of Variance and the Multifactorial Analysis of Variance. A two tailed t-test is used as opposed to one tailed test when one is seeking to determine if there is a difference between groups on an outcome such as in the current study (Munro, 2001). Power calculations are used as a test of the null hypotheses and the likelihood of rejecting the null hypothesis. A power of .80 is considered a reasonable value if there are few or no previous studies to guide selecting a value (Munro, 2001). Similarly a moderate effect size of 0.5 is also reasonable if previous research is not available as a guide of selecting effect size. Using Cohen's table, based on an effect size of .05 and a power of .80, the estimated sample size needed to test for differences in the means of two groups would be 64.

For regression analysis the formula to determine sample size is based on the effect size index, the desired power, and the number of independent variables. The effect size index (L) is the function of power and number of independent variables at a given level of alpha and can be obtained from a standardized table (Cohen, 1987). According to Cohen (1987) there are three levels of effect size. A small effect is defined as an R^2 of 0.02, moderate R^2 of 0.13 and large as R^2 of .30. For the current study a power of 0.80 at an alpha of .05 will be used as in the previous calculations. A moderate effect size of 0.13 will be selected. The standard calculation recommended for the sample size calculations in regression analysis is below:

$$N = \frac{L\,(1-R^2)}{R^2} + u + 1$$

N = Total sample size

L + effect size index

u = number of independent variables

$$N = \frac{7.78\,(1-0.13)}{0.13} + 1 + 1$$

$$N = 54$$

Measures

Gender

A self-reported gender (male or female) was included in the demographic section of the Baseline Questionnaire.

Diagnosis

Students were classified as diagnosed using the Council of State and Territorial Epidemiologists (CSTE) definitions for asthma prevalence as a guide (CSTE, 1995). Physician diagnosed asthma was defined as a positive response to the survey question, "Did a doctor or other health professional ever tell you that you have asthma?" in addition to a positive response to questions about use of prescription medication for asthma and /or a positive response to having wheeze episodes in the last year. The latter question was also used to distinguish students who were diagnosed, but not currently experiencing symptoms (ever-diagnosed from those who were diagnosed and

symptomatic (diagnosed). Undiagnosed asthma (but symptoms consistent with asthma) was defined as reported use of medication for asthma symptoms, in addition to a report of episodes of wheeze during the past year, in the absence of a student report of a physician diagnosis of asthma. Students that did not fulfill CSTE criteria for diagnosed asthma were classified as "no diagnosis".

Severity

To classify participants by severity, the frequency of daytime and nighttime symptoms used in the asthma severity classifications of the National Asthma Education and Prevention Program Expert Panel II (NAEPP-II), (1997) were applied to student responses. Investigators interpreted an assigned numeric values when terms such as "frequent" and "continual" were used in the NAEPP-II criteria (1997).

Perceived Social Support

The Multidimensional Scale of Perceived Social Support (MSPSS) is a 12 item survey developed by Zimet, Dahlem, Zimet, & Farley (1988) to measure perceived emotional support (PES). The sources of support assessed in the instrument by three separate subscales with 4 items each are friends, family and significant other. The scale also provides an overall global rating of perceived emotional support. The MSPSS is self-administered, requires a fourth grade reading level and has been found to take no longer than 10 minutes to complete. It was administered via the computer as a part of the baseline assessment. The items from the MSPSS can be found in appendix B, number 76-91. Responses to the MSPSS range from 1- strongly disagree to 5-strongly agree. The instrument has been administered to demographically diverse groups of subjects across multiple studies (Canty-Mitchell & Zimet, 2000; Cecil, Stanley, Carrion, & Swann, 1995;

Dahlem, Zimet, & Walker, 1991). The MSPSS has been found to be a reliable instrument when evaluated for stability of responses over time and internal consistency. In the sited studies the coefficient alphas for the total scale ranged from .77-.92. Coefficient alphas for the family, friends and significant other subscale ranged .81-.93, .78-.94 and .79-.98 respectively. These values are indicative of strong reliability that has been established among multiple diverse subject groups. In the current study the Chronbach's alphas were within the range of previous studies for the total scale and each subscale. The alpha for the total scale was .902, and for the subscales family, .860, friends, .876 and special person .889.

Phase of Asthma Self-Regulation Development

The Asthma Self-Regulation Development Interview (ASRDI) is a structured interview developed by Zimmerman, et al. (1999) to test a four phase model of self-regulatory control of asthma (Zimmerman, et al., 1999). The ASRDI was modified to a self-report format for the parent study in consultation with Dr. Sebastian Bonner one of the developers of the instrument and a consultant on the parent project. The instrument was developed to measure four sequential phases of asthma self-regulation development. The four phases of self-regulation have been identified as (phase 1) asthma symptom avoidance, (phase 2) asthma acceptance, (phase 3) asthma compliance, and (phase 4) asthma self-regulation. The modified version of the instrument can be found in Appendix B in items 47-59. Initial testing of the original instrument revealed an inverse relationship between phase of self-regulation and asthma morbidity outcomes. In other words as parents became more self-regulated asthma symptom days, functional limitations and emergency department visits all declined significantly. In pilot testing of the instrument

by Zimmerman et al. (1999) the symptom experiences of children were determined by proxy (a parent). The current proposal will gather data directly from the affected individual, urban adolescents. This variable will be referred to as PASRD.

Asthma Health Related Quality of Life

The Pediatric Asthma Quality of Life Questionnaire (PAQOLQ) is a self administered measure of the disease specific functional impairments experienced by children age 7-17. This instrument is a 23-item questionnaire that measures the 3 domains of physical functioning/activity limitations (5 items), emotional functioning (8) items, and physical symptoms (10) items.

The domains identified in the PAQOLQ are representative of the most frequently included domains in health related quality of life. This factor allows for evaluation of construct validity by comparison of findings among similar instruments. During development the PAQOLQ was assessed in comparison to the Feeling Thermometer which is a generic health related quality of life scale and the Global Rating Change questionnaire. Children were evaluated over two study periods. The first study period was between weeks 2 and 5, and the second study period was between weeks 6 and 9. The instruments were administered to the children and results were evaluated for a change in score over time versus stability of the scores and the results were compared. A comparison group of stable patients were identified and intraclass correlations of the ratio of between subject variance and the total variance were determined to validate discriminative properties. Results indicate that the PAQOLQ has high discriminative reliability and high construct validity based on cross sectional analysis between clinic visits (Juniper et al. 1996).

When using quality of life measures it is critical to determine a value that represents a minimal important change. This change is described as the smallest change in the domains score that patients perceive as beneficial. The score determined for the PAQOLQ is 0.5. This score is consistent with other studies that have sought to develop standards for change over time (Juniper et al., 1994). Determining the minimal change will allow investigators to know at which point interventions should be stopped due to a ceiling effect or evaluated over time for improvement when a floor effect is identified.

Youth under the age of 18 present special challenges when evaluating quality of life in terms of ability to meaningfully complete a questionnaire. The ability to accurately express functional limitations and changes in emotional functioning is determined by age physical and mental health and maturity. Health providers often seek the opinions of parents in regards to a minor child's functional status and physical symptoms. However parental reports in some cases do not add to the child's report and in fact can be inaccurate (Juniper, et al., 1997). The PAQOLQ was derived by input from children age 7-17. Developers were conscious to use the terminology of the child to minimize difficulty with interpretation.

Beyond the wording of items in the instrument itself concerns also evolved around the ability of the child to interpret the 7 point likert scale and discriminate between responses. Testing by 37 children validated the ability of children ages 7-17 as being reliable respondents when using the questionnaire. Intra class correlations of .95 were determined for within subject scores. Scores were consistently high among different domains and age groups as well. Validity of the instrument for use within children age 7-17 was established. The only noted administrative problems with the PAQOLQ by

developers was the difficulty younger children (less than 10) experienced when answering questions related to the concept of last week. However to overcome this barrier, identifying an event that had occurred within the past week and re-framing the question within the context of the event, children were able to increase the reliability of their responses. This variable will be referred to as QOLTot and subscales will be referred to as QOLActivit, QOLSymptom, and QOL Emotion.

In the current study the Chronbach's alpha was determined for each subscale and for the total scale. Previous studies using the PAQOLQ have not reported this value (Guyatt, Juniper, Griffith, Feeny, & Ferrie, 1997; Juniper, Guyatt, Feeny, Griffith, & Ferrie, 1997; Juniper, Guyatt, Feeny, Ferrie, Griffith, & Townsend, 1996. A limitation of the current estimated values is that one item from the physical symptom subscale is missing and students completing the items on the activity subscale entered more than one value for items listed. An average of the values entered was accepted as the final score. The total scale alpha was .903. The apha's for the subscales were as follows; Activity Limitations, .707, Physical Symptoms, .921 and Emotional Functioning .920. Each alpha except the Activity limitations subscale was above the desirable subscale of .80 (Munro, 2001). Further testing will be needed to determine if the scoring procedure of the current study contributed to the lower alpha as opposed to the reliability of the subscale.

Asthma Health Outcomes

Hospitalizations and Emergency department visits were quantified using items similar to those used in the National Cooperative Inner City Asthma Study and the Behavioral Risk Factor Surveillance Survey which examined asthma morbidity over periods of 2 weeks and 12 months respectively (Centers For Disease Control & Prevention, 2000

[CDC]; Mitchell et al., 1997). This strategy allows us to compare findings in the current proposal to those found in national samples.

Subjective asthma symptoms are important health outcome indicators. Youth affected by asthma report symptoms of asthma such as wheezing, cough, difficulty breathing, disturbances in sleep, functional limitations in age appropriate activities such as sports, missed work, missed school and embarrassing intrapersonal social experiences related to asthma (Yeatts & Shy, 2001). Additionally when compared to healthy peers, youth with asthma report lower perceived well-being, and greater emotional symptoms (Creer, Stein, Rappaport, & Lewis, 1992; Taylor, & Newacheck, 1992; Nacon, & Booth, 1991)

Asthma symptoms were quantified based on self-report of experiences for the past 30 days. Youth were asked if they experienced asthma symptoms, restricted their activity due to symptoms or were awakened at night due to symptoms. These outcomes include those recommended by the NHLBI Expert Panel II report (1997) for the assessment of asthma severity and morbidity. Further asthma symptoms such as cough and wheeze have been identified by youth as a significant source of embarrassment that interfere with feelings of normalcy.

Table 2

Summary of Major Study Variables and Their Measurement

Variable	Measure	Description	Level of Measurement	Range	Analysis
Perceived Emotional Support *Subscales* PES Family (4 items) PES Friends (4 items) PES Special Person (4 items)	Multidimensional Scale of Perceived Social Support	12 item Self-Report Instrument	Ordinal	1-5 (high)	Mean of Total Scale and/or mean of each Subscale
Phase of Asthma Self-Regulation *Phases* *Phase I*- Asthma Symptom Avoidance *Phase II*- Asthma Acceptance *Phase III*- Asthma Compliance *Phase IV*-Asthma Self Regulation	Modified Asthma Self-Regulation Interview	11 item Self-Report Instrument	Categorical	Phase 1-4 (high)	Algorithm to determine Phase of Self-Regulation based on responses to questions
Disease Self-Management Behavior	The number of days within the past 7 that rescue medication was near enough for quick use.	Single item Self-Report	Continuous	1-7	Mean # of days

Table 2 (cont'd.)

Variable	Measure	Description	Level of Measurement	Range	Analysis
Asthma Health Related Quality of Life *Subscales* Physical Functioning Symptoms Emotional Functioning	Pediatric Asthma Quality of Life Questionnaire	23 item Self Report Questionnaire	Ordinal	1-7(high)	Mean of Total Scale and/or mean of each Subscale
Health Outcomes 1.Emergency Department Visits 2.Hospitalizations	Items 1 & 2 measured by a single question each	Item 1 & 2 self-report of Emergency Department Visits and Hospitalizations for the past 12 months	Continuous	Emergency Department Visits 0-… Hospitali-zations 0-….	Mean # of days

Table 2 (cont'd)

Variable	Measure	Description	Level of Measurement	Range	Analysis
3. Days experiencing asthma symptoms 4. Days had to slow down or stop activities due to asthma 5. Nights awakened due to asthma symptoms	Items 3-5 measured by a single question each	Items 3-5 self report of experiences for each item over the past 30 days.	Continuous	0-30	Mean # of days
Gender	Single Question	Self-Report	Categorical	Male Female	
Diagnosis	Multiple Questions	Self-Report Algorithm	Categorical	Diagnosed No diagnosis	Algorithm to determine if diagnosed with symptoms over the past 12 months or symptoms and inhaler use over the past 12 months without a diagnosis by a doctor

Table 2 (cont'd.)

Variable	Measure	Description	Level of Measurement	Range	Analysis
Severity	Multiple Questions	Self-Report Algorithm	Categorical	Mild Intermittent Mild Persistent Moderate Persistent Severe Persistent	Algorithm to determine asthma severity

Data Analysis

The demographic characteristics of the study participants, and each major variable were analyzed using descriptive statistics. The analysis included frequencies, measures of central tendency, measures of variability, and cross tabulations. To test the differences between group means t-test and one-way analysis of variance (ANOVA) was used. Descriptive statistics were calculated for age, gender, race, grade, and diagnosis of asthma for the total population. Additionally each variable was analyzed to determine if there were significant differences between the means based on gender, diagnosis, and asthma severity. When analyzing subscales for differences between scales, t-test, were used to determine if there were significant differences between the scales. All instruments were tested for reliability using Chronbach's alpha.

Research Questions & Planned Analysis

Each research question and the planned analysis are presented below:

Question 1: What is the perception of emotional support among urban adolescents with asthma?

Analysis: Descriptive statistics including means, and standard deviations were used for analysis of each subscale and the total scale. Paired t-test for independent samples was also used to determine if the mean differences between the various sources of support were significantly different.

Question 2: Does PES differ by gender, diagnosis, or asthma severity?

Analysis: To determine if there were significant mean differences by gender, diagnosis or asthma severity a separate One-Way ANOVA was run using gender, diagnosis and asthma severity as the factors.

Question 3: Does Phase of Asthma Self Regulation Development (PASRD) differ by gender, diagnosis, or severity?

Analysis: The Crosstabulation procedure was employed to determine the number of persons in each phase of asthma self-regulation development by gender, diagnosis and severity. Next the Chi Square statistic was computed separately for each group (gender, diagnosis and severity) to determine if the differences in the frequencies were statistically significant.

Question 4: What is the relationship between PES and PASRD?

Analysis: Initially a MANOVA was run to examine the mean differences in PES by PASRD. Secondly to test for an association linear regression was employed.

Question 5: What is the relationship between PES and Disease Self-Management Behavior?

Analysis: Linear regression was employed to determine if there was a relationship between PES and Disease Self-Management.

Question 6: What is the relationship between PASRD and Disease Self-Management Behavior?

Analysis: Linear regression was employed to determine if there was a relationship between PASRD and Disease Self-Management.

Question 7: What is the effect of PASRD on the relationship between PES and Disease Self-Management Behavior?

Analysis: Disease Self-Management Behavior was hypothesized as a mediator or a moderator in the relationship between PES and Asthma Health Related Quality of Life. In order to determine if this hypothesis held, several steps were employed. First linear

regression was employed to determine the relationship between PES and the dependent variable Asthma Health Related Quality of life. Second linear regression was used to determine the association between PES and the mediator Disease Self-Management. Finally multiple regression was used entering PES and Disease Self-Management Behavior simultaneously with Asthma Health Related Quality of Life as the outcome. Secondly a moderation model was tested using multiple regression. In this analysis the terms PES and PASRD were entered first followed by the interaction term PES*PASRD with Asthma Health Related Quality of Life as the outcome.

Question 8: What is the effect of Disease Self-Management Behavior on the relationship between PES and Health Outcomes?

Analysis: Disease Self-Management Behavior was hypothesized as a mediator or a moderator in the relationship between PASRD and Health Outcomes. The steps outlined in question 7 were used to test both mediation and moderator models using the appropriate variables for the current question.

Question 9: What is the effect of Disease Self-Management Behavior on the relationship between PES and Asthma Health Related Quality of Life?

Analysis: Disease Self-Management Behavior was hypothesized as a mediator or a moderator in the relationship between PES and Asthma Health Related Quality of Life. The steps outlined in question 7 were used to test both mediation and moderator models using the appropriate variables for the current question.

Question 10: What is the effect of Disease Self-Management Behavior on the relationship between PASRD and Health Outcomes?

Analysis: Disease Self-Management was hypothesized as a mediator or a moderator in the relationship between PASRD and Health Outcomes. The steps outlined in question 7 were used to test both mediation and moderator models using the appropriate variables for the current question.

Question 11: What is the effect of Disease Self-Management Behavior on the relationship between PASRD and Asthma Health Related Quality of Life?

Analysis: Disease Self-Management was hypothesized as a mediator or a moderator in the relationship between PASRD and Asthma Health Related Quality of Life. The steps outlined in question 7 were used to test both mediation and moderator models using the appropriate variables for the current question. As a result of findings that suggested a negative relationship between PASRD and Asthma Health Related Quality of Life Hierarchical Regression was employed to determine the contribution of gender, diagnosis, and asthma severity towards explaining this relationship.

Chapter 4

RESULTS

Descriptive statistics for the demographic characteristics of the study population will be presented first followed by descriptive statistics for the study variables stratified by gender, diagnosis, and severity of asthma. Questions 1-3 will be answered in this section of the chapter as these questions pertain to descriptive findings within the study population. Finally each research question will be stated followed by the analysis used to answer the question.

In the current study as previously identified, youth with a diagnosis of asthma and current symptoms and youth with current symptoms and no diagnosis were eligible to participate. The inclusion of youth without an asthma diagnosis may have in part contributed to skip patterns in the responses as some questions were not clearly applicable to each participant. Although some participants opted not to respond to all questions the results presented includes all available data. The inclusion of all available data resulted in changes in the denominator for the different scales and subscales within the following results section. All statistical analysis for the study was completed using the Statistical Package for Social Sciences (SPSS) version 11.5 for windows.

Sample Characteristics

Participants in the study ranged in age from 13-18 with a mean age of 15.29. There were more female participants than males, 194 (63.3%) verses 111 (36.4%) respectively. The majority of students were in grade 9 (118, 38.7%) followed by grade 10 (105, 34.4%) and 11 (73, 23.9%), while the fewest were in grade 12 (4, 1.3%). Although students in grade 12 were not recruited or eligible to participate in the study five

inadvertently took the baseline survey which is the source of the data for the research presented. The exclusion of 12th grade students was more important for the parent study due to the need for completion of a one year intervention and one year follow up. Because there was no rationale to delete the students from the supplemental study the data was included in all analysis. Participants were asked if they were enrolled in a Medicaid insurance plan. Of the 294 persons responding to this question, 141 (46.2%) answered yes, 43 (14.1%) answered no, and 110 (36.1%) answered don't know (see Table 3).

Covariates: Gender. Each study variable was compared by gender to determine if males and females differed significantly. All of the results with the exception of those that apply to the PES variable and PASRD are discussed in the following section. The results for the PES variable are discussed in the section that addresses research question number one and the PASRD results will be discussed in the section that focuses on research question number 3. Analysis for gender differences helped to determine if adolescents with asthma varied significantly indicating a need for gender specific interventions.

DSM and each health outcome variable were analyzed using one-way ANOVA to test for differences between means by gender. No statistically significant differences were found (see Table 4). Significant gender differences were found for the asthma health related quality of life variable. The total scale results were $F(1, 250) = 1.064$, $MSE = 19.18$, $p = .002$. The mean score for males was significantly higher than females, 5.57, $SD = 1.25$ and $M = 4.98$, $SD = 1.48$ respectively. These results indicated that males reported greater asthma health related quality of life than females.

Table 3

Demographic Characteristics of Study Population (N = 305)

Variable	n	%	M	SD	Range
Age	303		15.26	1.00	13-18
Gender					
Male	111	36.4			
Female	194	63.6			
Race					
Black	272	89.2			
Other	28	10.8			
Grade					
9th	118	38.7			
10th	105	34.4			
11th	73	23.9			
12th	4	1.3			
Insurance					
Medicaid	141	46.2			

Diagnosis of Asthma.

There were 199 (65.2%) participants that reported a diagnosis of asthma and current symptoms of asthma and 98 (32.1%) that did not have a diagnosis of asthma but who reported respiratory symptoms consistent with asthma. Of those with a diagnosis of asthma 64.8% were females. Of those without a diagnosis 61.2% were females. There were no significant differences by diagnosis between males and females $\chi^2 = .368$, $p = .608$.

Analysis of the remainder of the study variables by diagnosis revealed several statistically significant differences. Each study variable mean was greater for persons with a diagnosis of asthma however, only 3 variables reached statistical significance. Using a one-way ANOVA, DSM, number of ER visits, and QOLTot each demonstrated statistically significant mean differences (see Table 5). The mean number of hospitalizations for the study population trended toward significance, $p = .063$. The mean value of DSM for persons without a diagnosis was .27, (SD = 2.28) compared to persons with a diagnosis (M = 3.98, SD = 3.01). These results indicated that persons with a diagnosis of asthma carried their inhaler more often than persons without a diagnosis. There were fewer emergency department visits for persons without a diagnosis (M = .27, SD = .657) compared to persons with a diagnosis (M = 1.21, SD = 3.01). This may indicate less disease severity among persons not diagnosed. Disease severity by diagnosis will be discussed later. On the quality of life total scale, the mean was lower for persons with a diagnosis (M = 4.97, SD =1.43) compared to persons without a diagnosis (M = 5.63, SD = 1.36). This finding indicated poorer quality of life among person's with a diagnosis of asthma. See Table 5 for the remaining means of study variables.

Asthma Severity.

Over half of the participants, (175, and 57.4%) were found to meet criteria for the mild intermittent asthma severity classification. The remainder of the participants asthma severity classifications were as follows, mild persistent 45(14.8%), moderate persistent 59 (19.3%), and severe persistent 23, (7.5%).

Asthma severity was first stratified by asthma diagnosis. Among persons with a diagnosis of asthma 99 (49.7%) were classified within the mild intermittent category compared to 71 (73.2) persons without a diagnosis. See Table 6 for the remaining classifications by diagnosis. The relationship between these variables was further analyzed to determine if there were significant differences between participants by diagnosis and severity classification. The Chi Square test indicated that there were significant differences between the two groups ($\chi^2 = 16.13$, $p = .001$) (see Table 6).

Next asthma severity was stratified by gender to determine the count and the percent of males and females within each classification. Among males 64 (58.7%) met criteria for the mild intermittent asthma as compared to 111 (57.5%) females within this classification. Few participants met criteria for severe persistent asthma. Of the participating females 17 (8.8%) were classified as severe persistent and for males 6 (5.5%) were within this category. Refer to Table 7 for the additional frequencies for the remaining categories of asthma severity by gender. To further analyze the relationship between these two variables, the Chi Square test for significance was conducted for severity classification to determine if males and females differed. The results were not significant, ($\chi^2 = 5.141$, $p = .162$) indicating that males and females did not differ by disease severity.

Table 4

One-Way ANOVA of Study Variables by Gender

Variable	df	MSE	F	p - value
DSM	1 181	10.22	1.06	.304
Numervis	1 297	9.60	3.44	.065
Numhosp	1 229	1.21	.380	.538
Activity Affected	1 300	74.55	1.31	.253
Symptom Days	1 302	32.18	.657	.418
Nights Awakened	1 300	38.80	1.17	.280
QOLTot	1 250	19.81	9.94	.002

Table 5

Means, SD and One-Way ANOVA of Study Variables by Diagnosis

Variable	n	M	SD	df	MSE	F	p - value
DSM							
No	.23	.96	2.28	1			
Yes	158	3.98	3.01	179	183.65	21.34	.000
Numervis							
No	96	.27	.657	1			
Yes	197	1.21	3.01	291	56.70	9.07	.003
Numhosp							
No	56	.18	.636	1			
Yes	170	.69	2.03	224	11.19	3.49	.063
Symptom Days							
No	97	5.11	7.38	1			
Yes	199	5.83	6.90	294	33.40	.670	.414
Activities Affected							
No	97	4.40	7.46	1			
Yes	199	5.92	7.60	294	151.17	2.64	.105
Nights Awakened							
No	97	2.49	5.49	1			
Yes	199	3.48	5.93	294	63.60	1.89	.170
QOLTot							
No	82	5.63	1.36	1			
Yes	153	4.97	1.43	243	23.29	11.65	.000
QOLSymp							
No	86	5.59	1.45	1			
Yes	171	4.91	1.55	255	26.16	11.31	.001
QOLActiv							
No	93	4.97	1.55	1			
Yes	189	4.35	1.51	280	24.01	10.29	.001
QOLEmot							
No	90	6.14	1.34	1			
Yes	1.87	5.35	1.60	275	37.62	16.16	.000

Next study variables were analyzed to detect differences between the means at each level of asthma severity. The variables Symptom Days, Activity Affected and Nights Awakened were not included in this analysis as they also represented aspects of asthma severity. The means for each study variable when stratified by asthma severity were statistically significant (see Table 8). The mean value for each of the variables was lowest at the mild intermittent level of severity and all study variables increased in value for each level of asthma severity with the exception of DSM and QOL. The means for the DSM variable were less predictable in that the means were lowest for the mild intermittent level (M = 2.79, SD =3.15) followed by the severe persistent level (M = 3.21, SD =2.80). The mild persistent level (M = 3.96, SD = 2.83) and the moderate persistent level (M = 5.02, SD =2.72) were the highest means. The finding that means were lower for adolescents with severe persistent asthma may represent a blurring of severity as perceived by the affected individual when symptoms reach a severe persistent level. See Table 9 for a listing of all of the mean scores by variable and asthma severity.

The quality of life variable was highest at the mild intermittent level (M = 5.77, SD = .651) and the value declined with increasing asthma severity indicating worsening quality of life with increasing asthma severity (see Table 9).

Predictor Variables: *Perceived Emotional Support*

Perceived Emotional Support was analyzed to determine the mean scores of the total scale and subscales (Family, Friends, Special Person). Descriptive and inferential statistical techniques were used to analyze PES. This analysis provided the analytical response to research questions number one and two.

Table 6

Crosstabulation of Asthma Severity by Diagnosis

	Severity				
	Mild Intermittent	Mild Persistent	Moderate Persistent	Severe Persistent	Total
Nodiagnosis	71	11	9	6	97
% Within Nodiagnosis	73.2 %	11.3 %	9.3 %	6.2%	100%
Diagnosed	99	33	50	17	199
% Within Diagnosed	49.7 %	16.6 %	25.1 %	8.5 %	100 %

Chi Square = 6.13, p = .001

Table 7

Crosstabulation of Asthma Severity by Gender

	Severity				
	Mild Intermittent	Mild Persistent	Moderate Persistent	Severe Persistent	Total
Male Count	64	12	27	6	109
% Within GENDER	58.7 %	11.0 %	24.8 %	5.5%	100 %
Female Count	111	33	32	17	193
% Within GENDER	57.5 %	17.1%	16.6 %	8.8 %	100 %

Chi Square = 5.141, p = .162

1. What is the perception of emotional support among urban adolescents with asthma?

2. Does PES differ by gender, diagnosis, or asthma severity?

The overall mean for the PES scale was 4.01, (SD = 0.73). The mean score for the special person subscale was highest at 4.12 (SD = .90), followed by the friends subscale (M =3.98, SD = 0.89 and the family subscale (M =3.93, SD =.91) (see Table 10). The possible range of scores was 1-5 with higher scores indicative of greater PES. Paired sample t-test of the subscales was employed to determine if the differences between the means were significant. Results indicated that family and special person (t = 3.70, p<.000) and friend and special person (t = -2.72, p =.007) were significantly different (see Table 11).

Next multivariate analysis of variance was employed to determine the main effects and interactions for gender, diagnosis, and asthma severity on PES. Gender was the only variable that demonstrated a main effect on PES (F = 7.32, df 3, p = .000).
See table 12 for the complete analysis. There were no significant interactions between the variables Gender * Severity, or Gender*diagnosis on PES. In order to further understand the main effect of gender on PES, subscale tests for between subject effects were reviewed. All subscales except family were found to be significant by gender, friend (F =11.01, df 1, p = .001), and special person (F =10.35, df 1, p = .001) (see Table 13). The means for males (3.89) and females (3.90) on PESFamily subscale failed to reach statistical significance. However, the remaining means for the subscales for PESTot, PESFriends, & PESSpecial were all greater for females than males (see Table14). These

Table 8

One-Way Analysis of Variance of Study Variables by Asthma Severity

Variable	df	F	p - value
DSM	3 179	6.04	.001
Numervis	3 292	10.85	.000
Numhospi	3 226	5.87	.001
QOLTot	3 245	26.6	.000

Table 9

Means and SD of Study Variables by Asthma Severity

Variable	n	M	SD
DSM			
Mild Intermittent	97	2.79	3.15
Mild Persistent	27	3.96	2.83
Moderate Persistent	46	5.02	2.72
Severe Persistent	14	3.21	2.80
Numervis			
Mild Intermittent	171	.36	.859
Mild Persistent	44	.70	1.35
Moderate Persistent	58	1.81	3.96
Severe Persistent	23	2.87	5.17
Numhosp			
Mild Intermittent	122	.21	.718
Mild Persistent	37	.49	1.04
Moderate Persistent	53	1.08	2.80
Severe Persistent	18	1.72	3.19
QOLTot			
Mild Intermittent	143	5.77	1.15
Mild Persistent	39	4.51	1.21
Moderate Persistent	48	4.48	1.53
Severe Persistent	19	3.80	1.36

findings indicate that overall females perceive greater emotional support, than males and that this finding holds true when sources of support are from friends and special persons .

Phase of Asthma Self-Regulation Development

Phase of Asthma Self-Regulation Development (PASRD) was analyzed to describe the number and percent of persons that met criteria for each of the 4 phases. Most participants met criteria for phase 1(138, 45.2%). The fewest number of participants met criteria for phase 2 (28, 9.2%). The remaining participants were distributed as follows, phase 3 (78, 25.6%), and phase 4 (59, 19.3%). Phase of Asthma Self-Regulation Development was also analyzed to determine if there was variation by gender diagnosis, and severity. This analysis answered research question number three.

3. Does Phase of Asthma Self-Regulation Development differ by gender, diagnosis, or asthma severity?

Cross tabulations were employed to determine the frequencies at each phase of self-regulation development. Further the Chi Square statistic was used to identify if the differences between the groups were statistically significant. When PASRD was stratified by gender, more females were represented at each level. Significant differences between males and females were found at phase I ($\chi^2 = 4.03$, $p = .045$) and phase II ($\chi^2 = 4.39$, $p = .036$), but not at phase III or phase IV (see Table 15). Of the 295 persons responding to the PASRD questions, 96 did not have a diagnosis of asthma. There was a statistically significant difference between persons with a diagnosis of asthma and persons without a diagnosis at phase I ($\chi^2 = 49.12$, $p < .000$), phase III ($\chi^2 = 19.98$, $p < .000$) and phase IV ($\chi^2 = 16.81$, $p < .000$) (see Table 16).

Table 10

Means and SD of Overall PES and Subscales

PES Scale	n	Mean	SD
PESTotal	297	4.01	0.73
PESFamily	298	3.93	0.91
PESFriends	302	3.98	0.89
PESSpecial	303	4.12	0.90

Table 11

Pairwise Comparisons of Sources of PES

PES Sub-Scales	t-Value	p-values
PESFamily * PESFriend	.831	.407
PESFamily * PESSpecial	3.70	< .000
PESFriend * PESSpecial	-2.72	.007

Table 12

Multivariate Analysis of PES by Gender, Asthma Severity, and Diagnosis

Variable	F	df	Sig.
Gender	7.32	3	$p < .000$
Severity	.245	9	$p = .988$
Diagnosed	1.45	3	$p = .226$
Gender*Severity	1.12	9	$p = .280$
Gender*Diagnosis	.548	3	$p = .650$
Severity*Diagnosis	1.34	9	$p = .208$

Table 13

Test of Between Subject Effects for PES by Gender

Variable	F	df	p value
PESTotal	7.02	1	p = .009
PESFamily	.004	1	p = .951
PESFriend	11.01	1	p = .001
PESSpecial	10.35	1	p = .001

Table 14

Estimated Marginal Means for PES by Gender

Dependent Variable	Gender	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
PESTotal	Male	3.79	.126	3.54	4.04
	Female	4.16	.075	4.01	4.31
PESFamily	Male	3.89	.160	3.58	4.21
	Female	3.90	.095	3.72	4.09
PESFriend	Male	3.69	.150	3.40	3.99
	Female	4.25	.089	4.08	4.43
PESSpecial	Male	3.77	.154	3.47	4.08
	Female	4.332	.091	4.15	4.51

Next PASRD was analyzed using the crosstabulation procedure to determine the differences between participants at each phase of asthma self-regulation development by asthma severity. The highest percentage of participants at phase I, were categorized as Mild Intermittent (97, 56.1%). At phase II, the greater percentage of participants was categorized as Severe Persistent (4, 17.4%). Phase III and Phase IV were similar in that the greatest percent of participants met criteria for the Moderate Persistent category of asthma severity (19, 32.2%) and (19, 32.2%) respectively. See Table 17 for the additional crosstabulation results.

Disease Self-Management Behavior

Persons with asthma are directed to always keep their rescue inhaler close enough for quick use. In this study participants that had an inhaler kept it near slightly more than half of the time within the past 7 day period (M =3.56, SD = 3.10). Analysis for differences between males and females on Disease Self-Management Behavior was not significant (F (1, 181) = 1.06, MSE = 10.22, p = .304. Further analysis demonstrated that participants with a diagnosis of asthma carried an inhaler more often than participants without a diagnosis. Although this finding was statistically significant (F =7.04, df 1, p = .009 it should be interpreted cautiously. Of the students responding to this question 62 (20.3%) reported carrying an inhaler zero days. This response may be indicative of behavior or it may represent persons that did not have an inhaler. Statistically significant differences also were found by severity for participants in terms of carrying their inhaler (F (3, 179) = 6.04, MSE = 53.6, p = .001. In general the means of DSM increased as severity increased. The exception to the trend of this analysis was for the severe

persistent category where the mean was found to be the second highest of all categories. See Table 9.

Health Outcomes

Health outcomes consisted of emergency department visits, hospitalizations and the following 3 items that represented asthma symptom experiences over the past 30 days; (1) number of days that asthma symptoms were experienced, (2) number of days activities were changed due to asthma symptoms and (3) number of nights awakened by asthma symptoms. Participants reported a mean of 0.89, (SD, 2.51) emergency department visits and a mean of 0.57 (SD, 1.79) hospitalizations over the past 12 months. Asthma symptoms experiences over the past months were as follows; symptom days M = 5.37, SD = 7.53, days activities changed M = 5.52, SD = 6.99, and nights awakened M = 3.1, SD = 5.75.

Each health outcome was analyzed by One-way ANOVA for differences by gender, diagnosis, and asthma severity and has been discussed in previous sections.

Asthma Health Related Quality of Life

Asthma Health Related Quality of Life was analyzed for total scale scores followed by subscale scores. The possible range for the mean scores is 0-7 for the total AHRQOL and the subscales, with higher scores indicative of better quality of life. The means of each subscale were compared for significant differences using pairwise comparisons.

The mean for the total scale score was 5.198, SD, 1.434. The mean score for the emotional functioning subscale was highest at 5.618 (SD =1.55), followed by the symptoms subscale (M = 5.138, SD =1.552) and the activity limitations subscale (M = 4.56, SD = 1.53). Next each subscale was paired and compared for statistically significant

differences between subscales. Pairwise comparisons using t-test indicated that the means of each subscale were significantly different from the other (see Table 18).

QOL was analyzed using One-way ANOVA's to examine this variable for mean differences by gender, diagnosis and severity. The results for this analysis have been discussed previously.

Research Questions

In the following section of this chapter the results of the study will be presented according to the remaining research questions posed beginning with question number 4.

Question 4: *What is the relationship between PES and PASRD?*

PES total scale scores and each individual subscale score was utilized in this analysis. The subscale analysis were conducted due to the variation in source of support represented by each subscale (family, friend and special person) to determine if the source of support affects PASRD differently. The Phase of asthma self-regulation differed also in terms of identifying the point at which the individual was currently self-regulating their asthma. Therefore each phase of asthma self-regulation development was also be analyzed to determine if PES varies at each phase.

To evaluate the differences in the mean score for each source of support at the four phases of asthma self-regulation development a MANOVA was conducted. The results revealed statistically significant differences in the means for SocTotal and for each subscale by phase of self-regulation development, SocTotal ($F, (3) = 5.24$, $p = .002$), SocFamily ($F (3) = 5.49$, $p = .001$), SocFriend, ($F (3) = 3.03$, $p = .029$, and SocSpec ($F (3) = 3.74$, $p = .012$) see Table 19. The mean PES score for total support and each subscale were consistently highest at phase IV of asthma self-regulation development

Table 15

Crosstabulation of PASRD by Gender

PASRD	Gender	n (%)	Chi Square	p-value
Phase I	Male	58 (53.2)	4.034	.045
	Female	80 (41.2)		
Phase II	Male	5 (4.6)	4.39	.036
	Female	23 (11.9)		
Phase III	Male	25 (22.9)	.702	.402
	Female	53 (27.3)		
Phase IV	Male	21 (19.3)	.005	.946
	Female	38 (19.6)		

% = percent within Gender

Table 16

Crosstabulation of PASRD by Diagnosis

PASRD	Diagnosis	n (%)	Chi Square	p-value
Phase I	No	71 (74)	49.12	.000
	Yes	61 (30.7)		
Phase II	No	10 (10.4)	.142	.707
	Yes	18 (9.0)		
Phase III	No	9 (9.4)	19.98	.000
	Yes	67 (33.7)		
Phase IV	No	6 (6.3)	16.81	.000
	Yes	53 (26.6)		

% = percent within diagnosis

Table 17

Crosstabulation of PASRD by Asthma Severity

PASRD	Mild Intermittent n (%)	Mild Persistent n (%)	Moderate Persistent n (%)	Severe Persistent n (%)
Phase I	97 (56.1)	18 (40.0)	13 (22.0)	7 (30.4)
Phase II	9 (5.2)	7 (15.6)	8 (13.6)	4 (17.4)
Phase III	44 (25.4)	10 (22.2)	19 (32.2)	5 (21.7)
Phase IV	23 (13.3)	10 (22.2)	19 (32.2)	7 (30.4)

% = percent within severity

(M = 4.33, SD = .553), family (M = 4.28, SD = .675), friends (M = 4.26, SD = .801), and special person (M = 4.44, SD = .673) see Table 19. The mean PES scores were also consistently lowest at phase II of asthma self-regulation development with the exception of PES Friends.

Regression analysis was conducted next to determine if PES was associated with PASRD. Total PES was a significantly associated with PASRD (R = .150, B = .247, MSE .095, β = .150, p = .010. However, despite the statistical significance, PES failed to explain a reasonable amount of the variance in PASRD, R^2 = .02. Due to this finding, further analysis by subscales was not performed.

Question 5: *What is the relationship between PES and Disease Self-Management Behavior?*

To test the relationship between PES and disease self-management regression analysis was conducted. Total PES was not found to be a significant predictor of DSM (R = .121, B = .522, MSE, .322, β = .121, t = 1.62, p = .107.

Question 6: *What is the relationship between PASRD and Disease Self Management Behavior.*

This relationship was also tested by regression analysis. PASRD was found to be a significant predictor of DSM (R = .285, B = .747, MSE = .187, β = .285, t = 1.62, p < .000. PASRD was found to explain 8 percent of the variance of DSM, R^2 = .081. In general, mean DSM behavior increased sequentially with each phase of asthma self-regulation development (M = 2.51, SD = 3.00, M = 3.54, SD = 2.72, M = 3.31, Sad = 3.11, M =5.04, SD = 2.77). The exception in this finding was that the mean of phase 2 was greater than the mean of phase 3. The results indicate that as phase of asthma self-

Table 18

Pairwise Comparison of QOL Subscales

Variable	t	p – value
QOLSymp*QOLActiv	-8.36	.000
QOLSymp*QOLEmot	-8.56	.000
QOLAct*QOLEmot	-14.06	.000

regulation development increased the participant was more likely to carry their rescue inhaler.

Question 7: *What is the effect of PASRD on the relationship between PES and DSM?*

Phase of asthma self-regulation development could potentially have either acted as a mediator or moderator on the relationship between PES and DSM. Mediators identify how an association occurs between an independent variable and a dependent variable (Bennett, 2000). Prior to testing for a mediator effect, there must first be a statistically significant relationship between an independent variable and a dependent variable (Bennett, 2000). In the current study as tested previously by regression analysis, there is not a significant relationship between PES and DSM. Therefore the potential for a mediation effect could not be tested.

Moderators differ from mediators in that they affect the strength and or direction of associations between an independent variable and a dependent variable (Bennett, 2000). When testing for a moderator affect of a variable, a significant relationship does not have to exist between the independent variable and dependent variable the moderator is expected to affect.

To answer question 7, a test for an interaction between PES and PASRD using regression analysis was performed. Regression analysis testing for the moderating role of PASRD indicated that the interaction term (PES * PASRD) accounted for a significant portion of the variance of disease self-management beyond that accounted for by PES and PASRD alone, $R^2_{change} = .100$, $F_{change}(3, 175) = 6.49$, $p < .000$ (see Table 20 for regression analysis). These results indicate that PASRD moderates the relationship between PES and DSM.

Table 19

Multivariate Analysis of PES by PASRD

PES PASRD	n	M	SD	F	df	p - value
PESTotal				5.24	3	.002
1	134	3.95	.652			
2	28	3.80	1.01			
3	74	3.93	.822			
4	59	4.33	.553			
PESFamily				5.49	3	.001
1	134	3.91	.900			
2	28	3.48	1.24			
3	75	3.88	.884			
4	59	4.28	.675			
PESFriend				3.03	3	.029
1	137	3.95	.811			
2	28	3.93	.999			
3	76	3.81	1.01			
4	59	4.26	.801			
PESSpecial				3.74	3	.012
1	137	4.00	.879			
2	28	3.98	1.17			
3	77	4.12	.937			
4	59	4.44	.673			

Question #8: *What is the effect of Disease Self-Management Behavior on the relationship between PES and Health Outcomes?*

In testing the effect of DSM on the relationship between PES and health outcomes the same strategy was used as in question seven. A mediation effect was hypothesized in the study model. However due to the fact that the PES was not a significant predictor of any of the health outcomes there was no relationship to mediate (see Table 21).

Next a moderation effect is tested. In step one of the regression analysis PES and PASRD were entered as predictors of the health outcome variables. The first step allows the researcher to see the main effects of each independent variable on the dependent variable. The results of this analysis do not have to demonstrate a significant relationship between the independent variables and the outcome variables (Bennett, 2000). During step two, the interaction term that represented the joint relationship between PES and PASRD was entered to test for a moderation effect. In this step of the analysis the interaction term must explain a statistically significant amount of the variance in the dependent variable to demonstrate a moderator effect (Bennett, 2000). In this study there were no significant effects between the interaction term PES*PASRD and any of the health outcomes (see Table 22).

Question #9: *What is the effect of Disease Self-Management Behavior on the relationship between PES and Asthma Health Related Quality of Life?*

The first step to test for a mediation effect was to regress PES on the dependent variable QOL. Results indicated that there was no significant relationship between PES

Table 20

Regression Analysis for the Moderator Effect of PASRD on the Relationship between PES and DSM

IV	DV	R	B	SE	β	t	p - value
PESTot	DSM	.317	-1.08	.792	-.251	-1.36	.173
PASRD			-1.46	1.21	-.562	-1.20	.229
PESTot*PASRD			.527	.291	.965	1.81	.072

Table 21

Regression Analysis of PES on Health Outcomes

IV	DV	R	R^2	B	SE	β	*t*	p-value
PESTot	Numervis	.001	.000	.004	.203	.001	.021	.983
	NumHosp	.121	.015	-.294	.162	-.121	-1.81	.071
	Symptom Days	.034	.001	.311	.539	.034	.577	.564
	Activity Affected	.011	.000	-.109	.585	-.011	-.186	.853
	Nights Awakened	.056	.003	.408	.428	.056	.953	.341

and QOL, (R = .071. B = .143, SE = .128, β = .071, t = 1.11, p = .267). Therefore criteria for a mediation effect could not be pursued. Test for a moderating effect of DSM on the relationship between PES and QOL were conducted next. In this analysis the variables were entered into the regression model as indicated previously to test for a moderator effect. Results indicated no statistically significant effect of the interaction between the variables PES and DSM on QOL (see Table 23).

Question #10: *What is the effect of Disease Self-Management Behavior on the relationship between PASRD and Health Outcomes?*

Again the initial analysis included test for the main effect of PASRD on the dependent variables for the health outcomes was performed. Results of this analysis demonstrated several statistically significant relationships. PASRD had a significant main effect on number of emergency department visits $R^2 = .152$, SE = .120, t = 2.64, p = .009. There was also a statistically significant effect of PASRD on days activities affected (p = .017), and nights awakened (p = .027) (see Table 24). The main effect for PASRD on symptom days trended towards significance, p = .076. Next analysis was run to test for a main effect of PASRD on the mediator DSM. This analysis was completed for question 6 and demonstrated a significant relationship.

The final step in a mediator analysis is to enter the independent variable, mediator variable, and outcome variables simultaneously. To detect a mediator effect, the mediator must be a significant predictor of the outcome variable and the direct relationship of the independent variable to the outcome variable is less significant than it was in the second equation (Baron & Kenny, 1986). Each outcome variable that reached statistical significance was entered in a separate equation. Results did not identify any mediation

Table 22

Regression Analysis for the Moderation Effect of DSM on the Relationship between PES and Health Outcomes

IV	DV	R	B	SE	β	*t*	p-value
PESTotal	Numervis	.111	.231	.518	.053	.446	.656
DSM			.422	.463	.411	.912	.363
PESTotal*DSM			-.079	.112	-.331	-.704	.482
PESTotal	Numhosp	.173	-.381	.414	-.126	-.921	.359
DSM			.115	.346	.166	.333	.740
PESTotal*DSM			-.009	.084	-.057	-.111	.912
PESTotal	Activity Affected	.241	.591	1.13	.059	.521	.603
DSM			1.94	1.02	.837	1.90	.058
PESTotal*DSM			-.355	.247	-.658	-1.43	.152
PESTotal	Symptom Days	.238	.609	.973	.071	.626	.532
DSM			1.38	.874	.697	1.58	.114
PESTotal*DSM			-.230	.212	-.498	-1.08	.278
PESTotal	Nights Awakened	.127	.215	.830	.030	.259	.796
DSM			.456	.746	.275	.611	.542
PESTotal*DSM			-.061	.181	.159	.340	.734

effects of the DSM on PASRD and health outcome variables entered into the regression model (see Table 25).

The next phase of the analysis was to test the relationships between PASRD, DSM and Health Outcomes and to determine if DSM acted as a moderator in this relationship. As in the previous interaction models the term PASRD*DSM was entered into the regression model along with PASRD and DSM as a single term. There were no significant relationships found with the interaction term for each outcome variable indicating that DSM did not act as a moderator on the relationships between PASRD and health outcomes (see Table 26).

Question 11: *What is the effect of Disease Self-Management Behavior on the relationship between PASRD and Asthma Health Related Quality of Life?*

The first phase of the analysis was to run a regression for PASRD on AHRQOL. Results indicated a significant negative relationship between PASRD and AHRQOL, R2 = .109, B = -.329, SE = .071, β = -.329, t = -5.50, $p < .000$.The second phase of this analysis was answered in the previous question indicating a significant relationship between PASRD and DSM. In the third equation DSM failed to act as a significant predictor of AHRQOL, $R^2 = .109$, B = .011, SE = .041, β = .021, t = .253, p = .801 indicating that a mediation model did not exist (see Table 27).

The next phase of the analysis of the relationships between PASRD, DSM and AHRQOL was to determine if DSM acted as a moderator in this relationship. As in the previous interaction models the term PASRD*DSM was entered into the regression model along with PASRD and DSM as single terms. There were no significant relationships found with the interaction term for each outcome variable indicating that

DSM did not act as a moderator on the relationships between PASRD and QOL although this relationship trended towards significance $p = .067$, (see Table 28).

PASRD was found to be a predictor of QOL. Although it was anticipated that PASRD would predict QOL the relationship was not anticipated to be a negative relationship. To further understand this relationship hierarchical regression was run with all of the predictor variables to determine their contribution to this outcome.

Using hierarchical regression each predictor variable was entered using an a priori approach. Asthma severity was entered first followed by diagnosis, PES, and PASRD. Results indicated that asthma severity ($R = .488$, $R^2 = .238$, $p < .000$), followed by PASRD ($R = .546$, $R^2 = .298$, R^2 change $=.042$, $p < .000$) accounted for the majority of the variance explained (see Table 29). In order to determine if males and females differed on the above relationships the analysis was run again using a split file technique in hierarchical regression to determine if the relationships held among males and females separately. Results indicated that PES was a significant variable in the model for males but not females and that PASRD was significant for females but not males (see Table 30).

Table 23

Regression Analysis of the Moderation Effect of DSM on the Relationship between PES and QOL

IV	DV	R	B	SE	β	t	p-value
PESTotal	QOL	.122	-.098	.280	-.047	-.349	.728
DSM			-.252	.246	-.511	-1.02	.307
PESTotal*DSM			.050	.060	.441	.844	.400

Table 24

Regression Analysis of the Main Effect of PASRD on Health Outcomes

IV	DV	R	B	SE	β	*t*	p - value
PASRD	Numervis	.152	.317	.120	.152	2.64	.009
	Numhosp	.070	.104	.098	.070	1.06	.290
	Symptom Days	.102	.593	.333	.102	1.77	.076
	Activity Affected	.138	.862	.359	.138	2.40	.017
	Nights Awakened	.128	.610	.274	.128	2.22	.027

Table 25

Regression Analysis for the Mediation Effect of DSM on PASRD and Health Outcomes

IV	DV	R	B	SE	β	*t*	p - value
Model 1							
PASRD	Numervis	.106	.131	.208	.049	.629	.530
DSM			.081	.079	.080	1.01	.312
Model 2							
PASRD	Activity Affected	.199	.831	.487	.130	1.70	.090
DSM			.287	.186	.118	1.54	.123
Model 3							
PASRD	Nights Awakened	.095	.389	.380	.079	1.025	.307

Table 26

Regression Analysis for the Moderation Effect of DSM on the Relationship between PASRD and Health Outcomes

IV	DV	R	B	SE	β	*t*	p - value
Model 1							
PASRD	Numervis	.108	.199	..320	.075	.621	.536
DSM			.128	.189	.127	.680	.497
PASRD*DSM			-.019	.067	-.064	-.279	.780
Model 2							
PASRD	Activity Affected	.219	1.52	.733	.230	2.08	.039
DSM			.800	.444	.328	1.80	.073
PASRD*DSM			-.197	.155	-.279	-1.27	.206
Model 3							
PASRD	Nights Awakened	.095	.419	.574	.085	.730	.467
DSM			.086	.348	.046	.246	.806
PASRD*DSM			-.008	.121	-.015	-.069	.945

Table 27

Regression Analysis for the Mediator Effect of DSM on the Relationship between PASRD & QOL

IV	DV	R	B	SE	β	*t*	p - value
PASRD	QOL	.270	-.347	.105	-.277	-3.29	.001
DSM			.011	.041	.021	.253	.801

Table 28

Regression Analysis for the Moderator effect of DSM on the Relationship between PASRD & QOL

IV	DV	R	B	SE	β	*t*	p - value
PASRD	QOL	.306	-.571	.161	-.456	-3.55	.001
DSM			-.146	.094	-.295	-1.54	.124
PASRD *DSM			.062	.034	.438	1.84	.067

Table 29

Hierarchical Regression for Predictors of QOL

Model	R	R^2	Change in R^2	Sig. F Change
Step 1	.488	.238	***	.000
Severity				
Step 2	.499	.249	.012	.058
Diagnosis				
Step 3	.507	.257	.008	.122
PESTotal				
Step 4				
PASRD	.546	.298	.042	.000

Table 30

Hierarchical Regression for Predictors of QOL by Gender

Model	R	R^2	Change in R^2	Sig. F Change
Step 1				
Severity				
Male	.478	.229	***	.000
Female	.504	.254	***	.000
Step 2				
Diagnosis				
Male				
Female	.488	.238	.010	.317
	.518	.268	.014	.092
Step 3				
PESTotal				
Male	.551	.304	.066	.008
Female	.522	.273	.005	.304
Step 4				
PASRD				
Male	.572	.327	.023	.105
Female	.570	.325	.052	.001

Chapter 5

DISCUSSION

Asthma is a common disease among urban adolescents yet little is known about the unique needs of this group in terms of factors that influence asthma self-regulation development, disease self-management, health outcomes and asthma health related quality of life. The unique needs of adolescents are often neglected due to the fact that they are generally studied collectively with children or adults. Adolescence is a period of significant cognitive, physical, social and emotional development. During this time in life youth are transitioning from childhood into adulthood. An understanding that this period of life is characterized by developmental growth and transition begs for separate studies to identify the unique needs of adolescents.

If not properly managed, asthma can be life threatening (ALA, 2005). Although deaths due to asthma are rare among children, the frequency of asthma related deaths increases with age (ALA, 2005). Adolescence is a period of declining disease self- management behavior. Poor disease self-management is related to poorer disease control which places adolescents at greater risk for disease related morbidity, and mortality. Further potential life long behaviors for disease management are established during adolescence. Therefore it is essential to understand factors that positively influence disease self-management during adolescence in an attempt to establish effective life long behaviors that achieve positive health outcomes and that promote asthma health related quality of life.

The primary goal of this cross sectional, correlational study was to examine the relationships between perceived emotional support, phase of asthma self-regulation development and disease self-management behavior among urban adolescents with

asthma. Additionally the study sought to determine if PES, PASRD, and DSM were directly or indirectly associated with health outcomes and asthma health related quality of life. This study extended previous research of adolescents with asthma in that it focused specifically on urban adolescents and because the factors identified to influence disease self-management behavior have not previously been studied among this population.

Predictor Variables

PES represented one of the social support functions as an environmental factor within the proposed model for this study. Social support has been identified as important to developing youth and their success as they assume greater responsibility for DSM. However, the efficacy of the specific support function varies depending on the behavior. PES was considered to be relevant due to the age of the study participants being a period of transition when youth assume primary responsibility for DSM. Also sources of support such as parents, friends, and social contacts are the most influential persons in the adolescent's social environment.

Among the participants in the study PES scores were at the higher end of the scale indicating greater perceived support. This finding does not compare directly with other populations that have been studied using the same scale as the range of responses in the current study were modified from 1-7, to 1-5, however general comparisons can be made. When the unmodified Multi-dimensional Scale of Perceived Social Support (response range 1-7) was administered to healthy urban adolescents (Canty-Mitchell & Zimet, 2000) the means were similar to findings in the current study in that they indicated a higher perception of emotional support and the ranking of the highest mean score to the lowest mean score followed the exact same pattern in both studies. The current study

extends what is known regarding PES in that the instrument has now been used in an adolescent population with a chronic disease and the results are similar to a healthy urban population with special person being highest followed by friends and then family. The similarities in scores and the pattern in scores may indicate that there is no difference between healthy urban adolescents and urban adolescents with asthma in terms of their global perception of emotional support.

Gender differences on the PES variable were found to be significant. The scores of males were significantly lower than females for total support and each subscale except family support. The gender variation is similar to studies of adolescents with diabetes where females perceived greater general and disease specific emotional support than males from friends (La Greca et al. (1995); Skinner, John, & Hampson, 2000). According to Barbee et al. (1993) gender differences likely represent the stereotypical differences that characterize females as being more socially skilled, emotionally sensitive, expressive, and concerned with personal relationships than males. Differences between males and females must be considered when developing interventions to promote emotional support from sources other than the family. Evidence from the current study and the studies cited indicate that emotional support may be more relevant for males and may require enhanced or different strategies than those designed for females when support is from sources other than familial.

A poorer perception of emotional support raises concerns regarding adolescent males in general and more specifically those with a chronic disease such as asthma. Poorer perceptions of emotional support especially from friends could place males at higher risk for negative health outcomes as well as higher risk behaviors such as smoking which has

negative health consequences for asthmatics. During adolescence youth are known to gradually gravitate towards friends and away from parents, a relatively stable source of emotional support. For males this may be a transition that is more unstable than for females and may contribute to isolation, depression and high risk behaviors. This raises considerable concern as youth who engage in high risk behaviors are less likely to engage in disease self-management.

The finding that PES did not differ by gender when family was the source may represent the stability of the family relationship that is well established prior to adolescence. Such a hypothesis is supported in a study by Shroff Pendly et al. (2002) who found that when the mean of perceived family support was compared between children (8-12yrs) and adolescents (13-17 yrs) there were no significant differences. This finding could also indicate that provisions of emotional support are not gender specific within families. An awareness that PES from families is perceived similarly between males and females informs researchers that interventions to enhance emotional support from families for urban youth need not be gender specific.

The PES variable was also analyzed to determine if the source of support was significantly different among adolescents. Means of the Family and Friends subscales were not significantly different. In contrast the Special Person subscale was significantly different than family and friends subscales. This finding is similar to the results from the study by Canty-Mitchell & Zimet, (2000). Despite the fact that the sources special person differs from the other subscales, there have been no known published studies that identify who the special person represents. Special person may overlap with friends or family members, but the individual may count on one family member such as the mother and

consider her as having an additional or special role above and beyond that considered within the familial role. Additional research is needed to clarify who the Special Person is that adolescents identify as a source of emotional support.

PES & DSM

Once the PES variable had been fully analyzed the next step was to determine if there was a direct effect on DSM. In the current study there was no relationship between PES and DSM. These findings differ from a study of African American adolescents with asthma from a southern state, where participants with greater social support reported greater disease self-management (Sin et al., 2005). The studies are similar, but not equivalent in that in the Sin, et al. (2005) study, the type of support studied was a global measure of support not emotional support, and disease self-management was measured using a 27 item questionnaire as compared to a single item. However, the comparison is made to point out how the relevance of support function (perceived emotional support vs. affect, affirmation, and aid or tangible support) may vary in association with the selected outcomes.

PES has been studied among adolescents with diabetes for associations with disease self-management behavior. Within this population, PES was not related to tasks such as insulin administration or blood glucose testing which are considered key tasks in diabetic self-management. Instead PES from family was oriented toward praise, and encouragement of self care efforts, conveying a sense of acceptance, and helping adolescents maintain a positive outlook on their diabetes (La Greca, 1995). PES from friends was primarily oriented towards helping the adolescent feel accepted and showing sensitivity to the adolescent's feelings about having diabetes.

There are several hypotheses that could explain the failure to find an association between PES and DSM in the current study. One of the reasons this relationship was not demonstrated in the current study may be that it does not exist. Of the studies reviewed in the literature that focused on adolescents and perceived emotional support, none were found that demonstrated a relationship with disease self-management behavior. Another point to consider is the variability in social support function (emotional, instrumental, informational and appraisal) and its association with disease self-management. Youth may find emotional support beneficial and important, but this type of support may not be related to implementing a task, as much as it may be related to maintaining a positive attitude about having asthma. In a qualitative study of adolescents with asthma, Knight, (2005) found that adolescents that had adequate social support did not identify feelings of shame, or feeling different when using inhalers in school or sports. La Greca et al. (1995) suggest that diabetic adolescents that have inadequate sources of emotional support (specifically from friends) may feel uncomfortable telling their friends about their disease and these same youth may also lack and important support resource for diabetes care. In the current study emotional support was measured as a global form of support, it is not clear if a disease specific form of emotional support would have yielded different results. Further 32% of the study population did not have a diagnosis of asthma and therefore although they carried an inhaler and used it for respiratory symptoms they may not associate medication use with the diagnosis asthma. Finally having a single item to represent DSM was inadequate. Individuals with asthma must implement a number of activities, all of which fall under the heading of DSM. In the current study, only one of

the task related activities was identified and this may have been insufficient to fully represent the concept.

PES Health Outcomes & Asthma Health Related Quality of Life

The study model depicts indirect relationships between PES, and health outcomes and between PES and AHRQOL. The indirect relationships were hypothesized as being mediated by DSM. As an initial step in testing a mediator relationship, analysis for direct relationships are tested. There were no direct relationships between PES and any health outcomes or AHRQOL therefore a mediation model could not be tested.

Some variables may act as a mediator or a moderator depending on the theory being tested (Frazier, Tix & Barron, 2004). In the current study DSM could potentially be conceptualized as a moderator variable in part because of the lack of evidence against this association. If this were the case this finding would suggest that PES interventions would vary in effectiveness based on the level of DSM. Alternately, according to Cohen & Cohen, (1983) this relationship is symmetrical meaning the level of the independent variable could also explain the association. However analysis did not show an interaction effect of DSM and PES on Health outcomes or AHRQOL.

PASRD & DSM

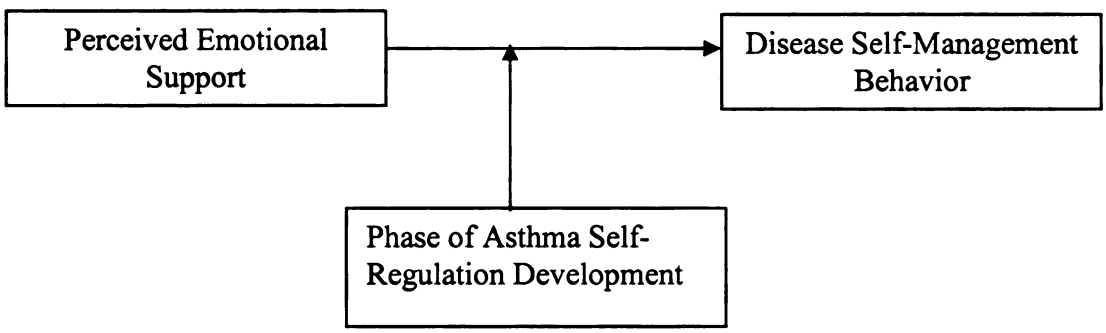
The second predictor variable of DSM was phase of asthma self-regulation development. Persons that are diagnosed with asthma are hypothesized to transition through 4 phases of self-regulation that begin with acceptance of the diagnosis of asthma followed by the progressive and sequential development of thought processes to manage asthma proactively. Phase of asthma self-regulation was hypothesized to act as a mediator in the relationship between PES and DSM. However after determining that PES

was not a significant predictor of DSM, steps were taken to evaluate PASRD as a moderator. Theoretically, PASRD could act as a moderator as this concept is represented by 4 different phases. In the current study PASRD was found to act as a moderator in the relationship between PES and DSM (see Figure 2).

As a moderator PASRD acts as an independent variable that affects the strength and or direction of the association between PES and DSM. According to Chmura, Wilson, Fiairburn, & Agras (2002) as a moderator PASRD acts to identify on whom and under what circumstances treatments have certain effects. Prior to testing for the moderation affect, a MANOVA was conducted and the mean scores for PES were consistently highest at phase IV and lowest at phase II. This finding supports the potential effect of a moderator in which PES is predictive of DSM depending on the phase of asthma self-regulation. The moderation effect of PASRD on the relationship between PES and DSM was also found to be significant. These results may also indicate that other forms of support such as instrumental or informational support are effective depending on the phase of self-regulation development. Further investigations are warranted to study this relationship as no known published studies exist for comparison of findings.

Another hypothesis that may explain the moderator effect of PASRD is that as the individual becomes more knowledgeable and is progressively able to plan how to handle the day to day observation, judgment and evaluation associated with asthma self-regulation emotional support may be more important for maintenance of self-regulation

Figure 2. Moderator Model of PES and DSM



than for development of self-regulation. Phase 4 is described as the period when support is withdrawn as the adolescent becomes increasingly self-regulating (Clark, & Zimmerman, 1990). The finding is also consistent with discussions by Clark and Zimmerman (1990) who describe the need for various "social and physical support" that should be introduced during the learning and instructional phase of self-regulation development that is ultimately withdrawn over time.

The literature is void of evidence from scientific studies of factors that influence the progression of youth with asthma through the phases of self-regulation. The current study adds to the scientific body of knowledge by identifying descriptive findings of urban adolescents and PASRD as well as exploring associations between PASRD and an environmental factor (PES) and behavior (DSM).

PASRD, DSM, Health Outcomes and AHRQOL

During the next phase of analysis, direct relationships between PASRD and Health Outcomes, and PASRD and AHRQOL were examined. These steps were taken prior to testing a mediation model with DSM acting as a mediator. PASRD was found to have

direct effects on number of emergency department visits, days activities were affected and nights awakened due to asthma. These results are similar to findings by Zimmerman et al. (1990) which were discussed previously. In the analysis of the direct effect of PASRD on AHRQOL, a negative relationship was found. This was not anticipated as intuitively and from a theoretical perspective one would expect that as one progressed through the phases of asthma self-regulation development, that health related quality of life would improve. Therefore, additional analyses were conducted to explore factors that might explain these findings. The results are discussed later.

Next the mediation model was tested for the variables predicted by PASRD. None of the models were found to be significant. Again once the mediation model was found insignificant the moderation model was tested. The moderation model also failed to demonstrate a significant interaction between PASRD and DSM on the outcomes identified.

According to Clark et al., (2001) disease self-management strategies are goal driven. Each of the different outcomes evaluated would be expected to represent different goals by the adolescent. In other words some adolescents may have a goal of minimizing emergency department visits, where as others may have a goal of increasing the number of days for which they experience fewer activity restrictions. Each goal would also likely represent different disease self-management behavior to the adolescent. Representing DSM by one item limited the opportunity to detect different behaviors that adolescents use to achieve the outcomes of interest. Also the cross sectional design of the study is representative of the individual's state of self-regulation at one moment in time. PASRD is hypothesized to be a sequential process that is developed over time. Therefore, a

longitudinal study could yield different results. Additional investigations are necessary to further understand the relationships hypothesized in the current study as well as the study results.

PASRD & AHRQOL

The relationship between PASRD and AHRQOL was tested using a regression model and found to be negative. This relationship has not previously been tested in the literature. Theoretically, as one develops self-regulation skills morbidity and mortality might be minimized and therefore AHRQOL would improve. Hierarchical regression was used to identify the variables within the study that contributed most to the relationship between PASRD and AHRQOL. Findings indicated that Asthma Severity explained 23% of the variance. In the final model there were significant negative relationships between severity and PASRD with AHRQOL and a significant positive relationship between PES and AHRQOL.

National guidelines define asthma severity by self report of the frequency of asthma symptom experience in addition to objective measures of airway obstruction. In the current study symptoms such as cough and wheeze, activity restrictions and night time awakenings did not vary between persons with a diagnosis of asthma and those without. Within the regression model there was no relationship between diagnosis and AHRQOL. Therefore, findings that disease severity is negatively related to AHRQOL has far reaching implications.

Limitations

Although this study offered insight into factors hypothesized to influence DSM, Asthma Health Outcomes and AHRQOL there are limitations in terms of implications

and interpretation of the results that must be acknowledged. There are both design and methodological flaws that contribute to the limitations of the study. Urban African American adolescents were the population of interest for this study. This population has been described as having a greater prevalence of asthma and greater morbidity and mortality experiences when compared to their Caucasian counterparts. Adolescence also represents a unique transitional period of life when social, physical, cognitive and emotional changes differentiate them from children and adults. Also having a greater understanding of factors that may affect morbidity and mortality and potentially the related cost of care further supported the decision for the selected population. However, due to the unique socioeconomic characteristics of the study population and difference between adolescents, adults or children, the study findings cannot be readily generalized to other populations.

The cross sectional design was selected for the study, as adequate research regarding the variables of interest among urban African American adolescents is limited. Due to the limited existing knowledge the study was designed to primarily describe what was not already known. Although the reported results included inferential statistics these findings are not suggested to implicate causality which would require a longitudinal experimental design. Further when reporting a negative relationship between variables the author can only use theory to suggest the direction of each variable in an attempt to explain the findings.

Measurement of several of the study variables may have also resulted in limitations on both the analytical test that could be used as well as the ability to interpret results. The MSPSS is a valid reliable instrument that measures a global perception of PES. However,

Social Support is multidimensional and perhaps would have been better represented by studying more of the functions (instrumental, informational, appraisal) of this concept to gain a greater understanding of how each function may have contributed to outcomes. In the same vein, DSM is also multidimensional however in the current study a single item was utilized to represent this concept. Disease self-management regimens prescribed for adolescents are often complex and include administration of multiple medications, avoidance of asthma triggers and use of peak flow devices to monitor disease severity. In the current study, the frequency of carrying an inhaler was the only measure of DSM. Although carrying and inhaler is an important part of DSM and is a recommendation that should be carried out on a daily basis, this factor alone is inadequate to fully represent DSM.

Implications

Findings from the current investigations have implications for clinical practice and future research of factors that influence DSM. Despite the limitations related to the exploratory focus of the study the results provide both new information and inferences regarding relationships that may exist between study variables.

Clinical Implications

A holistic approach to the management of health problems includes the recognition of factors beyond pathological processes which affect health outcomes and health related quality of life. An important focus of holistic care includes counseling on health behaviors that are implemented as a part of DSM. Counseling clients on health behavior has been described as having promising potential towards disease prevention and management (Glasgow et al., 2005). Although the current study findings will require

additional investigations before recommendations can be formalized the focus of study is on factors that influence health behavior which could aid clinicians in the future to positively impact health outcomes during clinic visits.

According to Clark, (2003)

> The extent to which the person holds the requisite knowledge and beliefs to support an action depends, in part, on a range of external factors. These may include role models that can be observed making efforts in asthma situations: interpersonal relationships through which emotional and instrumental social support is given and received; and almost certainly , technical advice from a clinician who provides therapeutic recommendations, p. 293).

Clark (2003) goes on to suggest that persons with a chronic disease may need assistance to modify external factors in order to enhance ones ability to be self-regulating.

The clinician is in a key position to assess and provide assistance to clients through acts such as counseling in order to help them become self-regulating. Studies such as the current one and others will provide critical information on factors that the clinician must address in order to effectively support self-regulation development and the associated changes in health behavior. The traditional focus of disease self-management has been to provide advice and recommendations that was guided by pathological mechanisms of disease. Over time health outcomes have demonstrated that a broader approach to disease management is necessary. This broader approach is inclusive of health behavior counseling which must take into account social contextual factors that influence disease self- regulation development and disease self-management behavior.

Treatment advice from clinicians to youth affected by asthma includes directions such as follow an asthma action plan, avoidance of triggers and knowledge of how and when to use medications. The most common means of assuring that youth achieve the targeted treatment objectives is via education. Despite the clear evidence to support how essential education is towards achieving health outcomes, there is an equal level of support that clearly indicates education alone is inadequate. Clinicians such as Advanced Practice Nurses (APN's) are in a perfect position to assist youth by focusing on psychosocial factors that provide the context for self-regulation development and disease self-management. This proposed model of care would allow APN's to explore the efficacy of using psychosocial factors to influence and or improve disease self-management behavior in clinical practice.

The current study also adds to the scientific body of knowledge regarding the role of emotional support and PASRD. As previously noted the study was not experimental in design and therefore results are only inferential in nature. However findings suggest that there is a relationship between PES and PASRD, and that the relationship between PES and DSM is moderated by PASRD. Clinicians must rethink current practices that for the most part are void of services to address non-medical factors that could make a difference in health outcomes that have yet to be achieved using traditional models of care.

PES was found to be directly related with PASRD and PASRD was found to be directly related to DSM. Because of the nature of these variables it is more difficult to demonstrate their effectiveness especially in a demographically and socioeconomically diverse population. However, studies such as the current one are beginning to provide

evidence for the efficacy of how psychosocial variables influence DSM which can be used to inform clinicians of the value of addressing these issues in clinical practice.

Research Implications

Disease self management is complex and few gains have been made towards providing scientific evidence of effective strategies to promote related behavior as well as improve health outcomes. However of the studies that have reported successful programs to enhance disease self-management many have been based on a theoretical understanding of human behavior (Clark, 2003). The current study used a behaviorally based theory to guide the selection of the variables included. Behavioral theory was also used as the bases for the hypothesized relationships within the study.

Although there were noted limitations of the results related to the hypothesized relationships in the study they cannot be considered a failure of the underlying theory. The findings of the moderated relationships between PES, DSM and PASRD were weak, but clinically and statistically significant. Each variable is one that can potentially be addressed during a clinic visit and that may contribute towards improving health outcomes. The variables in this project had not previously been studied in the selected population and findings can be utilized to inform future research. Therefore findings should be considered as informative and additive to what is known about the study population. Findings such as the role of gender in PES were found to be similar to previous research. Also PASRD was negatively related to QOL and asthma severity explained this relationship.

Conclusion

Urban adolescents with asthma face daily challenges of implementing disease self-management behaviors that are essential to minimizing the risk of disease related morbidity and mortality and enhancing asthma health related quality of life. These challenges come at a time in life when normal developmental transitions are occurring that make the needs of this population unique from children and adults. Although great strides have been made in the scientific community regarding the complex physiological pathways of airway inflammation, and hyperresponsiveness, little is known about the equally complex environmental factors that influence asthma self-regulation, disease self-management behavior, health outcomes and asthma health related quality of life.

There were a number of findings from this study that have been identified and discussed in the results and discussion section of this paper. However the following will serve to summarize these findings in a concise manner for the reader. First, the covariates gender, diagnosis and severity each contributed to the findings in different ways. Gender differences were only found for the variable PES. This finding is consistent with previous research in healthy adolescents and in adolescents with a chronic disease. Results from the current study of adolescents with asthma were similar to studies of perceived emotional support among healthy adolescents and adolescents with diabetes. Adolescents with a diagnosis of asthma carried their inhaler more frequently than those without a diagnosis. This finding alone is difficult to interpret. Carrying an inhaler may have been a result of having more persons with a prescribed inhaler among diagnosed adolescents. Further investigation is needed to determine if persons without a diagnosis and with an inhaler differed from the described population. A precautionary interpretation would be

that persons with a known diagnosis of asthma may engage in disease management behaviors differently than persons whose respiratory symptoms are treated as an episodic illness for which long term disease management is not appropriate. Persons without a diagnosis may not have been offered the same directions/education regarding inhaler use or the need to carrying the prescribed rescue inhaler at all times. Asthma severity was not found to vary by gender. However differences were found when participants were stratified by diagnosis. Seventy three percent of non diagnosed participants met criteria for mild intermittent asthma. This finding is consistent with other studies where it has been noted that persons with mild intermittent symptoms of asthma often go undiagnosed.

Second, the environmental factor PES was found to be at the higher end of the scale among adolescents with asthma. All PES subscales differed by gender except the family subscale. When the subscales were compared to determine if they were different, the special person subscale was different from family and friends. Findings on the PES variable were similar to those reported on healthy urban adolescents. In future research of PES investigators must plan to identify who the special person is among study participants. Third, PES was found to have a significant relationship with PASRD. This finding represented an original finding and has potential as a new line of inquiry. Fourth, no relationship was found between PES and DSM. This finding was consistent with previous research among adolescents with diabetes. Fifth, no relationship was found between PES and Health Outcomes or AHRQOL. These relationships had not previously been tested among urban adolescents with asthma and represent a new finding that must be interpreted cautiously. Sixth, PASRD was found to be associated with DSM. This also

represents an original finding and an opportunity for a new line of inquiry. Seventh, PASRD was found to act as a moderator between PES and DSM. Again this is an original finding and additional investigations are needed to validate results. Eighth, there was no effect of DSM on the relationship between PES and Health Outcomes or PES and AHRQOL. This was an original line of inquiry and the results should be interpreted with caution as with any findings that have not been replicated. Ninth, DSM had no effect on the relationship between PASRD and Health Outcomes. This was an original line of inquiry and again results should be interpreted cautiously especially due to the identified limitations of the variable DSM as it was operationalized in the current study. The tenth and final contribution was the finding that the relationship between PASRD and AHRQOL was negative. This was also an original finding and one that was unexpected. Within the study the covariate asthma severity was found to explain this relationship. This finding will inform future research efforts that will need to further investigate these findings.

Next Step

The "next step" is always a daunting task for researchers. Depending on the outcomes of a study the next step may be explicitly clear or may require serious thought. In the case of the current investigation the next step requires serious thought as there are a number of paths that could be taken. This investigator believes that the next step towards developing a research agenda that flows from the current study is to maintain a focus on urban adolescents with asthma. The morbidity and mortality among this population demonstrates clear health disparities when compared to Caucasian counterparts yet effective treatment options exist. Among urban adolescents disease self-management

behavior holds promise as a potentially effective means of influencing and improving health outcomes and health related quality of life. Therefore future research will continue to focus on factors that influence disease self-management.

In the current study only one function of emotional support was investigated. The instrument tested was a global measure of emotional support and may not have been sensitive to the needs of individuals affected by asthma. To better understand this relationship it will be important to develop an instrument that is both reliable and valid in measuring social support. Additionally the instrument should measure more than one function of support and it should be disease specific. Measuring the different functions of support would allow investigators to gain a broader understanding of the differences between each function and how each function uniquely contributes to disease self-management behavior.

Another factor to consider and include in future research is to adequately measure disease self-management. Results from the current investigation raise concern regarding the finding that self-regulation development was negatively correlated with asthma health related quality of life. This finding could be indicative of implementation of DSM that is ineffective. Ineffective DSM may result in consuming thoughts associated with self-regulation that negatively affect asthma health related quality of life. A clearer understanding of the multidimensional aspects of DSM will allow for a clearer interpretation of results. Therefore a more comprehensive measure of DSM would be adopted in future research.

Finally the use of a theoretical model to guide future research is essential. The model used in the current research focuses on the relationships between the individual their

environment and behavior. The self-regulation perspective of SCT is centered on how these factors influence the individual's ability to process their thoughts and actions to achieve disease control. According to Clark (2003) the affected individual should always be at the center of chronic disease control efforts unless personal or situational factors exist that alter the individuals ability to participate in disease self management.

The self-regulation perspective of SCT remains consistent with the future research agenda of this investigator. Therefore this theoretical model will be used during the next phase of investigation. The initial study focused on multiple variables as independent factors as well as sources of influence on DSM, health outcomes and health related quality of life. The future research will take a step back to assure that the variables of interest are measured in a valid reliable manner that will better allow the investigator an opportunity to determine their significances in the study of disease self-management among urban adolescents with asthma.

APPENDICIES

Lung Health Survey

The purpose of this survey is to learn more about the respiratory (lung) health and the health behaviors of high school students. Some **of the answers may not fit your situation, but please answer them as best you can**. Some of the questions **may seem like a repeat** of other questions, but **please try to answer all of them**. Your answers to this survey will be kept **PRIVATE** and will not be shared with parents, teachers, or other school staff.

This survey is about your respiratory health (how well your lungs work and how well you are able to breathe).
* Please answer the following questions.

1.	Have you ever had **wheezing or whistling in the chest at any time**?	[1] Yes [2] No
2.	Have you had wheezing or whistling in the chest in the **last 12 months**?	[1] Yes [2] No
3.	Have you had wheezing or whistling in the chest WITHOUT A COLD in the **last 12 months**?	[1] Yes [2] No
4.	**How many attacks** of wheezing have you had in the last 12 months? [IF NONE, PUT 0]	_____ number of attacks
5.	In the last 12 months, how often, on average, **has your sleep been disturbed** due to wheezing?	[1] Never awoken with wheezing [2] Less than 1 night per week [3] One or more nights per week
6.	In the last 12 months, has wheezing ever been **severe enough to limit your speech** to only one or two words at a time between breaths?	[1] Yes [2] No
7.	In the last 12 months, has your chest sounded wheezy **during or after exercise?**	[1] Yes [2] No
8.	In the last 12 months, have you had a **dry cough at night, apart from a cough associated with a cold or chest infection**?	[1] Yes [2] No
9.	Have you had tightness or heaviness in the chest in the **last 12 months**?	[1] Yes [2] No

THESE NEXT FEW QUESTIONS ARE ABOUT THE LAST 12 MONTHS.....[FROM September 2002 or LAST SCHOOL YEAR to September 2003. IF THESE SITUATIONS HAVE <u>NOT</u> HAPPENED TO YOU, ANSWER Zero (O)

10. In the past 12 months, how many times **<u>did you go to the emergency room</u>** because of your wheezing, coughing, chest tightness or chest heaviness or trouble breathing? _____ number of times

11. In the past 12 months, how many times **<u>did you go to the doctor</u>** because symptoms like wheezing, coughing, chest tightness or chest heaviness or trouble breathing were getting worse? _____ number of times

12. In the past 12 months, how many times **did you have to <u>stay in the hospital overnight</u>** because of wheezing, coughing, chest tightness or chest heaviness or trouble breathing? _____ number of times

13. In the past 12 months, about how many times did you **<u>refill your prescription</u> for a puffer or inhaler with medicine** you use to treat wheeze, cough, chest tightness or trouble breathing? (These puffers may also be called a rescue or quick relief medication, like Albuterol or Ventolin.) _____ number of times

NOW THINKING ABOUT YOUR LAST SCHOOL YEAR OR IN OTHER WORDS, THE 2002-2003 SCHOOL YEAR. PLEASE TELL US.....

14. <u>During the last school year</u>, how many days did you miss school **for any reason?** _____ number of times

15. <u>During the last school year</u>, how many days of school did you miss **due to wheezing, coughing, chest tightness/heaviness?** _____ number of times

NOW THINKING ABOUT THE LAST MONTH OR THE LAST 30 DAYS....

16. **In the last 30 days, <u>how many days</u>** did you have wheezing, coughing, chest tightness or chest heaviness? _____ number of times

17. **In the past 30 days**, how many days did you have to **<u>slow down or stop your activities</u>** because of wheezing, coughing, chest tightness or chest heaviness? _____ number of times

18. **In the past 30 days,** how many nights did you **<u>wake up</u>** because of wheezing, coughing, chest tightness or heaviness? _____ number of times

19.	**In the past 30 days**, how many days did you have to **change your plans** because of wheezing, coughing, chest tightness or heaviness?	_____ number of times
20.	**In the past 30 days,** how many days did you have to **take medicine** because of wheezing, coughing, chest tightness or heaviness?	_____ number of times
21.	**In the past 30 days,** how many days did you **miss school for any reason**?	_____ number of times
22.	**In the past 30 days,** how many days of school did you **miss due to wheezing, coughing, chest tightness/heaviness?**	_____ number of times
23.	Do you currently have a job?	_____ number of times
24.	**In the past 30 days, how many days of work** did you miss due to wheezing, coughing, chest tightness/heaviness? [IF YOU DO NOT WORK, PUT 0]	_____ number of times
25.	Has a doctor or other health care provider ever told you that you have asthma?	[1] Yes [2] No

NOW WE WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT SMOKING....THIS INFORMATION WILL BE KEPT PRIVATE AND WILL NOT BE SHARED WITH OTHERS.

26.	Have you ever tried smoking cigarettes, even 1 or 2 puffs?	[1] Yes [2] No
27.	On the days that you smoked in the last 30 days, did you smoke more than 2 cigarettes on those days?	[1] Yes [2] No
28.	How many cigarettes have you smoked in the last 30 days? [IF NONE, PUT 0]	____Number of cigarettes
29.	How many cigarettes have you smoked in the last 7 days? [IF NONE, PUT 0]	____Number of cigarettes
30.	How many cigarettes have you smoked in the last 24 hours? [IF NONE,PUT 0]	____Number of cigarettes
31.	How many cigarettes per day do you USUALLY smoke? [IF NONE, PUT 0]	____Number of cigarettes
32.	How old were you when you first started smoking? [CHECK BOX IF NEVER SMOKED]	____years [ ] check here if never smoked
33.	Do you think that you may try smoking within the next 6 months?	[1] Yes [2] No [3] I=m a current smoker
34.	How many people that live with you smoke inside your home? [IF NONE, PUT 0]	____Number of persons

35. Which of the following people that live with you smoke? (Circle all that apply)

[1] mother (step or foster mother)
[2] father (step or foster father)
[3] other adults (18 yr or older)
[4] other non-adults (less than 18)
[5] no one living with me smokes

HERE ARE MORE QUESTIONS ABOUT SMOKING. PLEASE ANSWER AS HONESTLY AS YOU CAN. YOUR ANSWERS WILL BE KEPT PRIVATE. IF YOU ARE NOT A SMOKER, CIRCLE THE LAST BOX (I AM NOT A SMOKER) FOR EACH QUESTION.

36. How soon after you wake up do you smoke your first cigarette?

[1] Within 5 minutes
[2] 6-30 minutes
[3] 31-60 minutes
[4] After 60 minutes
[5] I am not a smoker

37. Do you find it difficult not to smoke in places where smoking is forbidden (like church, at the library, in the movies, etc?)

[1] Yes
[2] No
[3] I am not a smoker

38. Which cigarette of the day would you hate most to give up? (For example, the first one in the morning? The one after dinner?, etc.)

[1] The first one of the morning
[2] All others
[3] I am not a smoker

39. Do you smoke more often during the first hours after waking than during the rest of the day?

[1] Yes
[2] No
[3] I am not a smoker

40. Do you smoke if you are so ill that you have to stay in bed most of the day?

[1] Yes
[2] No
[3] I am not a smoker

AND NOW, A LITTLE INFORMATION ABOUT YOU.....

41. How tall are you?

_____ feet
_____ inches

42. How much do you weigh?

_____ pounds

Puff City Baseline

Section: Introduction

Intro Text (T1)

You have been invited to participate in this program because you are having asthma symptoms including wheeze, cough, chest tightness, or shortness of breath. You may never have been TOLD that you have asthma, but if you are having these symptoms, you may have asthma. And that is why we would like for you to participate in this program.

When we ask you questions about "asthma" or "breathing problems," we are talking about when you wheeze, cough, have chest tightness, or feel short of breath.

Before you start, we need to find out what you are doing for your asthma or breathing problems now. Asthma or breathing problems are handled differently by each person. In the end, answers to these questions will help us to see if the program was helpful to you.

Some of the questions may not fit your situation, but please answer them the best you can.

There are no right or wrong answers; it's whatever you think or actually do.

Your answers will be kept private. We will not share your answers with your parents, teachers or anyone outside of the project.

If you have any questions or need computer assistance in completing this survey, please see the orientation assistant (person wearing a blue button).

Section: Initial

Initial Assessment (T2)

First, please answer some general questions...

1. How old were you when you first started having asthma symptoms including wheeze, cough, chest tightness, or shortness of breath? (If you've had symptoms since you were born, put "0").*AgeSymptomStart*

- number

VALIDIF: isEmpty(AgeSymptomStart) or answerWithinRange(AgeSymptomStart, 0, 20)

2. Has a doctor or health care provider told you that you have asthma?*DoctorDiagnosis*

- Yes
- No
- Don't Know [DontKnow]

SKIPIF: isEmpty(DoctorDiagnosis) or DoctorDiagnosis == 'No' or 'DontKnow'

3. How old were you when a doctor or health care provider said that you have asthma? (If your answer is when you were born, put "0").*AgeParentTold*

- number

VALIDIF: isEmpty(AgeParentTold) or answerWithinRange(AgeParentTold, 0, 20)

Section: Effects of asthma
past 30 days (Past30Days)

Symptoms of asthma include wheeze, cough, chest tightness, or shortness of breath. We'd like to know how these symptoms have affected you. The next few questions are about your health during the past 30 days, that is, since {date30DaysAgo()}.

4. During the past 30 days, how many days did you have asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*Past30DaysDaysWheezing*

- number

VALIDIF: isValidPast30DaysAnswer(Past30DaysDaysWheezing)

5. During the past 30 days, how many days did you have to slow down or stop your activities because of asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*Past30DaysDaysAffectedActivities*

- number

VALIDIF: isValidPast30DaysAnswer(Past30DaysDaysAffectedActivities)

6. During the past 30 days, how many nights did you wake up because of asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*Past30DaysNightsAwoken*

- number

VALIDIF: isValidPast30DaysAnswer(Past30DaysNightsAwoken)

7. During the past 30 days, how many times did you change your daytime or evening plans because of asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*Past30DaysTimesChangedPlans*

- number

VALIDIF: isValidPast30DaysAnswer(Past30DaysTimesChangedPlans)

8. During the past 30 days, how many days did you take any medicine for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*Past30DaysDaysMedicine*

- number

VALIDIF: isValidPast30DaysAnswer(Past30DaysDaysMedicine)

9. Do you use your inhaler or puffer (like albuterol or ventolin) more than two times a week?*PufferTwoTimes*

- Yes
- No

CurrentJobQuery

10. Do you currently have a job?*CurrentJob*

- Yes
- No

AsthmaEffects

SKIPIF: isEmpty(CurrentJob) or CurrentJob == 'No'

11. During the past 30 days, how many times did you miss work because of asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*Past30DaysMissedWork*

- number

VALIDIF: isValidPast30DaysAnswer(Past30DaysMissedWork)

12. During the past 30 days, how many days did you miss school for ANY reason?*Past30DaysMissedSchool*

- number

VALIDIF: isEmpty(Past30DaysMissedSchool) or answerWithinRange(Past30DaysMissedSchool, 0, 30)

13. During the past 30 days, how many days did you miss school because of asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*Past30DaysMissedSchoolAsthma*

- number

VALIDIF: isEmpty(Past30DaysMissedSchoolAsthma) or answerWithinRange(Past30DaysMissedSchoolAsthma, 0, 30)

14. Is there a particular season or month when your symptoms like wheeze, cough, chest tightness, or shortness of breath are worse?*ParticularSeasonWorse*

- Yes
- No
- Don't Know [DK]

WorseSeasons*SKIPIF: isEmpty(ParticularSeasonWorse) or ParticularSeasonWorse in ['No', 'DK']*

15. Thinking about asthma symptoms like wheeze, cough, chest tightness, or shortness of breath, during what season or month are your symptoms worse? (Choose all that apply.)*WorseSeasons*

- Fall (Sep, Oct, Nov) [Fall]
- Winter (Dec, Jan, Feb) [Winter]
- Spring (Mar, Apr, May) [Spring]
- Summer (Jun, Jul, Aug) [Summer]

WorseSeasonsDetails*SKIPIF: isEmpty(WorseSeasons)*
LOOP: for aSeason in WorseSeasons

16. Thinking of a typical month (30 days) during {aSeason}, how many days would you have asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*NumDaysSymptoms{aSeason}*

- number

VALIDIF: isEmpty(NumDaysSymptoms{aSeason}) or answerWithinRange(NumDaysSymptoms{aSeason}, 0, 31)

last 12 months (Last12Months)

17. Asthma attacks, sometimes called episodes, are periods of worsening asthma symptoms like wheeze, cough, chest tightness, or shortness of breath.

These next few questions are about asthma episodes during the past 12 months. Try your best to remember.

18. During the past 12 months, how many asthma attacks or attacks of asthma symptoms like wheeze, cough, chest tightness, or shortness of breath have you had?*Last12MonthsNumEpisodes*

- number

VALIDIF: isEmpty(Last12MonthsNumEpisodes) or answerWithinRange(Last12MonthsNumEpisodes, 0, 365)SKIPIF: isEmpty(Last12MonthsNumEpisodes) or Last12MonthsNumEpisodes < 1

19. During the past THREE (3) months, how many asthma attacks or attacks of asthma symptoms like wheeze, cough, chest tightness, or shortness of breath have you had?*Last3MonthsNumEpisodes*

- number

VALIDIF: isEmpty(Last3MonthsNumEpisodes) or answerWithinRange(Last3MonthsNumEpisodes, 0, 93)
HadEpisodes*SKIPIF: isEmpty(Last12MonthsNumEpisodes) or Last12MonthsNumEpisodes < 1*

20. During the past 12 months, how many times did you have to stay overnight in the hospital for worsening asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*NumHospitalOvernights*

- number

VALIDIF: isEmpty(NumHospitalOvernights) or answerWithinRange(NumHospitalOvernights, 0, 365)
HospitalStays*SKIPIF: isEmpty(NumHospitalOvernights) or NumHospitalOvernights < 1*
LOOP: for OvernightNum in HospitalOvernights

--- The next few questions are about your *{visitRecency(OvernightNum)}* overnight stay in the hospital.

21. What was the date of your {visitRecency(OvernightNum)} hospital overnight stay? It's okay to estimate. Do the best you can.*HospitalOvernightDate{OvernightNum}*

- (response group)

22. How many nights did you stay in the hospital?*HospitalOvernightNumNights{OvernightNum}*

- number

23. Were you in the Intensive Care Unit (also known as the ICU)?*HospitalOvernightICU{OvernightNum}*

- Yes
- No
- Don't know [DK]

24. Within two weeks after this hospital stay, did you see your regular doctor for a followup appointment?*HospitalOvernightDidScheduleFollowup{OvernightNum}*

- Yes
- No
- Don't know [DK]

ICUVisits*USEIF: NumHospitalOvernights < 1 or NumICUVisits < 1*

25. Have you ever been in the Intensive Care Unit (also known as the ICU)?*EverInICU*

- Yes
- No
- Don't Know [DK]

ERVisitsQuery

26. During the past 12 months, how many times did you make a visit to the emergency room (ER) because of worsening asthma symptoms like wheeze, cough, chest tightness, or shortness of breath??*NumERVisits*

- number

VALIDIF: isEmpty(NumERVisits) or answerWithinRange(NumERVisits, 0, 365)
ERVisitDetails*SKIPIF: isEmpty(NumERVisits) or NumERVisits < 1*
LOOP: for ERVisitNum in ERVisitsList

--- The next few questions concern your *{visitRecency(ERVisitNum)}* emergency room visit ---

27. What was the date of your {visitRecency(ERVisitNum)} visit? It's okay to estimate. Do the best you can.*ERDate{ERVisitNum}*

- (response group)

28. Which of the following Emergency Rooms did you go to?*ERName{ERVisitNum}*

- Emergency room at Children's Hospital [CHM]
- Emergency room at Henry Ford Hospital [HFHS]
- Emergency room at St. John's Hospital [StJohns]
- Emergency room at Detroit Riverview Hospital [DetRiverview]
- Emergency room at Sinai Grace Hospital [SinaiGrace]
- Emergency room at Detroit Receiving Hospital [DetReceiving]
- Some other Emergency room [Other]
- Don't know [DK]

29. Were you admitted to the hospital to stay overnight?*ERAdmitted{ERVisitNum}*

- Yes
- No

30. Within two weeks after this visit to the emergency room, did you see your regular doctor for a followup appointment?*ERScheduledFollowup{ERVisitNum}*

- Yes
- No
- Don't know [DK]

DoctorVisits

31. Not including hospitalizations or emergency room visits, how many times during the past 12 months have you seen ANY doctor FOR ANY REASON?*Last12MonthsDoctorVisitsAnyReason*

- number

VALIDIF: isEmpty(Last12MonthsDoctorVisitsAnyReason) or answerWithinRange(Last12MonthsDoctorVisitsAnyReason, 0, 365)

32. Not including hospitalizations or emergency room visits, how many times during the past 12 months have you seen a doctor for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*Last12MonthsDoctorVisitsAsthma*

- number

DoctorDetails*SKIPIF: isEmpty(Last12MonthsDoctorVisitsAsthma) or Last12MonthsDoctorVisitsAsthma*

33. Was this your regular family doctor or do you see this doctor ONLY for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*DoctorRegularOrAsthmaOnly*

- I see this doctor ONLY for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath. [AsthmaOnly]
- I see this doctor for EVERYTHING including asthma symptoms like wheeze, cough, chest tightness, or shortness of breath. [OtherReasons]
- Don't know [DK]

SpecialistQuery*SKIPIF: isEmpty(Last12MonthsDoctorVisitsAsthma) or Last12MonthsDoctorVisitsAsthma*

During the past 12 months, have you seen any of the following specialists for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?

	Yes	No	Don't Know [DK]
34. An allergist? *Last12MonthsAllergist*	.	.	.
35. A pulmonologist? *Last12MonthsPulmonologist*	.	.	.
36. A lung or breathing specialist? *Last12MonthsLungSpecialist*	.	.	.
37. Some other specialist for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath? *Last12MonthsOtherSpecialist*	.	.	.

38. When was the last time you saw this doctor?*LastTimeSawDoctorMonth*

- fillin

LastTimeSawDoctorYear

- fillin

Section: Equipment
Equipment (Equipment)

These next few questions are about the instructions you have received about managing your asthma or breathing problems.

37. How easy is it for you to follow the doctor's instructions about using your prescribed medicine for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*HowEasyToFollowDoctorInstructions*

- 1- Very easy [1]
- 2
- 3- Fairly easy [3]
- 4
- 5- Not easy at all [5]

- I do NOT take prescribed medicine for wheeze, cough, chest tightness, or shortness of breath. [DontTake]

SKIPIF: isEmpty(HowEasyToFollowDoctorInstructions) or HowEasyToFollowDoctorInstructions == 'DontTake'

38. Do you usually follow your doctor's instructions for taking your prescribed medicine for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*UsuallyFollowInstructions*

- Yes
- No

39. Do you use a spacer device with your puffer or inhaler? (A spacer is a separate device that catches the mist from the puffer or inhaler.)*UseSpacer*

- Yes
- No
- Don't Know [DK]
- I do NOT have a puffer or inhaler. [DontTake]

SpacerInfo

USEIF: UseSpacer == 'Yes'

40. What type of spacer do you have?*TypeSpacer*

- Type A [TypeA]
- Type B [TypeB]
- I have both types [Both]
- Don't Know [DK]

USEIF: UseSpacer == 'Yes'

41. When was the last time you used the spacer?*LastUsedSpacer*

- Within the past 2 weeks [Within2Weeks]
- Within the past 2 months [Within2Months]
- Within the past 12 months [Within12Months]
- More than 12 months ago [MoreThan12Months]
- Don't Know [DK]

42. Do you have a peak flow meter? (This is a device that shows how hard you can blow air out of your lungs.)*HasPeakFlowMeter*

- Yes
- No
- Don't Know [DK]

PeakFlowMeterInfo

USEIF: HasPeakFlowMeter == 'Yes'

43.When was the last time you used the peak flow meter?*LastUsedPeakFlowMeter*

- Within the past 2 weeks [Within past 2 weeks]
- Within the past 2 months [Within past 2 months]
- Within the past 12 months [Within past 12 months]
- More than 12 months ago
- Don't Know [DK]

Some people carry their puffers or inhalers around with them, and some don't. Please tell us...

44. How often do you take your puffer or inhaler with you wherever you go?*InhalerWherever*

- I carry it or have it with me everyday. [EveryDay]
- I carry it or have it with me most days. [MostDays]
- I carry it or have it with me only on some days. [SomeDays]
- I usually don't carry it or have it with me. [UsuallyNoCarry]
- I never carry it or have it with me. [NeverCarry]
- I don't have a puffer or inhaler for asthma or breathing problems. [DontHave]

Thinking about the past seven days...

45. How many days was your asthma inhaler or puffer near enough for you to be able to get to it quickly in an emergency?*Last7DaysHowManyDaysInhalerNear*

- number

VALIDIF: isEmpty(Last7DaysHowManyDaysInhalerNear) or answerWithinRange(Last7DaysHowManyDaysInhalerNear, 0, 7)

Section: Knowledge
Knowledge (Knowledge)

46. Do your teachers or any other school staff know that you have asthma or asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*KnowTeachers*

- Yes
- No
- Don't Know [DK]
- I have never been told that I have asthma. [NeverTold]

47. Has a doctor outlined an asthma care plan for you that advises you on what to do in case you have asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*KnowAsthmaCarePlan*

- Yes
- No

48. Has a doctor outlined an asthma care plan for you that advises you on what to do in case you are exposed to things that could cause you to have an attack of asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*KnowExposedCarePlan*

- Yes
- No

49. Do you ever worry that you may not able to get to the doctor or hospital in time to get the care you need for an attack of asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*KnowWorry*

- Yes
- No
- Don't Know [DK]

50. Do you feel that asthma symptoms like wheeze, cough, chest tightness, or shortness of breath can be life threatening if nothing is done to treat it?*KnowLifeThreatening*

- Yes
- No
- Don't Know [DK]

51. Do you have any special method to check for early signs of an oncoming attack of asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*KnowEarlySigns*

- Yes
- No
- Don't Know [DK]

SKIPIF: isEmpty(HowEasyToFollowDoctorInstructions) or HowEasyToFollowDoctorInstructions == 'DontTake'

52. Do you have any special procedure for observing changes in your symptoms after you take prescribed medication for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*KnowObserveSymptomChanges*

- Yes
- No
- Don't Know [DK]

SKIPIF: isEmpty(HowEasyToFollowDoctorInstructions) or HowEasyToFollowDoctorInstructions == 'DontTake'

53. Do you have a systematic plan to adjust your medicine if asthma symptoms like wheeze, cough, chest tightness, or shortness of breath get better or worse?*KnowAdjustMedicinePlan*

- Yes
- No
- Don't Know [DK]

54. How much do you feel that your symptoms like wheeze, cough, chest tightness, or shortness of breath restrict daily activities or prevent you from being able to do the things you would like to do?*KnowRestrictDailyActivities*

- 1- Very much [1]
- 2
- 3
- 4
- 5- Not at all [5]

55. How serious can your asthma or breathing problem be?*KnowSerious*

- 1- Very serious [1]
- 2
- 3
- 4
- 5- Not serious at all [5]

56. How important is it for you to have regularly scheduled appointments with the doctor for your asthma or breathing problem?*KnowRegularAppointments*

- 1- Very important [1]
- 2
- 3
- 4
- 5- Not important at all [5]
- I have never seen a doctor for asthma or breathing problems. [NeverSeen]

SKIPIF: isEmpty(HowEasyToFollowDoctorInstructions) or HowEasyToFollowDoctorInstructions == 'DontTake'

57. How important is it to take all the medications at the exact dosage that the doctor has prescribed?*KnowExactDosage*

- 1- Very important [1]
- 2
- 3
- 4
- 5- Not important at all [5]

58. If the asthma medicine that the doctor prescribes does not seem to help your asthma symptoms like wheeze, cough, chest tightness, or shortness of breath, how important is it to continue taking it?*KnowContinueMedicine*

- 1- Very important [1]
- 2
- 3
- 4
- 5- Not at all [5]
- I have never taken medications for asthma or breathing problems. [NeverTaken]

59. Do you know who to contact if you are having problems with your asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*KnowWhoContact*

- Yes
- No

SKIPIF: isEmpty(HowEasyToFollowDoctorInstructions) or HowEasyToFollowDoctorInstructions == 'DontTake'

60. Who is responsible for making sure you take your medication for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath the way your doctor recommended?*PersonResponsible*

- My parents or guardian(s) make sure I take my medication the way the doctor recommended. [Parents]
- Some other adult besides my parent or guardian(s) makes sure I take my medication the way the doctor recommended. [OtherAdult]
- I, alone, am responsible for taking my medication the way the doctor recommended. [Self]
- Both me and my parents/guardians make sure I take my medication the way the doctor recommended. [ParentsSelf]

61. Who helps you decide when medical care is needed for your asthma symptoms like wheeze, cough, chest tightness, or shortness of breath? [check all that apply]*PersonDecides*

- Myself
- Parent/guardian [Parent]
- Another adult (not that is not a parent/guardian). [Other Adult]
- I do not get medical care for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath. [DontGet]

Section: Doc and depression
Doc attention (DocAttention)

Here are some more questions about your doctor.
SKIPIF: isEmpty(PersonDecides) or PersonDecides == 'DontGet'

62. Some people hardly ever see the SAME doctor when they get medical care for their asthma symptoms like wheeze, cough, chest tightness, or shortness of breath. Is this true for you?*DocRarelySame*

- Yes
- No

SKIPIF: isEmpty(PersonDecides) or PersonDecides == 'DontGet'

63. For some people, the breathing problems they have had in the past are IGNORED when they see a new doctor for asthma or breathing problems. Is this true for you?*DocHistoryIgnored*

- Yes
- No

Depression

64. Sometimes how we feel can affect our asthma or breathing problem. These next questions are about how you have been feeling lately.

During the past 6 months, were there times when you were very sad?*Dep6MonthsVerySad*

- Yes
- Sometimes
- No

65. During the past 6 months, has there been a time when you just weren't interested in anything and felt bored or just sat around most of the time?*Dep6MonthsBored*

- Yes
- Sometimes
- No

66. During the past 6 months, have you had times when you felt that life was hopeless and that there was nothing good for you in the future?*Dep6MonthsHopeless*

- Yes
- Sometimes
- No
-

67. During the past 6 months, were there times when you were grouchy or irritable, often in a bad mood, so that even little things would make you mad?*Dep6MonthsGrouchy*

- Yes
- Sometimes
- No

68. During the past 6 months, has there been a time when nothing was fun for you, even things you used to like?*Dep6MonthsNothingFun*

- Yes
- Sometimes
- No

69. During the past 6 months, have you lost a lot of weight?*Dep6MonthsWeightLoss*

- Yes
- Sometimes
- No

70. During the past 6 months, have you been so down that it was hard for you to do your schoolwork?*Dep6MonthsSchoolworkHard*

- Yes
- Sometimes
- No

Please tell us if you agree or disagree with the following statements:

71. When under stress, I tend to pray, meditate, or work on my spiritual life.*DepReligion*

- Strongly disagree [StronglyDisagree]
- Disagree
- Neutral
- Agree
- Strongly agree [StronglyAgree]

72. Compared with others my age, I take risks.*RebelRisks*

- Strongly disagree [StronglyDisagree]
- Disagree
- Neutral
- Agree
- strongly agree [StronglyAgree]

73. I like to do things that bother my teachers.*RebelBother*

- Strongly disagree [StronglyDisagree]
- Disagree
- Neutral
- Agree
- Strongly agree [StronglyAgree]

74. I enjoy doing things that people say I should not do.*RebelShouldnt*

- Strongly disagree [StronglyDisagree]
- Disagree
- Neutral
- Agree
- Strongly agree [StronglyAgree]

75. It is worth getting into trouble if I have fun.*RebelFun*

- Strongly disagree [StronglyDisagree]
- Disagree
- Neutral
- Agree
- Strongly agree [StronglyAgree]

social support (SocialSupport)

The following questions ask about friends, family and significant others in your environment that may provide you with emotional support.

Emotional support is your perception of feeling loved, valued, and special to others.

Respond to the following questions by thinking about how caring you feel others are as you experience the challenges of living with asthma.

	Strongly disagree [StronglyDisagree]	**Disagree**	**Neutral**	**Agree**	**Strongly agree [StronglyAgree]**
76. There is a special person who is around when I am in need. *SocSpecialPersonAround*	.	.	.	.	.
77. There is a special person with whom I can share my joys and sorrows. *SocSpecialPersonJoysSorrows*	.	.	.	.	.
78. I have a special person who is a real source of comfort to me. *SocSpecialPersonComfort*	.	.	.	.	.
79. There is a special person in my life who cares about my feelings. *SocSpecialPersonFeelings*	.	.	.	.	.

80. The special person in my life I thought of when answering the previous questions was a:*SocSpecialPerson*

- Relative
- Friend
- Teacher
- Coach
- Minister/Priest [Clergy]
- Other

social support (FamilySupport)

Now thinking about your family...

	Strongly disagree [StronglyDisagree]	**Disagree**	**Neutral**	**Agree**	**Strongly agree [StronglyAgree]**
81. I get the love and affection I need from my family. *SocFamilyLoveAffection*	.	.	.	.	.
82. When I need support my family really tries to help me. *SocFamilySupport*	.	.	.	.	.
83. I can talk about my problems with my family. *SocFamilyCanTalk*	.	.	.	.	.
84. My family is willing to help me make decisions. *SocFamilyDecisions*	.	.	.	.	.

85. The family member I thought of most when answering the previous questions was my:*SocMainFamilyMember*

- Mother
- Grandmother [GMa]
- Step Mother [StepMa]
- Foster Mother [FosterMa]
- Aunt
- Father
- Grandfather [GPa]
- Step Father [StepPa]
- Foster Father [FosterPa]
- Uncle
- Sister
- Step Sister [StepSis]
- Half Sister [HalfSis]
- Foster Sister [FosterSis]
- Brother
- Step Brother [StepBro]
- Half Brother [HalfBro]
- Foster Brother [FosterBro]

social support (FriendSupport)

Now thinking about your friends...

	Strongly disagree [StronglyDisagree]	**Disagree**	**Neutral**	**Agree**	**Strongly agree [StronglyAgree]**
86. When I need support my friends really try to help me. *SocFriendsSupport*	.	.	.	.	.
87. I can count on my friends when things go wrong. *SocFriendsWhenWrong*	.	.	.	.	.
88. I have friends with whom I can share my joys and sorrows. *SocFriendsJoysSorrows*	.	.	.	.	.
89. I can talk about my problems with my friends. *SocFriendsCanTalk*	.	.	.	.	.

90. The friends that provide me with the most support are:*SocFriendsGender*

- Male
- Female

91. I receive the most support from friends that are:*SocFriendsAge*

- Around my age [MyAge]
- A lot older than me [Older]
- A lot younger than me [Younger]

SocialSupportParents

92. Not including yourself, how many persons live with you now?*NumberHousehold*

- 1 to 3 people [OneThree]
- 4 to 6 people [FourSix]
- More than 6 people [MoreSix]
- I live in a youth home, youth facility, or shelter. [YouthHome]

VALIDIF: isEmpty(NumberHousehold)SKIPIF: isEmpty(NumberHousehold) or NumberHousehold == 'YouthHome'

93. Not including yourself, how many persons in your household less than 18 years of age have a diagnosis of asthma?*NumberUnderEighteen*

- number

VALIDIF: isEmpty(NumberUnderEighteen) or answerWithinRange(NumberUnderEighteen, 0, 100)SKIPIF: isEmpty(NumberHousehold) or NumberHousehold == 'YouthHome'

94. Not including yourself, how many persons in your household 18 years or older have a diagnosis of asthma?*NumberOverEighteen*

- number

VALIDIF: isEmpty(NumberOverEighteen) or answerWithinRange(NumberOverEighteen, 0, 100)

Families work differently. Please tell us how your family does things...

	Never	Rarely	Sometimes	Most of the Time [MostOfTheTime]	Always
95. My parent(s) know where I am after school. *SocParentsKnowWhereAfterSchool*	.	.	.	.	.
96. If I am going to be home late, I am expected to call my parent(s) to let them know. *SocParentsExpectCall*	.	.	.	.	.
97. I tell my parent(s) who I'm going to be with before I go out. *SocParentsWhoGoOut*	.	.	.	.	.
98. When I go out at night, my parents know where I am. *SocParentsKnowWhereGoOut*	.	.	.	.	.
99. I talk with my parent(s) about the plans I have with my friends. *SocParentsPlans*	.	.	.	.	.
100. When I go out, my parent(s) ask me where I'm going. *SocParentsAskWhereGoOut*	.	.	.	.	.

Section: Smoking
current smoking (CurrentSmoking)

These next few questions are about smoking. This information will be kept private and will NOT be shared with parents or teachers. We are very serious about keeping your information private.

101. Which of the following best describes your current smoking?*CurrentSmoking*

- I have never smoked [Never]
- I have tried smoking a few times [FewTimes]
- I used to smoke regularly but I quit [Former]
- I am a smoker [Smoker]

SmokingDetails*SKIPIF: CurrentSmoking == 'Never'*

102. Have you smoked on one or more of the past 30 days?*HaveSmoked30Days*

- Yes
- No

SKIPIF: HaveSmoked30Days == 'No'

103. Did you smoke MORE THAN TWO cigarettes on any day during the past 30 days?*TwoSmoked30Days*

- Yes
- No

SKIPIF: HaveSmoked30Days == 'No'

104. How many cigarettes have you smoked during the past 30 days? [Estimate if you don't know exactly how many].*NumCigs30Days*

- number

VALIDIF: isEmpty(NumCigs30Days) or answerWithinRange(NumCigs30Days, 0, 1200)SKIPIF: HaveSmoked30Days == 'No'

105. How many cigarettes have you smoked during the past 7 days? [Estimate if you don't know exactly how many].*NumCigs7Days*

- number

VALIDIF: isEmpty(NumCigs7Days) or answerWithinRange(NumCigs7Days, 0, 280)SKIPIF: HaveSmoked30Days == 'No'

106. How many cigarettes have you smoked during the past 24 hours? [Estimate if you don't know exactly how many].*NumCigs24Hours*

- number

VALIDIF: isEmpty(NumCigs24Hours) or answerWithinRange(NumCigs24Hours, 0, 60)

107. How old were you when you first started smoking cigarettes?*AgeStartSmoking*

- number

VALIDIF: isEmpty(AgeStartSmoking) or answerWithinRange(AgeStartSmoking, 5, 25)

108. During the past 30 days, how many days did you smoke marijuana (weed) or blunts?*Marijuana30Days*

- number

VALIDIF: isEmpty(Marijuana30Days) or answerWithinRange(Marijuana30Days, 0, 30)

109. During the past 30 days, how many days did you smoke cigars, cigarillos, or little cigars?*Cigars30Days*

- number

VALIDIF: isEmpty(Cigars30Days) or answerWithinRange(Cigars30Days, 0, 30)

household smokers (HouseholdSmokers)

110. Thinking of the persons that LIVE WITH YOU, which of the following persons smoke? (Check all that apply).*HouseholdSmokers*

- Mother (including Foster or Stepmother) [Mother]
- Father (including Foster or Stepfather) [Father]
- Other adults (18 yrs or older) [OtherAdults]
- Other non-adults (less than 17 years) [OtherNonAdults]
- No one in my household smokes [NoOne]

111. Do you spend one or more nights per week in a household where someone smokes?*SleepSmoker*

- Yes
- No

SKIPIF: SleepSmoker == 'No'

112. Thinking of the past 30 days, that is since {date30DaysAgo()}, how many nights did you sleep in the home of someone that smokes?*SleepSmoker30Days*

- number

VALIDIF: isEmpty(SleepSmoker30Days) or answerWithinRange(SleepSmoker30Days, 0, 30)

113. Sometimes pets or pests found in the home can be related to breathing problems. Do you have any of the following where you are living now? (Check all that apply).*PestsHome*

- Cockroaches [Roach]
- Mice or rats [Mice]
- Dog
- Cat
- Other furry pets like a hamster, gerbil, or guinea pig [FurryPets]
- Bird

114. Are you allergic to animals, molds, or pollen?*Allergic*

- Yes
- No
- Don't know [DK]

Section: PAQLQ
Activities (Activities)

Because you have asthma, you may have found some of the things you like doing difficult or not much fun.

Some people are bothered by asthma when doing some of the following activities.

115. Please check the box next to the THREE (3) things that have been bothered most by your asthma during the past week. These things must be activities that you do regularly.*QALActivities*

- Ball Hockey [BallHockey]
- Baseball
- Basketball
- Dancing (Ballet / Jazz) [Dancing]
- Football
- Playing at recess [PlayRecess]
- Playing with pets [PlayPets]
- Playing with friends [PlayFriends]
- Riding a bicycle [Bike]
- Running
- Jumping rope [JumpRope]
- Shopping
- Sleeping
- Soccer
- Swimming
- Volleyball
- Walking
- Walking uphill [WalkHill]
- Walking upstairs [WalkStairs]
- Laughing
- Studying
- Doing household chores [Chores]
- Singing
- Doing crafts or hobbies [Hobbies]
- Shouting
- Gymnastics
- Rollerblading / roller-skating [Roller]
- Skateboarding
- Track and field [Track]
- Tobogganing
- Skiing
- Ice skating [IceSkating]
- Climbing
- Getting up in the morning [GettingUpInMorning]
- Talking

ActivitiesReduce*USEIF: listCount(QALActivities) > 3SKIPIF: isEmpty(QALActivities)*

Please choose only three activities.*QALActivitiesReduced*

- (response group)

INVALIDIF: isEmpty(QALActivitiesReduced) or listCount(QALActivitiesReduced) > 3
ActivityDetailInfo*SKIPIF: isEmpty(QALActivities)*
LOOP: for AnActivity in QALActivities

Please tell us how much you have been bothered by doing these things during the past week because of your asthma symptoms like wheeze, cough, chest tightness, or shortness of breath.

	1- Extremely Bothered [1]	**2**	**3**	**4- Somewhat Bothered [4]**	**5**	**6**	**7- Not Bothered [7]**
{activityDesc(AnActivity)} *QALActivityBother{qalNumForAct(AnActivity)}{AnActivity}*	.	.	.	.	.	.	.

QALDetails

In general, how often during the past week did you:

	1- All of the time [1]	**2**	**3**	**4- Some of the time [4]**	**5**	**6**	**7- None of the time [7]**
116. Feel frustrated because of your asthma? *QALFrustrated*	.	.	.	.	.	.	.
117. Feel tired because of your asthma? *QALTired*	.	.	.	.	.	.	.
118. Feel worried, concerned or troubled because of your asthma? *QALWorried*	.	.	.	.	.	.	.

How bothered have you been during the past week by:

	1- Extremely Bothered [1]	**2**	**3**	**4- Somewhat Bothered [4]**	**5**	**6**	**7- Not Bothered [7]**
119. Asthma Attacks *QALAsthmaAttacks*	.	.	.	.	.	.	.

In general, how often during the past week did you:

	1- All of the time [1]	2	3	4- Some of the time [4]	5	6	7- None of the time [7]
120. Feel angry because of your asthma? *QALFeelAngry*	.	.	.	.	.	.	.

How bothered have you been during the past week by:

	1- Extremely Bothered [1]	2	3	4- Somewhat Bothered [4]	5	6	7- Not Bothered [7]
121. Wheezing *QALWheezing*	.	.	.	.	.	.	.

In general, how often during the past week did you:

	1- All of the time [1]	2	3	4- Some of the time [4]	5	6	7- None of the time [7]
122. Feel irritable (cranky/grouchy) because of your asthma? *QALIrritable*	.	.	.	.	.	.	.

How bothered have you been during the past week by:

	1- Extremely Bothered [1]	2	3	4- Somewhat Bothered [4]	5	6	7- Not Bothered [7]
123. Tightness in your chest *QALChestTightness*	.	.	.	.	.	.	.

In general, how often during the past week did you:

	1- All of the time [1]	2	3	4- Some of the time [4]	5	6	7- None of the time [7]
124. Feel different or left out because of your asthma? *QALFeelDifferent*	.	.	.	.	.	.	.

How bothered have you been during the past week by:

	1- Extremely Bothered [1]	2	3	4- Somewhat Bothered [4]	5	6	7- Not Bothered [7]
125. Shortness of breath *QALShortnessOfBreath*	.	.	.	.	.	.	.

In general, how often during the past week did you:

	1- All of the time [1]	2	3	4- Some of the time [4]	5	6	7- None of the time [7]
126. Feel frustrated because you couldn't keep up with others? *QALFrustratedCouldntKeepUp*	.	.	.	.	.	.	.
127. Wake up during the night because of your asthma? *QALWokeUp*	.	.	.	.	.	.	.
128. Feel uncomfortable because of your asthma? *QALUncomfortable*	.	.	.	.	.	.	.
129. Feel out of breath because of your asthma? *QALOutOfBreath*	.	.	.	.	.	.	.
130. Feel you couldn't keep up with others because of your asthma? *QALCouldntKeepUp*	.	.	.	.	.	.	.
131. Have trouble sleeping at night because of your asthma? *QALTroubleSleeping*	.	.	.	.	.	.	.
132. Feel frightened by an asthma attack? *QALFrightened*	.	.	.	.	.	.	.

Think about all the activities that you did during the past week.

	1- Extremely Bothered [1]	2	3	4- Somewhat Bothered [4]	5	6	7- Not Bothered [7]
133. How much were you bothered by your asthma during these activities? *QALBotheredDuringActivities*	.	.	.	.	.	.	.

In general, how often during the past week did you:

	1- All of the time [1]	2	3	4- Some of the time [4]	5	6	7- None of the time [7]
134. Have difficulty taking a deep breath? *QALDifficultyDeepBreath*	.	.	.	.	.	.	.

Section: Demographics
Demographics (Demographics)

These next few questions will help us to describe the group of students taking part in this project.

135. What is your age?*Age*

- number

VALIDIF: isEmpty(Age) or answerWithinRange(Age, 10, 25)

136. What is your birthdate? (Please tell us month, day, and year in this format: 00/00/00)*DateOfBirth*

- date

137. What is your race?*Race*

- Caucasian (or White), non-hispanic [Caucasian]
- African American (or Black), non-hispanic [Black]
- America Indian [Amerindian]
- Asian
- Pacific Islander [PacificIslander]
- Hispanic
- Other or Multi-racial [Other]
- Unknown

138. Are you male or female?*Gender*

- Male
- Female

139. What grade are you in now?*SchoolGrade*

- 9th [9]
- 10th [10]
- 11th [11]
- 12th [12]

140. There are many health conditions that are associated with our size. Please tell us...

How much do you weigh?*Weight*

- number

VALIDIF: isEmpty(Weight) or 50 <= float(Weight) <= 750

141. How tall are you?*HeightFeet*

- -- height in feet -- [0]
- 3 feet [3]
- 4 feet [4]
- 5 feet [5]
- 6 feet [6]
- 7 feet [7]

142. What is the highest grade of school that your mother has completed?*MotherEducation*

- Less than 8th grade [LessThan8th]
- Some high school [SomeHighSchool]
- High school graduate [HighSchoolGrad]
- Some college [SomeCollege]
- College graduate [CollegeGrad]
- Don't Know [DK]

143. What is the highest grade of school that your father has completed?*FatherEducation*

- Less than 8th grade [LessThan8th]
- Some high school [SomeHighSchool]
- High school graduate [HighSchoolGrad]
- Some college [SomeCollege]
- College graduate [CollegeGrad]
- Don't Know [DK]

144. What health insurance do you have?*HealthInsurance*

- Aetna
- Blue Care Network [BlueCareNetwork]
- Blue Cross / Blue Shield [BCBS]
- Botsford Health Plan [BotsfordHealthPlan]
- Cape
- Care Choices [CareChoices]
- Children's Choice [ChildrensChoice]
- Cigna
- DMC Care [DMCCare]
- Great Lakes Health Plan [GreatLakesHealthPlan]
- Health Alliance Plan (HAP) [HAP]
- Health Plan of Michigan [HealthPlanOfMichigan]
- Kids Care [KidsCare]
- M-Care [MCare]
- Midwest
- Molina
- Omnicare
- Prudential
- SelectCare
- Total Healthcare [TotalHealthcare]
- Travelers
- Ultimed
- Wellness
- Don't Know [DK]
- No insurance [None]

145. Is this through Medicaid?*HasMedicaid*

- Yes
- No
- Don't Know [DK]

146. Does this health insurance cover the cost of medications your doctor may prescribe for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath?*MedicationCoverage*

- Insurance covers ALL of the cost of medications I take for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath. [AllCost]
- Insurance covers MOST of the cost of medications I take for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath. [MostCost]
- Insurance covers SOME of the cost of medications I take for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath. [SomeCost]
- Insurance covers NONE of the cost of medications I take for asthma symptoms like wheeze, cough, chest tightness, or shortness of breath. [NoneCost]
- Don't know [DK]

147. During the past 12 months, was there a period of time when you were not covered by health insurance?*HealthInsuranceGapLast12Months*

- Yes
- No
- Don't Know [DK]

Section: Goodbye
Goodbye

THAT'S IT! That's the end of the questions!

We are glad you have decided to try Puff City.

You should return to the computer for your first Puff City asthma management session sometime between [date] and [date].

Here's a preview of what you can expect: (bouncing building intro and music).

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