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UNIVERSITY OF SAN DIEGO

Hahn School of Nursing and Health Science

DOCTOR OF PHILOSOPHY IN NURSING

WHAT ARE THEY SAYING: VOICES FROM THE INNER CITY?  
LIVED EXPERIENCE OF INNER CITY AFRICAN-AMERICAN  
ADOLESCENTS WITH ASTHMA

by

Othello Childress

A dissertation presented to the

FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH  
SCIENCE

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In partial fulfillment of the

requirements for the degree

DOCTOR OF PHILOSOPHY IN NURSING

November 2006

Dissertation Committee

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## ABSTRACT

The purpose of this study was to investigate the lived experience of African-American adolescents with asthma who reside in an inner city community. The research in this area of interest is sparse, yet the morbidity and mortality rates related to asthma within the African-American population are greater than the general population. This study offers the experience of living with asthma from the perspective of the young African-American adolescent. Using phenomenological methodology, the nurse researcher selected 13 African- American adolescents; aged 12 to 15, who reside and attend middle school in the inner city. All of the participants had a confirmed medical diagnosis of asthma with varying severity. All had health insurance and were examined by their healthcare provider on an ongoing basis. The purposive sample represented variations in the adolescents' family structure. The principles of hermeneutic phenomenology guided the analysis of the data collections in 30 to 45 minutes, audio-taped interviews with each adolescent.

The following themes emerged during the data analysis process: My Asthma, My Life; describing the adolescents' knowledge of the disorder and the self-developed strategies used to live a "normal" life with asthma. The second theme: My Asthma, My World gives the adolescent' accounts of their relationships with others including family members and peers and how they have come to develop their terms with asthma without personification of the

disorder. The two themes constitute the foundation for the core theme: My Asthma, My Way; the lived experience of the African-American adolescents with asthma who resides in an inner city community.

This research indicates that African-American adolescents with asthma who reside in the inner city are aware of the disorder and respond to their bodies' symptoms to quickly resolve and prevent the effects of asthma on their daily life. The implications for nursing education, future research, and nursing practice are discussed.

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The journey continues.

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## CHAPTER ONE

### Introduction

Asthma is the most common chronic disorder among children and adolescents in the United States (Center for Disease Control and Prevention [CDC&P]), 2004; L.A. Health, 2004; Walders, Drotar, & Kersmar, 2000). Ethnic minorities residing within inner city communities have experienced the most dramatic increases in asthma risk (Fisher, Sussman, Artken, Harrison, Munro, Sykes et al., 1994; U.S. Department Health and Human Services [USDHHS], 2000; Weiss, Gergen, & Wagner, 1993). The greatest prevalence is among African-Americans, especially children living in inner city communities demonstrating disproportionately higher rates of morbidity and mortality (Castro, Schechtman, Halstead, & Bloomberg, 2001; Corn, Hamrung, Ellis, Kalb, & Sperber, 1995; Joseph, Ownby, Peterson, & Johnson, 2000; L.A. Health, 2004).

Little research has been done to understand the perspective of inner city African-American children and adolescents with asthma within their own reality. Knowledge about this population is limited because most researchers have examined the parent/caregiver's perspective focusing on the biomedical aspects of the disorder. The child's and adolescent's perspectives are often misinterpreted or intertwined within the parent/caregiver's points of view not offering a coherent portrait of this population (Guyatt, Juniper, Griffith, Feeny, & Ferrie, 1997; Handelman, Rich, Bridgemohan, & Schneider, 2004; Peterson, Sterling, & Stout, 2002; Sterling & Peterson, 2003). Other researchers have dealt with isolated factors such as the health status of African-

American children in the general population, including health beliefs, barriers to healthcare, and healthcare interventions (Bolton, Giger, & Georges, 2003).

Life for these children and adolescents is not experienced as isolated events but within the context of the total experience, their real world of the inner city and the African-American culture. An African-American child's and adolescent's subjective world is often more understated and indefinable than the factors by and through which researchers attempt to interpret the world of the inner city African-American child (Butz, Huss, Mudd, Donithan, Rand, & Bollinger, 2004; McQuaid, Kopel, Klein, & Fritz, 2003; Penza-Clyve, Mansell, & McQuaid, 2004; Yoos, Kitzman, McMullen, & Sidora, 2003; Yoos & McMullin, 1999).

As healthcare professionals struggle to help these individuals deal with and sort out their complex diagnosis, unanswered questions still remain of how the lives of inner city children and adolescents with asthma are affected as they attempt to maintain a normal yet challenging life (Handelman et al., 2004; Rich, Lamola, Armory, & Schneider, 2000; Sander, 1998). Healthcare professions including nurses who provide services to this inner city population with asthma are hindered in providing quality healthcare because of the scarcity of research that describes these children's and adolescent's reality in living with asthma. A critical exploration of these individuals' lived experience may bring a more in-depth understanding to the health disparity specific to this population.

## Statement of Problem

### *Prevalence*

Despite the many public efforts on the national, state, county, and local levels, African-American children and adolescents of the inner city bear the greatest burden from asthma. This disparity represents a disconnection in the types of outreach and treatment modalities offered and the audience of inner city communities (Bolton, Giger, & Georges, 2003). It is essential for the asthma agenda to understand this high-risk population. The prevalence of asthma has shown an increase over the past three decades (CDC&P, 2004) with African-Americans, especially inner city African-American children, being disproportionately affected by asthma. The prevalence of asthma within the African-American population has been reported to be as high as 26% of that population with African-American children being two times more likely to have asthma than White American children (Hardie, Janson, Gold, Carrieri-Kohlman, & Boushey, 2000; L.A. Health, 2004). Efforts are needed at multiple levels to understand why such disparity exists and to decrease the burden of asthma among African-American children and adolescents living in inner city communities.

### *Morbidity and Mortality*

African-American children and adolescents living in inner city communities have a morbidity rate five times that of the general population. They also experience three times the severe functional disabilities and mortality than White children (Boyle, Baker, & Kemp, 2004; Gergen, Mullay, & Evans, 1988; Hardie et al., 2000; National Center for Environmental Health, 2002). Unscheduled doctor's visits, emergency



department visits, hospitalizations, and missed school days suggest that African-American children may be less well-controlled than the general population, with lower rates of evaluation leading to sub-optimal healthcare (Scarfone, Zorc, & Capraro, 2001; Taggatt & Fulwood, 1993). Although poverty is often given as one of the factors associated with health disparities, research has shown that this disparity cannot be explained totally by poverty, lack of health insurance, or access to healthcare services (Zoratti, Havstad, Rodriguez, Roberts-Paradise, Lafata, & McCarthy, 1998).

In a retrospective chart review of discharges from 1956 to 1997 from a medical university in South Carolina, Crater, Heise, Perzanowski, Herbert, Morse, Hulsey, et al. (2001) found a progressive increase in asthma hospitalization in African-Americans and Whites under 18 years. The most prominent increase was in African-American children 0 to 18 years old. This represented a twenty-fold increase from 18 in 1970 to 370 in 1997. The study conclusions noted that predominantly impoverished African-American populations demonstrated a steady linear increase over three decades in childhood asthma hospitalizations. Over the time period of the study, changes in lifestyle may have contributed to the rise in hospitalizations; there were no major changes in housing conditions for the poor. During this period of time, the parallels also increased in other Western populations suggesting common factors contributing to the rise.

Other research studies link asthma morbidity with poverty. Litonjua, Carey, Weiss, and Gold (1999) investigated the effects of socioeconomic status (SES) on the relationship between race/ethnicity and asthma prevalence in families with a history of asthma or allergies. The parent-child cohort consisted of a nonrandom sample of Boston

residents. The aim was to select children who were at risk for atopy and asthma on family history, although the lack of atopy marker acted as limitations of the analysis. This researcher team concluded that racial differences in asthma exist in the cohorts and that these differences may be attributed to SES among the participants. This study, as with the study by Crater and colleagues (2001), suggest that the effect of SES appears to be a link in Westernized areas, possibly because poverty is associated with numerous environmental exposures exclusive to poor inner city populations such as pollutants, family dysfunction, stress from instability of single parent households, caregiver stress, psychosocial stress, and unsafe neighborhoods.

Community violence and asthma morbidity (Wright, Mitchell, Visness, Cohen, Stout, Evans et al., 2004) was examined among inner city community children from seven cities: Boston, Chicago, Manhattan, the Bronx, Dallas, Seattle, and Tucson. Researchers obtained reports of violence, negative life events, ruminations, caregiver stress, and caregiver behaviors to asthma management and trigger mitigation. Asthma management outcomes were measured by wheezing, sleep disruption, functional days, and the effects on the caregiver. These findings show that increased exposure to perceived or real violence contributes to a higher number of symptomatic days and more nights that the caregiver lost sleep. The association between exposure to violence (an inner city stressor) and asthma may facilitate in understanding the rise in morbidity and advance the healthcare professions' understanding of the disproportionate asthma burden among inner city children.

These studies, (Crater et al, 2001; Litonjua et al., 1999; Wright et al, 2004) reveal that family and social environments are important in the identification, management, and prevention of asthma symptom exacerbation. High rates of perceived family dysfunction in inner city communities accounted for high asthma morbidity in impoverished African-American children (Litonjua et al., 1999).

According to the Center for Disease Control and Prevention (CDC&P) (2002) the mortality rate of African-Americans with asthma is 200% higher than White Americans and 160% higher than Hispanics. Inner city African-American children contribute disproportionately to the current trend of increasing asthma morbidity and mortality (Eggleston, Buckley, Breyse, Wills-Karp, Kleeberger, & Jaakkola, 1999; Mannino, Homa, Akinbami, Moorman, Gwyann, & Redd, 2002; Wallace, Scott, Klinnert, & Anderson, 2004).

The mortality related to asthma in African-American children living within inner city communities is three times higher than White children (Hardie et al, 2000). With an emphasis being placed upon a self-care management regimen that may include several medications and daily monitoring, an ever-increasing number of children are able to retain a pre-diagnosis lifestyle. These children must continue in their roles and responsibilities of being a child, family member, and student living in the inner city. These individuals must maintain their presence in society bearing the constant reminder of asthma. In addition these children may have a risk of psychological and social maladjustment (Christaanse, Lavigne, & Lerner, 1989; MacLean, Perrin, Gortmaker, &

Pierre, 1992; Wade, Weil & Holden, 1997; Weil, Wade, Bauman, Lynn, Mitchell, & Lavigne, 1999).

A 1995 study by Corn and colleagues found that despite medical advancement in asthma pathophysiology, asthma related death continued to increase, especially among African-Americans. Information based on retrospective chart reviews revealed that all asthma deaths and near-deaths (except one) that occurred from 1986 to 1992 were in low SES African-American and Hispanic patients ( $x = 16.9$ ). Although the use of beta-agonist and steroids was used as markers of adverse outcomes, there was not a correlation between adverse outcome asthma and the overuse of beta-agonists.

The finding confirmed that patients who were more likely to have serious adverse asthma were African-American or Hispanic and of low SES, often with incomes below the national poverty guidelines and without medical insurance. Similar findings resulted from research conducted by Castro and colleagues (2001). Asthma mortality occurred in predominantly poor, lower educated African-Americans. All of the asthma deaths and near-deaths were clustered among African-Americans and Hispanics populations. This study did not account for patterns of access, follow-up care, and reliance on emergency department visits for primary care that may exhibit different patterns for these groups. In addition, this study did not consider the possibility that asthma severity may be greater among African-Americans and Hispanics. In contrast, a study by Grant, Lyttle, and Weiss (2000) concluded that both SES and African-American ethnicity are independently linked with high rates of asthma mortality and that ethnicity may be a greater contributor than that of SES.

Although asthma may be attributed to differences in SES, there may be inherent pathobiological differences between races that may explain a portion of the disparities (Litonjua et al., 1999). Research documents that in the United States African-Americans have higher Immunoglobulin E (IgE) airway responsiveness, and different immunological responses to environmental pollutants including dust mites, cockroaches, indoor fungi, and cigarette smoke. This population also has a tendency to be sensitized to cockroaches, while affluent White Americans tend to be sensitized more to cats. Understanding how these factors and exposures interact may help to gain insight into developing effective, efficient, and appropriate intervention for this population (Tartasky, 1999).

### *Health Beliefs*

Not much is written in the literature regarding African-American health beliefs because African-Americans are not a homogenous group. There is great diversity within the populations in attitudes, behaviors, and values related to health, health promotion, and disease prevention (Huff & Kline, 1999; Spector, 2000). Health beliefs have evolved from several aspects of culture and society. Historically in the African-American culture, there is a strong bond with family and extended family members and all may be involved in the care of one another (Littlejohn-Blake & Darling, 1993). Children with asthma exposed to multiple caregivers may have inconsistencies in their asthma management. Strong religious beliefs are a primary source of strength particularly in older African-Americans, who often place an unyielding confidence in God and prayer as a method of treating illness (Thompson & Butler, 2002). As

grandparents or older extended family members with this health belief care for a child with asthma, disruption in the child's medical management of their asthma is highly probable.

For African-Americans living in inner city communities, financial and community resources are often limited (Littlejohn-Blake & Darling, 1993), causing them to focus on meeting basic needs such as food and housing with little attention given to sustaining the health status of a child with a chronic illness who is in a non-acute health state. Past and current experiences with providers and healthcare systems that have been discriminatory and prejudicial caused many African-Americans to be suspicious of healthcare professionals (Bolton, Giger, & Georges, 2003). These factors of diverse cultural health beliefs, socioeconomic, healthcare experiences, family, and interpersonal factors can significantly influence the African-American's desire to seek healthcare.

A missing link in research and healthcare outcomes is the understanding of health beliefs and integrating health beliefs into interventions. Past research concentrated on racial differences related to the selection of a healthcare provider or the use of folk medicine and home remedies for healing common ailments (Chen, Fryer, Phillips, Wilson, & Pathman, 2005; Roy, Torrez, & Dale, 2004; Seid, Stevens & Varni, 2003; Wong, Asch, Anderson, Hays, & Shapiro, 2004). These two issues may offer some insight into health disparities in the African-American population. Understanding health beliefs is vital to closing the health disparity gap.

Long-standing traditions in African-American culture of health and healing practices may shape how they care for themselves today. African-American traditional medicine can be traced back to before enslavement in the United States (Littlejohn-Blake & Darling, 1993). Over time magical and herbal cures from Africa gave way to a blending of curative practices of Africa, Native American, and colonial European approaches. These include purgatives, bleedings, and preventives measures based on classical humoral pathology leading to complex ethnomedical practices with many regional variations reflecting spiritual power (Becker, Gates, & Newsom, 2004).

In response to slave owners' interest in strong slaves for work and sale, an ethnos of resistance was formed. Furthermore, spiritual transformation took place creating an internal world of resistance to slave owners, while linking an individual's well-being to the health of the larger community and community to its spiritual life, culminating in a collective version of self-reliance. This self-reliance collaborative continued after emancipation for several reasons including, such as a lack of access to healthcare, poor quality healthcare, lack of trust in the system because of experimentation such as the Tuskegee experiments, and resistance to the oppressive tactics of the White mainstream society (Becker et al., 2004). The work of Peterson et al. (2002) further illustrates how health beliefs influence the care and treatment given by adult primary caregivers of children with asthma.

The families in this study conceptualized on their cultural context to understand asthma. Much of the family's information about asthma came from other family members and personal experience. The study findings showed that families had their

own understanding and health model of asthma that differed from the biomedical model. For example, when stating what treatment the child should receive, five parents gave the response of “family protocol,” comprising treatments without or before consulting a healthcare practitioner. These home remedies included drinking cold water, lying down, stopping current activity, calming down, taking deep breaths, and sometimes ingesting peppermints.

Successful intervention programs incorporated community involvement, such as a program targeting inner city African-American children (Fisher et al., 1994; Fisher, Strunk, Sussman, Sykes, & Walker, 2004). Beginning with an assessment of an inner city community of culture versus standard medical care, the assessment examined deficits in basic care, noting barriers to care went further than financial ability and availability of care. A factor leading to the morbidity and mortality for this population are the misinterpretations of basic care and inadequate understanding of the seriousness of the disease. Furthermore, for inner city communities, violence and related risks are relevant and noteworthy, and attention to more than minimal problems like asthma care may be illogical. This intervention study is built on the inner strengths of the community and not on its deficits, thereby fostering a sense of empowerment for the individual and the community through the establishment of social ties.

Incorporating the findings from the assessment a neighborhood asthma coalition was developed (Fisher, Strunk, Sussman, Sykes, & Walker, 2004). The foundation and success of the coalition granted support to neighbor-to-neighbor and indigenous community health workers. This program focused on the community and its social



isolation, involved neighborhood residents in planning and implementing programs for asthma education and management provided by trained neighborhood residents. This type of intervention helped to reduce the burden of asthma among a socio-economically disadvantage group by incorporating community strength within the intervention.

### *Barriers*

Barriers to healthcare are often studied when addressing health disparities. The disproportionate incidence of asthma severity in the African-Americans raises grave concerns about what barriers could be present that inhibit healthcare for African-American children. The most frequently cited barriers are related to healthcare system and healthcare provider factors such as payer type (Roy et al., 2004; Wong et al. 2004). Healthcare system policies, private insurance, health maintenance organizations, and Medicaid may limit children's access to quality care, number of health visits, the number and type of medications, and medication delivery devices that can be dispensed (Monsour, Lanphear, & De Witt, 2000; Seid et al., 2003). Healthcare provider characteristics are related to continuity of care, provider availability, and limited hours of operation. There is limited data regarding the child's perspective of barriers to optimal asthma care and outcomes (Munro, Haire-Joshu, Fisher, & Wedner, 1996; Wade et al., 1997).

According to Cohall and Bannister (2001), poverty and limited access to healthcare are defining dynamics affecting the health status of most ethnic minorities. These dynamics, however do not fully account for the health disparities experienced by many ethnic minorities. Monsour, Lanphear, and De Witt (2000) investigated healthcare

barriers to asthma care and treatment in urban children from the perspective of the parent. This study brought to the forefront childhood asthma care and management from the parents' perception of barriers to asthma care that differs dramatically from those traditionally perceived by healthcare providers and academic researchers. The families' identified educational issues, healthcare provider/patient/family relationship, continuity and availability of providers, financial constraints, and environmental triggers as barriers. Although healthcare provider/patient/family relationships, along with the continuity and availability of providers, are seen as common barriers, this research offered new insight from the parent's perspective that may help explain why children from inner city communities have less optimal asthma health outcomes. Additional research from this perspective of the child or adolescent who resides in the inner city may bring further enlightenment to this disparity.

In a pilot study by Wallace et al. (2004), the parents of children with asthma who reside in impoverished communities were queried to better understand the experiences of these children as they attempted to access healthcare in an urban community. The findings of this study identified both family and system factors as barriers to optimal healthcare outcomes. The noted barriers were beliefs about medication addiction and adverse effects, not having a written exacerbation management plan, receiving care in primary care settings, and not having continuity in asthma care. The information from this study provides practice implications, however, further research is needed to identify and understand healthcare barriers from the child's

perspective. Studies related to urban health, specifically inner city health attempts to give credence to such healthcare barriers.

Early identification problems, adequacy of treatment programs, healthcare systems issues, cultural, developmental, and societal factors are all contributors to the health disparity of asthma among inner city African-American children. Numerous programs have been implemented to address this disparity. Programs are designed to offer general asthma health education, environment mitigation, identification, and school-based medical treatment/management programs (Levy, Heffner, Stewart, & Beeman, 2006; Liao, Morpew, Amaro & Galant, 2006).

#### *Intervention Programs*

The United States Department of Health and Human Services (2000) set asthma objectives in the *Healthy People 2010* report designed to reduce asthma morbidity and mortality rates. Effective management of asthma includes four components: patient education (avoiding or limiting contact with factors that may exacerbate the condition); adhering to an appropriate medication regimen; monitoring of the disease by the patient, caregiver, and healthcare professional; and active self-management by the patient (McQuaid et al., 2003). The high morbidity and mortality rates in the African-American children and adolescents indicates the importance of promoting (a) ongoing versus episodic care; (b) the mitigation of environmental triggers; (c) identification of the signs and symptoms of exacerbation; (d) symptom exacerbation management; (e) the initiation and improvement communication with caregivers, primary healthcare providers, school nurses, and teachers (Fisher et al., 1994; National Institute of Health,

1997), and (f) understanding the life of the inner city child or adolescent and the impact of asthma from the child's and adolescent's perspective.

Additionally, the National Heart, Lung, and Blood Institute/National Institutes of Health (NHLBI/NIH, 1997) emphasizes in the guidelines for asthma care and treatment the necessity for doctors, nurses, and other healthcare professionals to form partnerships with their patients and caregivers to promote effective care. The guidelines recommend that healthcare professionals evaluate cultural/ethnic beliefs and health beliefs that may influence self-management activities and modify educational approaches. Culturally relevant healthcare is essential in addressing the health disparity in the African-American population.

The increase in the prevalence of asthma over the past three decades affecting about five million children (CDC&P, 2004; National Center for Environmental Health, 2002) with the greatest burden among African-American children with morbidity and mortality rates being the highest in inner city communities' lower socioeconomic populations. The mortality rate is higher for African-American children than White children. Studies of inner city African-American with asthma discovered poor correlation between asthma knowledge and asthma management with health beliefs playing a major role in the application of appropriate asthma care. Other studies show that barriers to healthcare are a determining factor to healthcare seeking behaviors for the African-American population. Furthermore, researchers propose that health beliefs affect health behavior, and interventions designed only to improve asthma knowledge or provide treatment might have limited utility (Wade et al., 1997).

Numerous school-based asthma intervention programs have been introduced to address asthma related health disparities. Programs range from health education to identification of asthma and medical care. Two model intervention programs that include identification and specialized medical care are the Mobile Clinic® in Dade County and the Breathmobile® in Los Angeles County (Brito, Wurm, Delamater, Grus, Lopez-Hernandez, Applegrate et al., 2000; Jones, Morpew, Clement, Kimia, Dyer, Li et al., 2004). Both intervention programs are designed to identify underserved asthmatic children at schools and offer culturally sensitive asthma related healthcare. The research teams and medical staff from the Mobile Clinic® and the Breathmobile® developed a parent questionnaire to be administered at the school site to identify children with asthma. These studies indicated that a large proportion of the pediatric population with asthma could be identified. This type of identification process is valuable in meeting the challenge of establishing successful interventions that lead to improved health outcomes in the pediatric inner city asthma population.

Other successful school-based intervention programs are reported in literature. The following intervention program is specific to the inner city African-Americans pediatric population. Boyle et al. (2004) explored the beliefs about asthma and asthma management among schoolchildren, parents, and teachers in a public school that by choice had an all African-American student enrollment. Children in the study reported fear of not being able to breath and the limitations that asthma placed on their lifestyle. The teachers voiced concerns about not understanding how to manage a student with

asthma. Parents expressed the complexity of their life and the challenges of asthma care and management.

Traditionally, asthma interventions have been developed and implemented based on the perceived medical deficits of the patients such as healthcare access and affordable therapeutic regimes. Since this approach has yielded little if anything to decrease the incidence of morbidity and mortality with this illness, another approach to care is necessary. Conducting research directed to understanding the life of the inner city African-American children and their challenges living with asthma may offer insight. The African-American adolescent perspective of asthma can be of value in the planning and implementation of intervention programs that are supported by the adolescents' cognitive maturity and psychosocial development.

Conventional assessments and interventions have failed to provide these children with meaningful information, encouragement, and support that would alleviate asthma's disastrous effects on the health of African-American children residing in inner city communities. While these assessments and intervention programs are informative and somewhat useful, they continue to be traditional in their approach. By viewing poverty as a limiting deficit, researchers have undervalued the African-American child and caregiver's perspective of the disease by overlooking the child's inherent strengths and resilience (Becker et al., 2004; Tartasky, 1999). This presumption runs counter to the constructivist argument that all interventions should meet the patient where they are; and that knowledge for the learner must intersect and respect the patient's inherent knowledge. This proposal study is significant in that the lived experience of inner city

African-American adolescents living with asthma may enlighten caregivers, funding sources, families, and communities so that adequate and appropriate interventions can be created to reduce the morbidity and mortality of this disease in this population.

Something is missing from the data. Given the current advancements in medical science and therapies to control asthma, why is the incidence of asthma in the African-American population still increasing and why are our inner city African-American children still dying at rates far greater than the general population? Maybe it is time to hear from the adolescents who suffer from this disorder. Maybe they can tell us something that all the quantitative research has not been able to find. Exploring the lived experience of these adolescents and uncovering the meaning and understanding of asthma among inner city African-American adolescents can enhance nursing knowledge as well as evidence-based practice.

#### Purpose of Study

The purpose of this study is to explore the ways in which inner city African-American adolescents experience life with asthma. The goal of this study is to explore the daily lives of African-American adolescents, aged 12 to 14; the changes in their familiar environment, and that which is often taken for granted. This study's purpose is to describe and interpret the adolescent's understanding of reality of life as an African-American with asthma residing in an inner city community. The uncovering of information about the increased incidence for asthma health disparities in this population may also occur.

### Research Question

The research question to be investigated by this study is: What is the lived experience of young African-American adolescents with asthma who reside in inner city communities?

### Assumption of Study

The assumption of this research is that through common thought of society the prevalence of asthma in the inner city African-American adolescent population is related to barriers to care and non-compliance to traditional medical related asthma care and treatment.

### Significance of the Study

Numerous studies give account of current health status and health disparities among African-Americans in the United States. Inner city health issues and health outcome suggests that health disparities are found to extend beyond health education and SES that relate to healthcare barriers, health beliefs, and lack of intervention programs (Akinbami & Schoendorf, 2002; Bolton, Giger, & Georges, 2003; Halfon & Newacheck, 1993). Explanations for these differences have not been fully explained through the fragmented, isolated lenses of inner city health issues, culture, and psychosocial contexts, but must be viewed as a whole picture, e.g., the inner city African-American adolescent with asthma. Some isolated reasons cited for this burden of asthma among inner city children include genetic or biological predisposition, substandard living conditions that lead to environmental exposure to cockroaches, dust, and pollutants (Eggleston, Wheeler, Bollers, Wood, & Adkinson, 1992; Rosenstreich,



Eggleston, Kattan, Baker, Slavin, & Gergen, et al., 1997); under treatment with controller medications (Halterman, Yoos, Sidora, Kitzman, & McMullen, 2001); and inadequate self-management regimes (Walders, Drotar, & Keresmar, 2000). Studies that focus on barriers to health outcomes and intervention programs only allude to possible causes of asthma related health disparities presenting a fragmented picture of asthma within the African-American population.

In addition, studies involving children and adolescents often were conducted from the parent/caregiver, researcher, or other adult perspectives using adult standards. Understanding the perspective, lived experience of inner city African-American adolescent with asthma may give a clearer, in-depth understanding of some of the possible causes that have led to this healthcare crisis. The affects of inner city life takes a toll on the child as well as the adult through intrinsic and extrinsic barriers to healthcare, general living conditions, school and education, and other social issues. Issues surrounding adolescent health are often presented as a disjointed image from the parent/caregiver who is deemed the authority in the healthcare management of their child or adolescent.

### Philosophical Framework

There are significant knowledge gaps in the asthma literature. Such gaps appear to significantly affect the quality and appropriate scope of asthma care necessary to help African-American adolescents be successful in managing their asthma. There are concerns as to whether current research findings are a realistic reflection of what is occurring among inner city African-American adolescents with asthma. The life

experiences of inner city African-American adolescents is different from any other populations of adolescents and those living with a chronic health problem within such an environment have very different needs than other adolescents with similar health problems. Adolescent life experiences and beliefs cannot be quantified through traditional quantitative research methods.

Qualitative research presents tools to examine some compelling influences that work in the African-American adolescent's life. Qualitative research looks beyond the diagnostic outcomes to discover the context, motivation, and inspiration that is the why and how of behaviors (Rich & Ginsburg, 1999). Phenomenology, a research approach that asks about an individual's lived experiences, is an approach to understanding a person's perspective of a chronic disorder or illness (Benner, 1985; Holmes, 1990; Oiler, 1982).

Husserl (1965) defined it as the study of a phenomenon as it is perceived by one's consciousness. Vital to Husserl's approach is the fundamental recognition of experience as the ultimate ground and meaning of knowledge (Koch, 1995).

Phenomenology, according to Husserl (1965), is a return to the lived world, the world of experience, which is considered to be the starting point of all science.

Phenomenology suggest that a phenomenon be described, not explained, and focuses on the very things as they manifest themselves.

Phenomenological research focuses upon the meaning of experience. According to Evertz (2001), there are several major philosophy principles that characterize various

phenomenology designs. These principles encompass the nature of reality, meaning, experience, reasoning, and holism.

Reality is complex, forceful, and freely selected by human or man. There are multiple realities resulting in numerous explanations. Humans create meaning from their experiences with meanings dependent upon context. In order for a researcher to understand a phenomenon, the meaning of an experience must be uncovered by interaction with the human experiencing the phenomenon. Phenomenologists use inductive reasoning when engaged in the research process. Because life does not occur in isolated events, a phenomenon must be studied as a whole to ascertain the full understanding (Cohen, Tripp-Reimer, Smith, Sorfman, & Lively, 1994; Husserl, 1962; Munhall, 2001).

Meanings related to human behavior are an important component of Phenomenology as the individual describes the phenomenon under investigation from his/her own perspective. Insight of the world, as experienced by that human, is uncovered. Humans have an intimate relationship with their worlds and are inseparable from it (Boyd, 2001). According to Merleau-Ponty (1962) all human behavior is within the context of all that is surrounding them such as other people, object, circumstances, and situations.

Involvement in the world is unique for each human. Humans assure a particular orientation to their actions and consciousness that defines the way they are connected to their world. Through intentionality of consciousness all actions, gestures, habits, and human actions have meaning (Martins, 1992).

Phenomenology describes events from each individual's personal beliefs, values, and experiences. Thus, the unconscious affects the understanding of the experience as it was felt, as it was lived, as it was perceived, and as it was remembered. Within this context, one's perspective is based on the unique meaning of the time, place, and all other elements that framed the experience.

Husserl (1965) pioneered the concept of the "life-world," or "lived experience" as the experience of the individual from their point of view. According to Husserl, life-world is not readily accessible because it constitutes what is taken for granted or those things that are common sense or commonplace. The task is to re-examine the taken for granted experiences. Husserlian phenomenology brings to light the ultimate structures of the consciousness (essences), and to evaluate logically the role these structures play in determining the sense of it all (Dreyfus & Dreyfus, 1987). Phenomenology research means presenting a systematic view of mental content and assumes that this is possible if symbols representing the world are manipulated in the mind, permitting the external world to be brought into internal consciousness by cognitive processes. A person's knowledge, understanding, intentions, and actions originate in the mind, and the mind is the source of meaning and interpretation (Benner & Wrubel, 1989).

### *Hermeneutic Phenomenology*

Hermeneutic phenomenology has both descriptive and interpretive roots (Heidegger 1962; Husserl, 1965) The primary objective of hermeneutic phenomenology is the unswerving investigation and description of phenomena as experienced in life by using the practice of phenomenological reflection and writing to understand the forms

of life (van Manen, 1983). It gives an untainted voice to human experience (Jardine, 1990). According to van Manen, scholarly inquiry should be attentive to the lived experience and experience speaks for itself. Referring to this design of hermeneutic phenomenology as a human science approach implies that human science and semiotics are essential to phenomenological research design. Semiotic refers to the science of signs and language, spoken and unspoken. It is through language that meaning of lived experience is uncovered.

Using phenomenology to explore the lived experience of the inner city African-American adolescent with asthma can be a valuable way to uncover the meaning of the acute exacerbation of asthma, the experience of being surrounded by a protective shield when hospitalized for the disorder, and the reality of returning to an environment that contributed to the hospitalization in the first place where cultural norms, barriers to care, life stress, and other such factors may impact the health state of these adolescents.

The African-American adolescent must depend upon family and others at home and school for support. Studies have shown that the family may become overwhelmed and stressed by the commitment of caring for a child or adolescent with asthma (Bonner, Zimmerman, Evans, Irigoyen, Resnick, & Mullins, 2002; Sterling & Peterson, 2003). It is within this medically unprotected environment that the inner city African-American child with asthma must live and find meaning in life. The life experience of these children and adolescents cannot be quantified. Phenomenological research examines life experiences in an effort to give them meaning (Byrne, 2001). This current study is conducted within this context.

*Nursing Science and Phenomenology*

Nursing is a practice discipline that attempts to explain the meanings that persons attribute to the events related to health and illness (Allen & Jenson, 1990; Rose, Beeby, & Parker, 1995). According to Benner (1985), the meanings of health and illness can be understood only in the persons' situation. The investigator must have appreciation for the meanings of health and illness inner city African-American adolescents with asthma assign to their experiences, which are shaped by a shared language, culture, and history (Benner, 1985). Inner city African-American adolescents with asthma will share common meanings of health and illness with their peers, other African-American children and adolescents, and African-American adolescents with other chronic illness. To learn and know the meaning of asthma within this population, the nurse investigator must lay aside all prior knowledge, beliefs, and judgments about the lived experiences of inner city African-American adolescents with or without asthma (Cohen, Kahn, & Steeves, 2000; Lincoln & Guba, 1985). For example, the nurse investigator must lay aside previous knowledge related to health beliefs and practices that the African-American adolescents with asthma may use to cope with the burden of asthma and hospitalizations. It is imperative that the nurse investigator understands and focuses on the meanings that these adolescents assign to their life experiences of asthma.

The theory of phenomenology, which enlightens the meanings that persons assign to their lived experiences, is used to explain the lived experience of inner city African-American adolescents with asthma. This theory helps research investigators

understand the meanings of health and illness from the perspective of identified populations. The adolescent's perspective is influenced by their surroundings, culture, language, and history shared by others with similar experiences.

The goal of nursing science and nursing practice is to identify and provide holistic care of inner city African-American adolescent with asthma. Nursing can assist in providing help for these adolescents to manage the asthma related needs, but also meet their cognitive maturation and psychosocial developmental needs. Studies suggested that asthma might have a potential devastating affect of the lives of these adolescents. Studies are needed to address the adolescent's responses to their concerns about asthma and the effect it has on their daily life.

#### Implication for Nursing Practice and Nursing Science

##### *Nursing Practice*

Inner city African-American adolescents with asthma frequently seek healthcare from a system that is primarily designed for treatment of acute, short-term ailments of adults and for medical cures rather than long-extended care (Gadow, 1988). Findings from this study, which describes the meaning of adolescent asthma within the inner city African-American community, will provide information that might assist nurses and other healthcare providers, parents, school staff, and community members working with this population to respond more effectively and efficiently to the care and treatment needs of this population.

Furthermore, adolescents with asthma and other chronic illness receive little attention from the public policy arena. Often fragmented financial programs and

services exist to address the needs of chronically ill children. In addition to the obvious medical costs of hospitalization, physicians, medications, and diagnostic evaluations, other costs are generated that private insurance or Medicaid may not cover. These may include counseling, mental health services, mitigation of home environment, and additional medications and equipment for use during school hours. Nursing must be vigilant in empowering these adolescents and their families in the care and management of asthma. Understanding the lived experience of asthma in the African-American inner city adolescent population is a foundation to empowerment (Gregory, 2000; Telljohann, Dake, & Price, 2004).

In the past, the focus of nursing has been on the curative and maintenance of health. In its social policy, the American Nurses' Association (2003) describes nursing as the diagnosis and treatment of human responses to actual and potential health problems. As the prevalence of asthma among African-Americans rise, nursing has a key role in expanding the knowledge base related to asthma to improve the health outcomes for this population. This knowledge base will also enable healthcare providers to assist these adolescents by providing complex care essential to successful positive healthcare outcomes.

Much of the literature on asthma and asthma specifically related to the African-American population is intertwined with other data and the African-American population is misrepresented in the findings (Sterling, Peterson, & Weekes, 1997). Other research has investigated the quantitative aspects of asthma and health outcomes, while still other research focus on the caregiver and not the adolescent with asthma



(Mesters, Pieterse, & Meertens, 1991). This approach eliminates the conceptual and methodological issues involved in exploring the African-American adolescent as a distinct entity and limits the use of the findings for interpreting anything more than the experience of the individual (Field & Morse, 1985). The African-American adolescent's subjective world is more difficult to comprehend than the quantitative markers researchers use in their attempt to interpret their worlds (Sterling & Peterson, 2003). This current study is a starting point for nurses in giving voice to the inner city African-American adolescent with asthma.

### *Nursing Science*

The intent of phenomenological inquiry is to explicate the essence of the lived experience of a phenomenon in the search for the unity of meaning that is the identification of the essence of a phenomenon, and its accurate description through the daily-lived experience (Cohen, 1987; Field & Morse, 1985; Husserl, 1970). The findings of phenomenology research are descriptive, rather than predictive or explanatory. Phenomenological research has enhanced nursing's knowledge base. The aim of nursing research has been to develop nursing knowledge for nursing education and nursing practice, with the majority of nursing research aimed at nursing practice including evidence-based nursing practice.

In view of phenomenology's focus on the lived experience of inner city African-American adolescents with asthma, the findings for this study may be beneficial in delineating the humanistic care dimensions of nursing interventions. The application of phenomenological research enables nurses to ascertain better which humanistic

healthcare interventions are appropriate for a given contextual setting. It is crucial that nurses pursue humanistic elements of nursing care by discovering and uncovering the meaning of health and caring within the contextual reality of individuals, families, and groups. Knowledge related to the meaning of the patient's reality will enlighten the nurse of the qualities and characteristics of each individual's existence, which, in turn, will provide a more comprehensive understanding of the essence of the nursing profession.

Knowledge gathered from adolescent-orientated research has the potential for influencing curriculum development and the reorganization of adolescent health content to emphasize the role of the adolescent in illness. Subsequently, knowledge disseminated through nursing education can guide nursing practice in developing appropriate nursing and treatment plans to center on the adolescent as the unit of care and the parent/guardian as support and not as the primary caregiver.

Nursing is a practice discipline, evidenced by goals that are aimed toward people, to monitor and promote health (Meleis, 1991). To fulfill these goals nurses and other healthcare professionals need to understand basic phenomenon. The application of phenomenology in nursing research addresses and emphasizes how patients experience their illness and needs. The clinical implications mean that healthcare professionals prepare to take measures to fulfill the needs of different patients or patient populations.

#### Terms and Definitions

The following terms and definitions will be used to direct this research study:

**African-American:** Pertaining to or characteristic of Americans of African ancestry.

**Asthma:** A chronic reactive airway disease process.

**Disorder:** Refers to a specific malfunctioning of an individual's physical or psychological processes.

**Healthcare provider:** For this study, refers to a physician, nurse practitioner, physician's assistant, or registered nurse who directly or indirectly provides healthcare to the children diagnosed with asthma.

**Holistic perspective:** Refers to the interdependence and relatedness of emic and etic views of asthma.

**Illness:** Refers to an individual's psychological and social experience of a chronic condition.

### Summary

This study investigated the lived experience of inner city African-American adolescents with asthma. The findings provide important information that will directly affect the morbidity and mortality rates of inner city African-American adolescents with asthma. Qualitative methodology using a phenomenological approach was used to describe the informants' lived experience of being an inner city African-American child with asthma. Through a deeper understanding of the African-American adolescents' perspective of the experience, healthcare delivery may become more sensitive, effective, and efficient in providing care for this population leading to optimal health and personal outcomes.

## CHAPTER TWO

### Literature Review

This study examines the lived experience of inner city African-American youth with asthma in hopes that existing interventions can be tailored to mirror their life experience. Inner city African-American children face a multi-factorial risk to asthma due to their ethnicity, age, SES, and living conditions. The research supports the theory that inner city youth are most affected by the prevalence, morbidity, and mortality of asthma because of these factors, but leaves unanswered questions about how to effectively and efficiently address this problem. Current interventions are based on traditional, middle-class values, and principles that are often difficult to implement into the inner city way of life. This chapter discusses the biomedical model and its presentation in the African-American population, the cultural, social, health perspectives of African-American youths with asthma.

### Social Epidemiology of Urban Health

Numerous studies investigate the health status of minority populations based on their SES. Compounding evidence through a series of changes in the urban socioeconomic and demographic landscape since World War II has resulted in astounding and increasing rates of excess mortality in urban areas of intense poverty (Geronimus, Bound, Waidmann et al, 1996; Geronimus, Bound, Waidmann et al, 1999; McCord & Freeman, 1990). By 1990 African-American youths in some urban communities faced

lower probabilities of survival to age 45 years than White youths. Although popularized by images of homicide among urban youths, crime, teen pregnancy, ever increasing school dropout rates, chronic illnesses in early and middle adulthood were the key contributors to health inequalities in this population. Research by Tartasky (1999) and others referenced in this current study documents that these changes now are affecting a much younger population.

According to Tartasky (1999), the prevalence of asthma increased by 42% and the average annual death rate by 40%, a rate consistently higher in African-Americans with a substantial increase of 74% occurring in adolescents aged 5 to 14 years old (CDC&P, 1998). Research has established that inner city communities have disproportionately high rates of asthma-related morbidity and mortality among African-Americans, however, most have focused on one aspect of the inner city, SES of the population and have fail to investigate the full contextual aspects of urban life, particularly inner city life.

#### *Urban Planning and Urban Health*

The evolution of cities in the 20<sup>th</sup> century echoes changes in global and domestic political and economic wealth (Vlahov & Galea, 2002). The health in urban communities has evolved. Although the data is lacking to link changes in urbanization to the changing health status of populations, health in cities has frequently reflected the population movement and growth that shaped the urban landscape. At the turn of the 20<sup>th</sup> century, infectious diseases associated with populations crowding plagued cities in the United States. After revitalization in the middle of the century, the fiscal crises of

the 1970s were paralleled by growing disparities in the health of urban populations when compared with suburban and rural populations.

The roles that public health practices and interventions along with urban planning have played in the control of urban disease epidemics are well documented (Blankfield, Goodwin, Jaén, & Stange, 2002; Corburn, 2004; Eberhardt & Pamuk, 2004; Kirby & Kaneda, 2005; Wallace & Wallace, 1997). However during the past decades, urban health in North American has focused on the burden of disease in marginalized populations (Eggleston et al., 1999) without fully exploring the role that the urban context played both in the marginalization of the groups and in shaping the health status of these populations. For example, a large body of literature related to the prevalence, morbidity, and mortality of asthma among inner city populations has explored individual risk factors that are important within this group, often with a limited focus on how living in urban cities, especially inner city communities affects these risk behaviors. Relatively little work has been done that shed light on the relationship of the burden of disease and the concentration of minority groups in urban areas. The role that the urban environment plays in shaping health and disease is necessary to understand the full affect of the disease and the lived experience of the individual with the disease. Understanding urban factors that are health risks or protective factors can capitalize on the positive aspects of health and lead to the development of appropriate interventions and preventive measures (Vlahov & Galea, 2002).

“The idea that social conditions might influence health was forcefully asserted by nineteenth-century physicians who founded the field of social medicine” (Link &

Phelan, 1995, p. 86). As early as 1848, Virchow published his idea, radical at the time,” that medicine is a social science by recognizing the strong association between poverty and health. Increased awareness of the origins of some diseases made the link between dire housing, poor sanitation, and working conditions of poor people (Rosen, 1979). In fact, medical advances combined with broad public health initiatives lowered the incidences, reduced the negative effects, or eradicated such diseases as diphtheria, measles, typhoid fever, tuberculosis, and syphilis. Link and Phelan (1995) also make the connection between the creation of the modern welfare state and poor people’s limited access to healthcare as contributing factors.

Many of the factors that linked disease to SES were thought to be addressed by President Johnson’s “Great Society” legislative reforms of the 1960s. “One might have expected the association to wane and perhaps disappear altogether” (Link & Phelan, 1995, p. 86). This is the conclusion reached by Charles Kadushin, former professor at Columbia and Yale universities. His 1964 study of difficult-to-reach populations concluded that the link between disease and improved SES subsequent to 1964 would decrease because “the factors which intervene between social class and exposure to disease will become more and more equal for all social classes” (Kadushin, 1964, p. 75). Based on his study, Kadushin predicted that in the future poor Americans would be no more likely to develop disease than those from the middle or upper classes. Of course, this prediction was incorrect. Five decades later the link between disease, especially asthma, and SES continues. Thus, extensive research into this area is needed.

Evidence of SES effects on health outcomes involving a number of chronic conditions (Robert, 1999) has fueled interest in more extensive research .on the health effects of SES and the “mechanisms that may account for the community structure-health link” (Robert, 1999, p. 490). Past neighborhood effects research has focused primarily on the relationship between poverty and health (Browning & Cagney, 2003). Nevertheless, Wilson’s (1987) theory of social isolation contributes valuable information to the structural features of communities and the influence on individuals’ health.

Wilson (1987) defined a two-stage process of neighborhood decline that begins with “white flight,” or the event of middle class residents moving out of inner city communities that results the removal of local institutions, such as schools and churches, and the inability of poorer and less educated residents to maintain informal social controls. This process is followed by the remaining residents’ increasing exposure to urban decay. In most cases, risky behavior that compromises health in the remaining residents further contributed to community decline. “The structural context in which this process occurs most efficiently is one characterized by both widespread economic disadvantage and constrained mobility” (Browning & Cagney, 2003, p. 554).

Browning and Cagney (2003) researched the consequences of social isolation and the prevalence of poverty. Consistent with Wilson’s (1987) model of inner city decline, “stable poverty may encourage the dissemination of health-compromising subcultures” (p. 395). Nevertheless, stable communities that lack middle class and



upper class residents may experience declines in the quality and availability of health services (Fitzpatrick & LaGory, 2000).

Building on recent research into Wilson's (1987) concept of social isolation, Browning and Cagney (2003) focused on elements of community socioeconomic structures that go beyond poverty and are relevant to individual health concerns. These elements include ethnic heterogeneity, residential stability, and concentrated affluence. The researchers' focused on mechanisms that link community structural characteristics with health outcomes.

Structurally disadvantaged communities, suffering from deficits in local social support and sociability are less capable of sustaining viable social networks than more affluent communities (Berkman & Breslow, 1983). Social networks at the community level influence healthcare processes and positive response (Rook, 1990). "Evidence of the positive effects of social support on health is powerful and consistent" (Browning & Cagney, p. 395), suggesting that effective social support activity and community social engagement may be relevant and necessary for positive health outcomes (Browning & Cagney).

Wilson's (1987) theory states that the combination of immobility and poverty results in social and geographic isolation of inner city residents from access to mainstream sources of influence, followed by survival strategies that often involve problematic behavior. These behaviors include poor diet, drinking, smoking, and risky sexual activity that contribute to serious health consequences. A second aspect of social isolation may be anomie or detachment from conventional values (Wilson). Widespread

community level tolerance of risk behavior may facilitate the spread of such behavior within disadvantaged contexts, with consequences for health.

Lack of employment and widespread poverty, resulting in bleak economic prospects and other structural disadvantages generally lead to anomic social conditions (Durkheim, 1979; Sampson & Bartusch, 1998), in which inner city residents may question basic social norms. Inner city populations are likely to operate from short-term orientations that emphasize satisfaction of immediate needs, thus participating in health-compromising behaviors.

Inner city populations lack reasons to develop social cohesion (mutual trust and solidarity) and informal social control (shared expectations for pro-social action). “The pathways through which neighborhood collective efficacy may influence health include the social control of health-risk behavior, access to services and amenities, the management of neighborhood physical hands, and psychosocial processes” (Browning & Cagney, 2003, p. 552). Collective efficacy generates the social cohesion that aids in correcting or avoiding physical hazards such as decaying infrastructure and housing stock. Communities that have the resources to correct potentially harmful conditions and monitor vulnerable residents are more likely to enhance health. Widespread trust and community attachment reduces fear and improves self-respect that may lead to improve the health and well-being of residents (Kawachi & Berkman, 2000).

In summation, Browning and Cagney (2003), building on the conclusions of Tartasky (1999) and Wilson (1987), found a significant relationship between the impact of community structural characteristics, social organization, and culture on the status of

health, particularly asthma. These researchers' conclusion is that community affluence is a powerful predictor of health conditions among the individuals within the community.

*What is Urban, What is Inner City?*

Bielory (1996) defines "inner city" as a population living in poverty with a density of less than 10,000 persons per square mile. It is recognized and accepted that the effects of asthma are more common and pronounced in urban areas specifically, inner city communities (Browning & Cagney, 2003; Link & Phelan, 1995; Tartasky, 1999). Although the definition of inner city is not consistent throughout the literature, it is widely recognized that the effects of asthma and other chronic illnesses are more pronounced within inner city communities of urban areas (McFadden, 1997; Tartasky, 1999; Wing, 1993). The risk factors for the escalating asthma-related prevalence, morbidity, and mortality in the inner city are complex, and can be classified as (a) evolution of inner city communities, (b) social environmental built-in community factors, (c) socioeconomic factors, (d) physical environment, and (e) provision of health and social services.

Social Epidemiology of Inner City Health

The research findings of Geronimus (2000) states that the third intensifying factor of poverty is the deterioration of public facilities and their use for illegal purposes. Massive reductions in outlays to maintain and supervise public services areas such as parks, recreational facilities, other public facilities and public services, even public schools only led to the cascade of events that were triggered by these reductions

in city services in low-income minority neighborhoods. The increase in family homelessness prompted by urban renewal projects created profound disruption of social networks, which in turn led to multiple families and at times multiple generations living together or fleeing to other low-income communities which were slated for future urban renewal project (Fossett, Perloff, Peterson, & Kletke, 1990; Fossett & Perloff, 1995; Polednak 1996).

This social network deterioration set the stage for the crime and violence associated with inner city neighborhoods along with severe health and social problems. The prevalence of asthma, the reemergence of tuberculosis, stress related diseases, the sale and use of crack cocaine, and the increase in HIV/AIDS are some of the resulting outcomes of urban renewal of poor urban communities (Fossett et al., 1990; Fossett & Perloff, 1995; Polednak 1996; Wallace & Wallace, 1990).

The work of Ross and Mirowsky (2001) on neighborhood disorder adds to the body of literature on poverty and health in stating that living in a disadvantage neighborhood, such as an inner city community, is associated with poor health. Not only do residents of low-income neighborhoods feel less healthy, have more physical impairments, and more chronic health problems including asthma, hypertension, and arthritis, the impact of living in a low-income neighborhood is mediated by the disorder of the neighborhood. The residences of such neighborhoods face a threatening and harmful environment characterized by crime, incivility, and harassment, all of which are stressful and with chronic exposure impair one's physical, mental and social health, and well-being.

Work by Wallace and Wallace (1997) adds to this body of knowledge by stating that individual and family lives are profoundly affected by influences on the neighborhood scale. The neighborhood embodies ties, although weak through which the larger society conduit information, support, and social control to individuals and families. The relationships of occupation, common interests, and neighborhood go beyond strong kinship ties and race/ethnicity bonds that hold tightly together into isolated equivalence classes.

Wallace and Wallace (1997) suggest that the disintegration of strong ties that forced individuals to become reliant was the result of continued assaults of public policies of planned shrinkage and gentle neglect. The families that could leave these conditions did, families became afraid to congregate, whether it was on the streets or at the local park, and legitimate economic activity declined. As these weak ties eroded, opportunities narrowed and often disintegrated, the once strong individual and family ties were broken; those who were left in the old neighborhood was forced to be thrown back on their own resources which now no longer worked or were not available.

The purpose of the study by Wallace and Wallace (1997) was to bring to the forefront the socioeconomic determinants of health and how this is created through the marginalization and diffusion of disease and disorder in certain populations. This study found that public health is driven by contagious phenomena affecting socioeconomic processes, disease patterns, and behavioral processes at the neighborhood level. Inner cities communities suffer from urban decompose triggered and sustained by policy,

having a disproportionate influence on the health, safety, and well-being of the large proportion of the American population.

*Sociology of Poverty*

Work by Geronimus (2000) shows that the association between health and SES is among the most robust findings of social epidemiology. The list of social and psychosocial factors that demonstrate associations with morbidity and mortality, and that those in poverty suffer from increased exposure to most of them. Included in these factors are (a) material hardships, (b) psychosocial conditions related to acute and chronic stress, (c) the taxing or disruption of social support systems, and (d) environmental exposures. Further work by Geronimus brings insight to health and poverty by investigating the relationship of long-term or generational poverty in that persistent psychosocial conditions contribute to a greater inclination for the impoverished to engage in some unhealthy behaviors, experience depression, or engage in unyielding high-effort coping, which is a risk factor related for stress-related illnesses in low-income populations (Geronimus, 1992; James, 1994; Lantz, House, Lepowski, Williams, Mero, & Chen, 1998; Northridge, Morabia, & Ganz, 1998).

Others investigating the social epidemiology of urban health (Blankfield et al., 2002; Kirby & Kaneda, 2005; Link, Northridge, Phelan, Ganz, 1998) emphasized that those in lower SES have less opportunity than others to gain access to information, services, or technologies that could protect them from or ameliorate risk. There are further suggestions that the “dose-response” relationship to long-term poverty is more destructive to health than situational poverty circumstances, both for children,

adolescents, and adults (Link et al., 1998; Link & Phelan, 1995; Lynch, Kaplan, & Shema, 1997; Miller & Korenman, 1994). The increase in the prevalence, morbidity, and mortality related to disease and illness of the young and middle-aged adult years, suggest that the cumulative health impact of impoverished African-Americans.

### *Inner City and Healthcare*

Research of Geronimus (2000) suggests that when poverty within inner city communities is so intensified it interacts with characteristics of the urban environment to producing lethal combinations. The phenomenon of poverty entails several social and environmental contributing factors. The factors that relate to poverty include, economic restructuring, lack of adequate housing, and massive reductions in the infrastructure of the urban area. The role of race/ethnicity may also be a contributing factor.

Geronimus (2000) begins the discussion of the economic restructuring, commonly referred to as Urban Renewal Act of 1949 (Fullilove, 2001) or urban revitalization. This set into motion renewal projects in cities across the United States. At the outset, the project was designed to clear large city areas of the slum housing to make way for new modern developments. The vacant land was sold to private developers who used the opportunity to extend the central business district or to attract middle-income residents. Former residents were relocated to areas outside of the renewal area. Jobs brought to the renewed cities through the urban renewal projects moved away from manufacturing; unskilled or vocational labor type jobs, to a service sector economy. The service sector brought with it unreliable and shifting part-time hours with little or no health benefits and often no pension plan. This resulted in extraordinary high levels of

urban unemployment as well as the loss of well-paying, unionized jobs (Wallace & Wallace, 1990). This dispossession led to dire short-term consequences such as loss of money, loss of social organization, and psychological trauma. The long-term consequences are now being lived out in ill health and social paralysis (Diamant, Hays, Morales, Ford, Calmes, Asch et al., 2004; Fullilove, 2001).

The second factor related to the phenomenon of poverty as researched by Geronimus (2000) is the lack of adequate housing in major urban areas. This study states that the increase in housing process is a formidable problem for those with little or no income. Geronimus' citation of Wallace and Wallace (1997) brings to the forefront the scarcity of affordable housing has been exacerbated by reduction in municipal services that resulted in deterioration of the housing market.

Prior to the urban renewal project, African-American communities flourished. Within a short time post World War I, prosperity was seen within these communities. The growth of businesses, the expansion in organizations and associations, and the development of "urban village" lifestyle provided care to the needy, socialization of African-American children, and shared moral values. The Harlem Renaissance is the best-known example of this process (Fullilove, 2001). The decade of the 1950s saw communities that were vital.

The next decade however, saw a change. African-American represented only 10% of the United States population, but represented 66% of the residential areas targeted for urban renewal (Fullilove, 2001). African-Americans were forced out of urban renewal areas, resulting in the strengthening of segregation (Browning & Cagney,



2003). Those who resided in targeted renewal areas were only able to move to other ghetto areas and in some places these ghettos had no available housing. This forced families to share accommodations, creating severe overcrowding. Although public housing was viewed as a solution to the overcrowding, it confined African-Americans to ghettos. Urban renewal intensified the characteristics of urban environment that produced lethal combinations. Urban renewal destroyed communities and families' means of financial security, support systems, social networks, and community resources (Browning & Cagney, 2003).

#### Biomedical Model of Asthma in Children and Adolescents

##### *Pathophysiology*

Asthma is a multifaceted chronic inflammatory disorder of the airways (National Asthma Education and Prevention Program [NAEPP], 1997). There are two forms of asthma, childhood-onset asthma and exercise-induced bronchospasm (EIB). Childhood-onset asthma is associated with genetic susceptibility of the child to produce Immunoglobulin E (IgE) directed toward some common environmental allergens including animal proteins, mold, and dust mites (Baker, Friedman, & Schmitt, 2002). In contrast, EIB symptoms present during or minutes after vigorous exercise or other physical activity and is caused by the loss of heat, fluids, or both from the lungs during physical activity. The hyperventilation of cooler, dryer air into the respiratory tree causes bronchospasm. EIB peaks five to ten minutes after stopping activity and usually resolves within 20 to 30 minutes. Although exercise-induced asthma is present within

the African-American population, childhood-onset asthma is the most prevalent form within the African-American population (Jones et al., 2004).

Childhood-onset asthma cause morphologic changes to occur as a result of repeated airway changes due to inflammation that may be irreversible and contribute to remodeling, alteration in size, mass, and structure of the airways (Baker et al., 2002; Sears, 2000). Several immunohistopathologic changes include airway epithelium denudation, collagen deposition beneath the basement membrane, mast cell activation, and inflammatory cell infiltration. In addition to these changes, some patients experience subbasement membrane fibrosis. This can contribute to persistent lung function abnormalities (Greenberger, Tatum, & D'Epiro, 1999). According to the NAEPP (1997), these physiological changes result in recurrent episodes of wheezing, breathlessness, chest tightness, and cough. Inflammation may cause an associated increase in bronchial hyper-responsiveness to a variety of stimuli or triggers.

### *Etiology*

Several factors place a child at risk for the onset of asthma. They can be classified as generalized or localized (Woodcock & Peat, 1997). Identified risk factors include positive skin test, parental history of asthma, allergen exposure, respiratory infection, some aspects of diet, and affluent factors. It is not likely that a single environmental risk, but rather lifestyle changes, that may combine to cause the disorder to manifest in children (Wickens, Pearce, Crane, & Beasley; 1999). Also reported is increased use of antibiotics in infancy that may be associated with an increase risk of asthma development.

Other risk factors are associated with maternal smoking during pregnancy, passive smoke, and teenage pregnancy. Hu, Przsky, Flay, Zelli, Cooksey, and Richardson (1997) investigated the possible causes of the high prevalence of asthma, a significant association with the development of childhood-onset asthma was found. Bjorksten (1999), Aligne and Stoddard (1997), and the American Lung Association (1998) established risk factors related to passive or second-hand smoke. Martinez (1997) reported that early teen pregnancy is a risk in the development of childhood-onset asthma and asthma-related syndromes. This may be due to a difference in the lung development in children of young teenage mothers. In contrast, Oddy (2000) found an inverse association between exclusive breast-feeding and asthma development.

Risk factors related to diet have been identified to play a role in asthma development. As in the research by Oddy (2000), breast-feeding and avoidance of food during infancy, antioxidant vitamins, dietary cautions, and some fatty acids may provide protection to the airways (Weiss et al., 1993). Other dietary risk factors for asthma include consumption of fast foods, a low intake of milk, vegetables, fiber, vitamin E, calcium, magnesium, sodium, and potassium. When the dietary habits of 114 children with asthma and wheezing during asthma episodes was compared with 202 children in a control group, Hijazi, Abalkhail, and Seaton (2000) found that a low intake of vitamin E was associated with asthma development when adjusted for other factors. An inverse linear relationship was seen with a higher intake of milk and vegetables to the development of asthma. Finally, the NAEPP (1997) identified stress as a mechanism

that may contribute to asthma development by increasing the body's generation of pro-inflammatory cytokines, which promote inflammation of the airways.

### *Treatment*

In a partnership, the American Academy of Allergy, Asthma and Immunology (AAAAI) and the NEEPP, coordinated by the NHLBI, embarked on a best practices program for pediatric asthma. The goal of the asthma management program is for the child to lead as normal lifestyle as possible with control of symptoms while maintaining a normal level of activity (AAAAI, 1999).

The first step in the asthma management is the development of an asthma management plan. An asthma management plan consists of measures to keep asthma under control including regular medications and an action plan. The action plan describes interventions to implement when symptoms worsen including medications, contacting the primary healthcare provider, or seeking other means of healthcare including urgent care center or emergency room visits (Baker et al., 2002; Yoos et al., 2003; Yoos & McMullen, 1999). Within this management plan are specific components of promoting best practice include (a) assessment and monitoring of asthma severity and course of therapy, (b) control factors that contribute to the severity of the asthma-related respiratory episodes, (c) medication therapy including controller medication as well as quick acting medication for acute episodes, and (d) patient education, which should involve the child or adolescent, the family, and other caregivers (AAAAI, 1999).

Significant medical advances have been made in the identification and treatment of asthma. Medical research has just begun to uncover some of the causes of the

discrepancy of asthma found among African-American children and adolescents. These causes may be more closely related to asthma pathophysiology and medications prescribed for the control and treatment of asthma (Finkelstein, Lozano, Farber, Miroshnik, & Lieu, 2002; Rance & Trent, 2005).

### Asthma in African-American Adolescents

#### *Asthma Epidemiology Among African-Americans*

Asthma is a chronic disease of the respiratory tract. Childhood asthma has been identified as the leading cause of 20 million lost school days annually (McEwen, Johnson, Neatherlin, Millard, & Lawrence, 1998; Rodehurst, 2003; Telljohann et al., 2004). The overall prevalence of asthma is higher in African-Americans than White Americans and is more common in boys than girls. In addition, impoverished African-American children are more likely to received asthma related health services from emergency health services, be hospitalized from asthma related symptoms, and are most likely to die from asthma (Mannino et al., 2002; Yawn, Wollen, Scanlon, & Kirkland, 2003). Studies of asthma reveal that there may be a racial discrepancy associated with the disease. This discrepancy may be more than socioeconomic and environmental (Litonjua et al., 1999). The disorder presents inherent biological differences between races that may explain the discrepancies in prevalence, morbidity, and mortality rates.

#### *Pathophysiology in African-Americans*

Research studies show that racial differences in child-onset asthma may exist (American College of Allergy, Asthma & Immunology, 1998; Gregory, 2000). In relationship to asthma and allergic disorders, there is evidence that African-Americans

in the United States have higher serum levels of Immunoglobulin E (IgE) and greater degrees of airway responsiveness (Joseph et al., 2000, Litonjua et al., 1999; Sears, Burrows, Flannery, Her bison, Hewitt, & Hold away, 1991; Sherman, Hollered, Heffner, Seizer, & Weiss, 1993) with a different immunological response to smoking when compared to White Americans. Other discrepancies were found in association with serum IgE and methacholine reactivity, which is not positive in African-American asthma patients, while positive in other groups with asthma. Research suggests that the severity of asthma within the African-American population may be related to these two factors, IgE serum levels, and methacholine reactivity (Baker, Friedman et al., 2002; Carey, Weiss, & Gold, 1999).

Another factor that is vital in the pathophysiology of asthma among inner city African-American children is the words used to describe their asthma symptoms. Researchers found that African-Americans use different word descriptor than White American during bronchoconstriction. African-American used upper airway descriptors, such as tightness throat and voice tight, to describe the perception of asthma symptoms sensation. These descriptors reflect not only differences in the quality of breathlessness, but they also reflect a difference in the location of respiratory sensations (Hardie et al; 2000). Although Hardie and colleagues stated that the reason for the difference in symptom descriptors may be due to ethnic variation in pathway sensation or methacholine activity, ruling out methacholine a relationship between methacholine-induced symptoms and ethnicity.

An earlier study by Nelson and research colleagues (1999) on ethnic differences in the prevalence of asthma in middle class children uncovered possible pathophysiological differences. This team of researchers found that Black and White families with similar SES and residence in the same middle class community, Black children had greater risk of asthma and associated morbidity and mortality rates. With access to medical care and macro-environmental conditions being similar across the study population, the results of the study concluded that differences in biologic factors have a key role in asthma risk.

#### *Asthma Treatment in African-Americans*

Recent research studies brought to the forefront the use of emergency department services by inner city African-Americans with asthma. Several factors are said to be contributory to patterns of emergency department use (Fredrickson, Molgaard, Dismuke, Schukman, & Walling, 2004; Ford, Meyer, Sternfels, Findley, McLean, Fagan et al., 2001; Rand, Butz, Kolodner, Huss, Eggleston, & Malveaux, 2000) including parental difficulty in obtaining medications, episodic care, and self-management that does not conform to current guideline, and parents not being informed of preventive measures. However, a key factor in the treatment of asthma in African-Americans is the need for more asthma medications. A study conducted by Finkelstein et al (2002) concluded that there was a widespread under use of controller medications among Medicaid-insured children. In a collaborative study, Covar (2005) found that African-Americans with asthma required higher doses of glucocorticoids than Caucasians to inhibit the proliferation of inflammatory cell. This finding suggests that

African-Americans may have a predisposition that affects their ability to respond to certain medications at recommended doses.

Morgan, Crain, Gruchalla, O'Connor, Kattan, Evans et al. (2004) focused on home-based comprehensive environmental mitigation intervention to decrease exposure to indoor allergens, including dust-mite and cockroach allergens that resulted in reduced asthma-associated morbidity. The research team enrolled children 5 to 11 years of age in whom asthma had received a diagnosis of asthma by a physician at research centers in eight major cities. The objective of the study intervention was to provide the child's caregiver with knowledge, skills, motivation, equipment, and supplies needed to perform comprehensive environmental remediation. Using a social learning approach that emphasizes the importance of a person's attitude and expectations and modeled behavior in inducing behavioral change, each family received education with modeling of the targeted behavior. The caregiver was instructed to perform the mitigation behavior while the environmental counseling staff provided feedback.

Treatment invention consisted of creating an environmentally safe sleeping zone. This safe zone included allergen-impermeable mattress, box spring, and pillow covers. High-efficiency particulate air (HEPA) filter vacuum cleaners were used to clean carpeting and power brushes were used for bare floors. HEPA air purifiers were set in the child's bedroom to control passive smoke, cat or dog allergens, and mold. For children sensitized to cockroach allergen, professional pest control was provided. The health outcome was positive for the intervention group. Evaluated at 6, 12, 18, and 24 years of age, the intervention group showed significantly fewer asthma symptoms. In



addition, there were significant reductions in disruption of caregiver's plan, loss of sleep by the caregiver and child, and missed school days by children in the intervention group. There were also fewer unscheduled asthma-related emergency department visits. Indoor environmental mitigation is part of the asthma treatment guidelines, although most studies focus on the medication regime of treatment, not mitigation. This study shows that treatment within the inner city community residents' environmental mitigation is needed along with medication regime.

### *Self-Management Strategies*

The following qualitative studies illustrate the approaches that children and adolescents use to adhere to the self-management of asthma (Burkhart, Dunbar-Jacob, & Rohay, 2001; McQuaid et al, 2003; Penza-Clyve et al., 2004). In studies by Burkhart et al. (2001) and McQuaid et al., (2003), children 7 to 11 years and 8 to 16 years respectively, were examined to show the relationship between self-reported and electronically monitored adherence to recommended asthma self-management. Children and adolescents were interviewed to assess their knowledge and perception about asthma. The findings showed that children's adherence behaviors contained errors and that older children knew more about asthma and assumed more responsibility; their adherence was lower than that of younger children. These studies showed that no association was found between adherence and child knowledge, perception about asthma, or responsibility for asthma management.

Penza-Clyve et al. (2004) conducted focus groups with children with asthma, age 9 to 15 years, to generate descriptive data about asthma adherence. The participants

provided descriptions of their asthma experiences, including consequences, adherence barriers, and ways to improve adherence. The children stated as the consequences of asthma; feeling ill, limited peer interactions, and medication frustrations. Barriers to medication adherence were lack of motivation, remembering to take medications, and social barriers. Although children reported that parental reminders help, they were also annoying. However the children would not generate any strategies on their own.

As the picture emerges of inner city African-American children with asthma, images can be seen of these children and the at-risk position in which they are postured. Medical advancements and nursing interventions are necessitated to reduce the burden of asthma among this population. Effective intervention programs, however, must have a foundation based upon the holistic aspect of the disease including the lived experiences of these children.

#### *Lived Experience and African-American Health*

Individuals through their own perspective experience the concepts of health and illness. Kleinman (1980) illustrated disease and illness as explanatory concepts. The patient or caregiver and the healthcare practitioner develop separate explanatory models that are narratives of how each individual's views an illness experience, selects, and evaluates treatment. EMs form a dynamic inferred system composed of sector beliefs and values that create a clinical reality separation between patient/caregiver and healthcare provider. There are negative health outcomes when measurable discrepancies exist between patient and caregiver (Kleinman). It is important to define the model of

illness in which the patient operates in achieving optimal health treatment and management outcomes.

Kleinman's (1980) EM framework encompasses the crucial aspects of an illness (a) etiology; (b) onset of disease processes (signs and symptoms); (c) disease pathophysiology; (d) disease prognosis and course; and (e) disease treatment, management, and anticipated health outcome. An EM provides a template for dealing with, and understanding, the situation (Kleinman; Kleinman, Eisenberg, & Good, 1978). The perspective a patient or caregiver gives to these components is the product of the lived experience through learned knowledge and interaction with family, friends, and others (Mahoney & Engebretson, 2000). Explanatory models may also be cultural constructions that are a product of the patient's/caregiver's cultural knowledge and experiences (Fitzgerald, 1992). Kleinman points out that disease cannot be studied out of context because without context there is a distortion of social reality.

Thus, it is in the context of the interpersonal clinical relationship between the patient/caregiver and healthcare provider that the patient/caregiver is able to make sense of the illness experience. Several studies applied Kleinman's (1980) EM of illness to various diseases. Of the studies that examine childhood asthma, only one specifically explores the EMs of African-American caregivers of African-American children with asthma and few make reference to the elicited patient/caregiver models and the biomedical model of asthma or other diseases.

*Perception of Asthma to Healthcare Outcomes*

Kleinman's (1980) EM of illness is a suggested standard framework for communication between physicians and their patients. This is due to the comprehensive approach to patient perspectives of illness. Using all ten questions from Kleinman's model produces a comprehensive perspective of illness. Handelman et al. (2004) and Peterson et al. (2002) reduced the number of questions proposed by Kleinman in the study of African-American caregivers, thereby eliminating critical questions from the model in the study of pediatric asthma in an inner city population. Handelman and colleagues explored the perception of 19 children ranging from age 5 to 12 years and their mothers (n = 17) about the etiology, pathophysiology, chronicity, medication, treatments, and their morbidity and mortality fears related to asthma. The primary limitation of this study was the lack of information necessary to sufficiently define all components of the explanatory of illness. There is, however, reference to the established biomedical model of asthma.

One important way in which the mothers' perception of asthma differed from the biomedical model was in the concept of chronicity. The concept that the disease is present when the child is asymptomatic is difficult to convey, and this discrepancy is critical to patient understanding of the need for prophylactic or controller medications (Leickly, Wade, Crain, Kruszon-Moran, Wright, Evans et al., 1998). Mothers' perception deviated from the biomedical model was most obvious concerning treatment and medications. Almost one-half of the mothers thought that their children's various medications had the same function.

This study also revealed that inner city children with asthma and their mothers have fundamental differences between the biomedical model of asthma and patient and caregiver's perception of asthma. The work of Peterson and team (2002) supports other researchers (Heurtin-Roberts & Efrain, 1992; McSweeny, Allan, & Mayo, 1997; Patel, 1995) who have reported that asthma education be bi-directional. Two-way conversations are needed where the healthcare provider begins by learning how pediatric patients and their caregiver conceptualize asthma. Conclusions from the study by Peterson et al. stated the African-American families have their own explanatory models of asthma drawing from their cultural context and lived experience with asthma. These studies emphasize the importance of working with these concepts to formulate a model that the patient and caregiver can understand in making rational decisions about care and treatment of asthma (Moos, 2002; Sanders, 1998).

The following research study (Cohen, Franco, Motlow, Reznick, & Ozuah, 2003) is valued in enlightening the research arena on the perception of asthma among African-Americans, specifically those who reside within inner city communities. Cohen and colleagues (2003) offers the perceptions and attitudes of inner city adolescents with asthma. A 32-item self-completion questionnaire was used to elicit a response from 200-adolescents cohort with the most positive screen results for asthma. Students were surveyed regarding severity of asthma, perceptions, and attitudes; along with demographic information. Twenty-six percent of the sample population was African-American and 68% Hispanic with the mean age being 15.7 years. Although 70% reported being in control over their symptoms, approximately one-third had weekly

symptoms and 14% reported having daily symptoms. Almost one-half did not know the name of their asthma medications. This study uncovered the perception of inner city adolescents with asthma. The researchers' conclusions stated that these adolescents expressed feelings of anxiety, fear, and embarrassment about their asthma. Feelings of control were associated with positive attitudes toward self-treatment. In contrast, embarrassment was associated with negative attitudes of not being in control of their asthma.

The following two research studies utilized a nontraditional approach for inquiry to develop and explore childhood and adolescent's perspective of asthma. Rich, Patashnick, and Chalfen (2002) linked asthma and health behaviors by developing visual narratives and Kieckhefer and Spitzer (1995) employed triangulation, both qualitative and quantitative methodology of analysis to develop EM of asthma in children and adolescents.

Rich et al. (2002) studied EMs of asthma and health related behaviors. Twenty children, adolescents, and young adults between the ages of 8 and 25 years completed a Video Intervention/Prevention Assessment (VIA) to obtain EMs of asthma. This research combines participant-generated imagery, a technique developed in visual anthropology with qualitative inquiry to collect and analyze narratives of patients' illness experience. Although this is not the standard method to explore EMs, the results did elicit some of the questions posed by Kleinman (1980). The EMs of asthma held by the participants revealed a broad range of subjects including etiology, pathophysiology, prognosis, medications and fears related to asthma.

These researchers effectively derived patient EMs of asthma from VIA using unbiased methods. The purpose of this study was to examine why some patients not do follow their doctors' advice regarding of their physical condition. Analysis of the VIA participants' EMs of asthma revealed many inconsistencies between knowledge of asthma and the adolescents' behaviors. The participants in this study developed their own understanding and explanations of their condition and what makes it better. In contrast, the biomedical model focuses on the biological dysfunction and asserts that the patient is not just a malfunctioning organism. Finally, Rich et al. (2002) showed that rather than responding to a set of questions designed to reveal EMs of asthma, these researchers were able to observe how EMs extended the traditional concepts.

In an effort to understand the perception of school-age children with asthma, Kieckhefer and Spitzer (1995) examined the behaviors of this population as a link to symptom exacerbation. The purpose of this study was to examine the cognitive links school-ages children were able to make between their personal behavior and their asthma exacerbations. Seventy-five children who were respondents for a larger study served as the sample population for this study. Several instruments were used to collect data. These included, "My Behavior and My Breathing," a 12-item guided interview protocol to measure cognitive links the children made between their behavior and asthma exacerbation. "Asthma Behavior" was a 12-item questionnaire used to measure the child's level of personalized factual asthma knowledge. Finally, the instrument "I Can/I can't," a 12-item instrument was used to assess the child's sense of personal efficacy in adhering to asthma management behaviors. Although factual links were

made between behavior and breathing, the children's ability to explain why their behavior affected their breathing calls attention to the continued need for parents and healthcare providers to assist children in linking the facts they know in a process manner.

Although Kieckhefer and Spitzer (1995) made reference to biomedical model of asthma and proposed inconsistencies between the biomedical model and patient models, this study did not methodologically compare the two models to effectively demonstrate a need for change in current methods of communication between patient and clinician. Research by Rich et al. (2002) as well as Kieckhefer and Spitzer showed there is a significant relationship between the child and parent personal experience with asthma, and that the management and behaviors were more strongly effective by these models than by the biomedical model.

In summation, Kleinman (1980) maintained that congruence between the patient and caregiver explanatory models or perception can be connected to outcomes of healthcare in provisions of patient satisfaction and compliance to healthcare treatments. The designs of the previous studies utilized Kleinman's conceptual framework. Handelman et al. (2004); Rich et al. (2002), and Kieckhefer and Spitzer (1995) also followed Kleinman's conceptual framework. Although the researchers did not elicit EMs directly from the healthcare providers, congruency was made with the biomedical model. These studies addressed the results of healthcare, healthcare outcomes, lifestyle changes, and compliance with patients' and caregivers' perception.



Referenced studies showed that the patient and caregiver perception differed from that of the healthcare provider (Handelman et al., 2004; Kieckhefer & Spitzer, 1995; Rich et al., 2002). These findings may be used to explain the high morbidity and mortality rates related to childhood asthma in the African-American population.

### Adolescent Growth and Development

#### *Cognitive Maturity and Psychosocial Development*

Adolescents' cognitive maturity and psychosocial development are crucial in understanding their decision-making and application processes. Their perception of illness is related to their cognitive maturity and psychosocial development, both directly affecting the variables of resource gain, loss, or investment. Studies have examined the relationship between adolescents' knowledge of health and behavioral risk and their own risky behavior in real-life situations (Gerrard, Gibbons, & Bushman, 1996; Smith & Rosenthal, 1995). In general, adolescents do not seem to relate their knowledge about risks to their own risk-taking behaviors. They know the risks of involvement in certain behaviors and how it can affect their physical and mental health, their families, and future plans. Yet this knowledge does not seem to discourage them from engaging in risk-taking behavior such as not adhering to their asthma treatment plan or regimen (Adalbjarnardottir, 2002).

Central to the cognitive maturation is the psychosocial competence and the capacity to differentiate and coordinate perspectives by understanding the relationship between one's own thoughts, feelings, and desires and those of others. Competence in coordinating social perspectives is a basic capacity in social thought and action, in how

individuals understand and make meaning of social and moral issue and how they function in human relationships (Kohlberg, 1984; Selman, 1980; Sturdevant & Spear, 2002). Thus the adolescent's psychosocial development reflects on their own coping mechanisms and their application of that understanding in their relationships with family, friends, and other support systems. Integrating cognitive maturity and psychosocial development, with its three constructs of interpersonal understanding, personal meaning, and interpersonal skills, with the concepts of health and health beliefs is essential to understanding adolescent behavior, perceptions, and their physical, mental, and social health (Rudolph, 2002; Selman & Adalbjarnardottir, 2000).

African-American children are socialized to become part of the dominant culture while internalizing the values of their African heritage (Littlejohn-Blake & Darling, 1993). Family structure, cognitive maturity and psychosocial development however cannot determine the outcome of socialization. Children of middle-income African-American families are expected to mature at about the same of their White American counterparts, in contrast, children from low-income African-American families generally mature earlier because of the age at which they are required and expected to assume major family responsibilities.

#### *Social Support Systems*

Students attending urban schools often experience numerous environmental risks that may lead to stressful life events culminating in behavioral problems, academic failure, and low social and emotional competence (Gallay & Flanagan, 2000; Sameroff & Seifer, 1995). Meaningful relationships with others give support and assistance

during stressful situations such as the management of a chronic illness. The lack of available resources or personal support systems in times of challenging situations can become overwhelming. Adolescents with inadequate support experience lessened self-esteem and may turn to inappropriate sources for support (Espeland, 1998). Social support from family, school staff, and peers plays a vital role in the response to challenging situations, giving the sense of control-promotion from available resources.

Sartor and Youniss (2002) explored the link between adolescent identity achievement and parental support, social monitoring, and school monitoring; The Identity subscale of the Erikson Psychosocial Stage Inventory (Rosenthal, Gurney, & Moore, 1981) was used to assess the degree to which identity achievement versus identity confusion stage had been negotiated successfully. Data reflecting parental support was derived from the Interpersonal Relationship Scale (Barber & Shagle, 1992). The Behavioral Control Scale developed by Barber, Olsen, and Shagle (1994) was used to measure parental social monitoring. Finally, the School Monitoring Scale was developed to collect data about the amount of school-related interactions students had with their parents. The reliability of all of the instruments ranged from .790 to .860, with the School Monitoring Scale the lowest and the Interpersonal Relationship Scale the highest. The results of this study demonstrated a relationship between parental support and adolescent identity development. The findings showed that adolescent identity formation leads to a restructuring of parent-adolescent relationships rather than breaking ties with the family. Adolescence is a period of transition and exploration that cannot occur successfully without the established of a secure foundation to which

adolescents can return. During this transition period, parental support and involvement, and providing a secure foundation, is crucial to identity achievement and the development of a sense of self. Unfortunately, the sample of students were not ethnically diverse, they represented a suburban, middle-class Catholic school. Parental involvement among this population was likely to be high, influencing adolescent identity achievement differently. Despite the limitations, the findings from this study continue to validate the research findings from numerous other sources about the power of social support on adolescent identity formation.

This was reinforced by the work of Kenny, Gallagher, Alvarez-Salvat, and Silsby (2002) who explored the relationships between parental attachments, academic achievement, and psychological distress amongst a multiethnic sample of academically successful inner city high school students, and the sources of support, life stress, and patterns of resilience. The findings document the adaptive value of parental attachment among adolescents, suggesting that parental attachment support academic achievement and protect inner city adolescents from depressive symptoms. Close and supportive paternal relationship is important for positive psychosocial development in adolescence (Lamb, 1986; Schulman & Seiffge-Krenke, 1997). The study also revealed the involvedness of family relationships and recognized the significance of family and non-family support, including teachers, clergy, school counselors and peers were mentioned. Stable friendships with peers were an important source, along with having one or more close and stable friendships to rely on for emotional support. There were study limitations such as a specialized academically supportive school and students from

higher income families; but the theme of positive support systems and life success is prominent.

Other studies have described supportive relationships with healthcare professionals including the school nurse (Christian & D'Auria, 1997; Kintner, 1997; Nuttall & Nicholes, 1992; Weekes & Kagan, 1994; Weekes, Kagan, James, & Seboni, 1993). Research studies of children with chronic illnesses saw nurses as advocates, recognizing their fears and concerns. Nurses offered comfort, assistance, and health teaching. School can be challenging for a child with a chronic illness. School nurses often offer support by making arrangement for student to take medication on their own, thereby taking control over their diabetes and asthma management by arranging for privacy during testing (Nuttall & Nicholes, 1992). Nurses and other health professionals give support by lending a listening ear to children and adolescents with chronic illnesses (Weekes & Kagan, 1994). In addition, nurses and other healthcare professionals assist the adolescent in becoming proficient in their asthma management by validating effective management skills and intervening when modification is needed. Social support from family, teachers, and peers offer extra, intra and interpersonal resources that can help the adolescents with a chronic illness accept it and take control of the situation (Kintner, 1997), which is crucial in the successful transition of the adolescent's cognitive maturation and psychosocial development.

### *Summary*

Because of medication regimens, self-management strategies, acute exacerbations children with asthma may perceive that their life is not "normal" when

compared to their peers. They may attempt to be “normal” by mismanaging their symptoms. Support from peers, family, and healthcare professional is important for these children and adolescents with chronic illness. These studies give a fragmented picture of the lived experiences of children with a chronic illness, especially asthma. The voices of inner city African-American youth with asthma need to be heard to enhance the picture and to bring insight to the prevalence, morbidity and mortality burden in this population.

### Lived Experience and Chronic Illness

#### *Health and Social Outcomes*

One’s health-related quality of life is associated to numerous other variables including but not limited health beliefs and health behaviors. The results are reflected in self-esteem, school performance, and other psychosocial outcomes. The impact on the quality of life of urban children was the objective of a study by Montalto, Bruzzese, Moskaleva, Higgins-D’Alessandro, and Webber (2004). Using the KINDL, a generic quality of life instrument, children reported their health-related quality of life (HRQL). The researchers found that having asthma did not have a measurable effect on children’s HRQL, however compared to White Americans, minority children had poorer HRQL. Consistent with studies on gender development and chronic illness, boys perceived their current physical state slightly better than that of girls. In contrast, girls believed that they were better able to function in everyday life and had better relationships with families and friends. Noted also girls have a more positive way of coping with asthma than boy. Boys tended to deny the perceived impact of asthma on

their lives, partially to conform to normative masculine notions of a healthy body image (Meijer, Sinnema, Bijstra, Mellenberg, & Wolters, 2000; Sawyer, Rosier, Phelan, & Bowes, 1995; Willis, Miller, & Wyn, 2001). In general, African-American children were less able to function in daily situations, had poorer psychological and physical health, and overall health-related quality of life.

In a similar study by Mansour, Lanphear, and DeWitt (2003) urban elementary schoolchildren self-reported low HRQL scores as early as second grade. The analysis showed that the child's grade, the parent-child relationship, parent employment status, family income, type and presence of health insurance, and school connectedness were significantly associated with HRQL total score. With a sample population of 89% Black, 51% of the sample male and family incomes below \$20,000 per year, these findings reflect the child's own perception of impaired psychological and physical health.

The results of these studies indicate that there is not a direct relationship between asthma status and severity, and a child's HRQL. However, interventions designed to improve and understand the HRQL of inner city African-American children with asthma should focus on the child's social and emotional environment and subjective experiences. The lived experience of these children is mirrored in the results of these quality of life studies.

Numerous studies discuss the lived experience of children and adolescents with a chronic illness or disorder. The findings from these studies, although not specific to asthma or African-Americans or the inner city, help to increase the understanding of the

information uncovered through an investigation of lived experience. Phenomenological studies of lived experience bring findings that are left uncovered through quantitative research. These studies however, represent a gap in the research literature related to the defined population of this current study.

### *Adolescence and the Lived Experience of Illness*

In a phenomenological study by Baumann (2003), the findings showed that adolescent females explained the lived experience of feeling very tired uncovered three themes (a) struggling with being attentively present; (b) calming contentment; and (c) discomforting discordance. The conclusion of this study was that feeling very tired is a complex paradoxical rhythm. This study of 10 high school females adds to the literature on feeling very tired and its connection to health and quality of life, and expands understanding of human becoming.

In studies by While and Mullen (2004) and Wise (2002) focus in on the lived experience of chronic illness in the pediatric and adolescent populations. While and Mullen explored the lived experience of young people with sickle cell disease as they transferred to adult care. Eleven adolescents aged 12 to 16 years participated in this study. Data was reported from semi-structured interviews revealing three major themes (a) physical well-being; (b) prophylaxis; and (c) social and emotional well-being confirming the impact of sickle cell disease on the 'normal life' of this population.

The study by Wise (2002) complements the studies previously reviewed. The aim of this study was to uncover the experiences of pediatric patients liver transplant recipients from the period prior to transplantation, through surgery, and beyond. In-



depth conversations served as the source of data and phenomenological methodology guided the data collection and analysis. The themes that emerged from the data collection and analysis revealed (a) wanting to be connected to others; being the same and different, (b) the lack of ordinary experiences; being surrounded by sick people, (c) the notion of pain, being hurt, or being out of control with their lives, and the final theme (d) parental responses and feelings. The findings revealed that these nine youths and adolescents, ages 7 to 15 are faced with many challenges, including surviving a life-threatening illness while accomplishing normal developmental tasks. As with the findings from the study by While and Mullen (2004), the adolescents in this study were striving for normalcy in their lives.

Chronic illness not only affects the person with the diagnosis but family and friends are also affected. In the study by Gregory (2000) the ways in which chronic illness affects family practices and family relationships. The participants were adults and the medical diagnosis involved changes in the daily diet and nutritional planning. The findings gathered from the semi-structured interviews showed how people with two contrasting medical conditions and members of the same family, seem to preserve a sense of continuity through the disruptive process of attending to medically dietary recommendations. Thus, special diets tend to be assimilated into family practices in ways to promote a sense of continuity that is described as normalcy or leading a normal life.

Werle (2004) conducted a phenomenological study of the lived experience of violence. The study incorporated storytelling as a tool with 13 middle school students

ages 13 to 15 attending a public school in rural western Massachusetts. The purpose of this study was to explore eighth-grade students' responses to hearing stories about the lived experiences of violence. The findings lend support for the use of storytelling in teaching youth about violence by uncovering the thoughts and reactions while developing critical thinking skills.

Other studies support these findings, Forbes, While, Ullman, Lewis, Mathes, & Griffiths (2001), Atkins and Ahmad (2001), Read, (1998), and Gillibrand and Flynn (2000). The findings from the study by Forbes and researchers highlighted the perspective of adolescents with sickle cell disease and indicate that these adolescents need support founded on a range of expertise. Atkin and Ahmad noted how the medical model in isolation may not meet the needs of adolescents with sickle cell disease and recommend the use of a social model of disability (Read, 1998) for understanding the experience. These studies show the need for more studies regarding the perspective of adolescents of illness.

In summation, the adolescent perspective of the illness, family support and other support systems is important to the adolescent in their attempt to regain and maintain a "normal" live is a chronic illness or disorder.

### *Summary*

The literature review discussed the multi-contexts of the African-American adolescent's lived experience with asthma. The contextual factors of urban health, the pathobiological aspects of the asthma disorder, an individual's perspective of chronic illness, and adolescent cognitive maturity and psychosocial development were

presented. The review of literature offered qualitative, as well as quantitative, research studies.

The review of literature began with an in-depth discussion of the social epidemiology of urban health and how urban renewal provided the impetus of neighborhood deterioration. Building on the work of Geronimus (2000), Vlahov and Galea (2002) provided a greater understanding between the relationship economics and politics in the development of 20<sup>th</sup> century cities in the United States emphasizing that prior to the Urban Renewal Act, African-American communities flourished. Researchers Wilson, Browning, and Cagney (2003) along with Wallace and Wallace (1990) continued with a focus on the impact of the urban renewal projects on the family structure, neighborhood ties, financial security systems, and support units that led to substandard living conditions and the breakdown of social ties. The work of Browning and Cagney, Geronimus, and Fullilove (2001) brought to the forefront how the lethal combinations that produce poverty has increased the prevalence of chronic illnesses such as asthma and other negative health outcomes for those residing within inner city communities.

The literature review continued with a discussion of literature related to the biomedical model of asthma and the presentation of asthma within the African-American population. According to the NAEPP (1997), asthma is a multifaceted chronic inflammatory disorder of the airways. Asthma is associated with the body's response to common environmental allergens and the susceptibility of the child to produce IgE. The treatment goals are discussed which includes a normal lifestyle for the

adolescent with the control of symptoms. The research of Fredrickson and team (2004) along with research from Ford et al. (2001) examined the pathophysiological differences, response to triggers, and asthma management that are present in the African-American population.

Understanding the lived experience of chronic illness is influenced by one's perspective of the illness along with one's cognitive maturity and psychosocial development. Kleinman (1978) and explanatory models provided the foundation for the perspective of illness in the African-American adolescent population with asthma. Although established as a model of communication, explanatory models offer the patient's perspective of a disorder, such as asthma, by identifying how the patient incorporates the illness into his or her daily life.

Finally, the adolescent's cognitive maturity and psychosocial development is discussed as a crucial context to the lived experience. Adolescence is a time of rapid psychological, cognitive, and social growth. It is during this time period that the adolescent explores his or her world and attempts new adventures. This is also a time of much needed support from parents/guardians and other adults as the adolescent begins to become responsible for his or her actions, including health behaviors.

Although this literature review presents research as a foundation for the study of the lived experience of inner city African-American adolescents with asthma, there are gaps in the literature. These gaps represent the early African-American adolescent's perspective of their daily life in the inner city, their personal model of asthma, how it

affects their daily life, and how they have interpreted potential obstacles to live a “normal” life with asthma.

## CHAPTER THREE

### Methodology

#### *Introduction*

This chapter details the methods used in this study of the lived experience of young African-American adolescents with asthma who reside within one of this nation's inner city communities. The discussion begins with a description of the procedures that were employed to direct sample selection and data collection and continues with a description for data analysis, hermeneutic phenomenology. The discussion also addresses the protection of human subjects and potential harm to informants. This chapter also identifies the procedures that were used for data analysis. Finally, this chapter presents the methods incorporated to minimize researcher bias and to establish rigor.

#### Sample Selection

This section describes the procedures used during sample selection. The discussion identified the (a) the field site chosen for sample selection and (b) the strategies used for this nurse researcher to enter the field sites. Included also are the descriptions of the criteria and methods used for sample selection and data concerning the young African-Americans adolescents with asthma who reside in inner city communities. The discussion concludes with a description of the procedures used to

obtain informed consent from each informant's parent/guardian and assent for each adolescent informant's participation in the study.

### *The Field Sites*

The field site was a defined geographical area of a large urban public school district in Southern California. The specified field site encompassed five middle schools located and a defined population within an inner city community. The public school district provides student health services through Student Medical Services, School Nursing and Health Services, Parent and Teacher Association (PTA) Clinics, and the Breathmobile®; in partnership with Asthma and Allergy Foundation of America. This school district has developed and joined with outside agencies to provide physical, dental, and mental health services that enable children to be successful in their educational career. Throughout the remainder of this chapter, the word, "clinic" will be used to refer to the Breathmobile®.

Middle schools and the clinic servicing the designated area have been identified as the primary and secondary field sites, respectfully. The middle schools provided access to the young adolescent population who do not receive asthma related medical services from the clinic. Although students are permitted to carry their fast-acting inhaler, authorization from the healthcare provider and parent/guardian must be on file with the school nurse. Therefore, the school nurse is aware of students who may need his/her assistance during the school day. The clinic offers asthma related medical care. A physician, who is an asthma specialist, and two registered nurses staff the clinic. The clinic visits assigned schools every six weeks; the clinic staff assesses students' every

three months. With reoccurring acute exacerbations the students may be evaluated more frequently. Parents/guardians are encouraged to maintain medical follow-up with the student's primary healthcare provider to address other health concerns.

### *Entering the Field Site*

Firstly, this nurse researcher is an employee of the designated public school district and service as one of the School Nurse Administrators. The purpose of the study was described to the Director of School Nursing Services. Furthermore, formal application was made to the school district's Program Evaluation and Research Board (PERB) in the format of a research proposal for approval. Research guidelines have been established by the school district to protect not only the student population and others that may be involved in the research study but also to determine the overall benefits for the educational process of each student. Some of the items discussed in the research proposal were (a) the plan for sample selection, (b) strategies that were used to minimize risks to the young adolescents, and (c) the measures employed to maintain confidentiality of the student and data (Guidelines for Submitting Research Proposals). The approval from the Program Evaluation and Research Board (PERB Approval, Appendix J) was included in the University's research proposal. The signed Statement of Agreement for External Researchers is included (Statement of Agreement for External Researchers). Other documents necessary to begin the data collection process and to enter the field included: Institutional Review Board (IRB) approval from the University of San Diego (IRB Approval, Appendix K), and Protection of Human Subjects (Appendix D).



### *Sampling Criteria*

This study employed qualitative methodology. Rich and Ginsburg (1999) states that many of the life experiences, understandings, and beliefs place youth's health at risk are difficult to quantify, however healthcare providers need to assess and evaluate them. Qualitative research provides tools to examine these influences at work in the lives of today's youth. The individuals that participated in this study are referred to as "participant."

Two methods of sampling in qualitative research were utilized in this study: chain sampling and criterion sampling. Chain sampling employs the process of identifying and soliciting information from key community associates, e.g., the school nurse recognized potential participants. Criterion sampling requires the selection of identified participants by using established criterion (Patton, 1990). For this study, the criterion used for inclusion is (a) having a medical diagnosis of asthma; (b) being of African-American ethnic origin; (c) residing within an inner city community; (d) being 11 to 14 years of age; (e) attending middle school; (f) being willing to give assent to participate; and (g) obtaining parental consent.

The sampling and recruitment were planned to occur at five middle schools and two locations of the mobile asthma treatment clinic located with Southern California. Sampling and recruitment employed both chain and criterion sampling. School nurses, healthcare providers, and parents within the defined area were asked to identify potential participants who met the criteria of inclusion. Once identified, the school nurse

made the initial contact with the student and guardian. At that time, the researcher explained the study, the research schedule, the place of the interview, and to initiate the informed consent process.

In contrast to quantitative research where statistical significance is the aim, repetition and confirmation are the aim of qualitative research. Therefore, the number of participants was established by the saturation of data (Morse, 1994). Saturation refers to the repetition of data obtained during the course of data collection of phenomenon in question. This does not, however, give the researcher license to claim anything more than what is captured at one particular time by any participant offering data (Morse, 1994). It was estimated that data saturation would be reached with 15 to 20 participants. It is within the process of Existential Investigation as well as Phenomenological Reflection that data saturation was reached.

### *Introducing the Study*

The strategy used to introduce the study and select the sample consisted of making contact with the school nurses assigned to the designated middle schools and to reestablish contact with the physician and staff of the clinic. The school nurse was asked to distribute a letter about the study to each student who is eligible to participate in the study as they are referred to the health office (Letter to the Parent/Guardian, Appendix C). Contact information was included in the information letter for those interested in taking part as a participant in the research study. The school nurses identified a sufficient sample, thereby not necessitating the need to identify potential participants from the clinic.

Each letter briefly described (a) the nurse researcher's desire to hear the young adolescent's experiences about living with asthma, (b) the significance of the study, and (c) the monetary award that each participant would receive for his/her participation in the study. At the end of the letter, the parent/guardian and adolescent were afforded the opportunity to receive additional information about the study. Each parent/guardian and adolescent who desired additional information about the study was able to talk with the nurse researcher via a telephone call. An alternate mean of obtaining additional information was for the prospective participant to be given a card, stamped envelope, and asked to identify his/her name and telephone number on the card and mail it to the researcher. It did not occur; all clarification was completed at the time when the nurse researcher made contact with the parent/guardian.

During the telephone call, the nurse researcher described the purpose for conducting the study and the procedures that were used during the study. This nurse researcher stated her desire to learn about the young adolescent's thoughts and feelings about (a) their experiences with asthma and (b) its effects on the typical events of young adolescence, such as school-related activities. The nurse researcher also briefly described the interview process (Young Adolescent Interview Form, Appendix G), including the information that each interview would be audio-taped so that there would be an accurate account of the interview. Appendix G describes the interview questions. Each parent/guardian and adolescent was informed that at the end of each interview the adolescent would receive \$25 cash as compensation for completing the interview. The school nurses were offered lunch in appreciation of their assistance.

*Protection of Human Subjects*

The nurse researcher described the potential risks of embarrassment due the improper release of information, anxiety, or fatigue would be acknowledged and measures that would be provided to minimize them. To address anxiety and fatigue, the interview was conducted in a location that is deemed private and safe. As a precaution because the participants were minors, the interview took place in a location where the participant and nurse researcher were visible to others. Adequate time was allowed for questions and concerns. The participants were free to interrupt the interview at any time to rest or to stop the interview. The researcher remained after the interview to address any concerns that may have occurred during the interview. To ensure confidentiality, a number without the participant's name was placed on each form, field note, and audiotape. All audiotapes and field notes are now in a locked file cabinet and will be maintained for a period of no longer than two years after the completion of the study in the nurse researcher's home.

Participation in the study did not provide direct benefits to the participant. When the nurse researcher described the study, the parent/guardian and informant were told that the study participant's account of his/her experience with having asthma can assist nurses in planning and implementing asthma intervention programs that are appropriate for their age group. However, the participant and parent/guardian were made aware that the adolescent's healthcare might benefit from the information learned during the study.

*Informed Consent and Informed Assent*

The following procedures were used to obtain informed consent for the participant's parent/guardian and the participant's assent to be involved in the research study. An informed consent (Informed Consent for Parent/Guardian, Appendix C) was given to the parent/guardian. Each minor participant was provided with an informed assent (Informed Assent Form, Appendix D) for his/her involvement in the study in the presence of his/her parent or guardian. In compliance with the policy of the university's institutional review board, an adult in the informant's family was to have served as a witness the parent/guardian's and the adolescent's signature on the consent/assent form. Signatures were obtained on the consent/assent forms on the day of the interview. Each parent/guardian and informant was offered the choice of having the consent/assent read to him or her. To comply with policies of institutional review board, the nurse researcher read and explained information on the consent/assent forms to each participant as requested by the parent/guardian.

The nurse researcher followed standardized procedures to assure that the adolescent participant unmistakably understood his/her involvement in the study and his/her rights as a participant. The nurse researcher restated (a) the purpose of the study, (b) the concerns about confidential protection of the data, and (c) the adolescent's right to withdraw from the study at any time. Prior to obtaining the parent/guardian's signature and each informant's signature on the consent/assent forms, the nurse researcher inquired about each participant and parent/guardian to state his/her perceptions of the research study and his/her adolescent's involvement in the study.

Before signatures were obtained, each participant and parent/guardian was encouraged to ask any questions about the study. A copy of the consent/assent was properly distributed. Each parent/guardian received a signed copy of the consent and assent forms.

### *Summary*

This section described the field site and the procedures that were used to enable the nurse researcher to enter the research field and select the sample population. The discussion identified the criteria for sample selection and the strategy employed to introduce the study to middle school African-American adolescents with asthma residing within the inner city communities. This section also discussed the protection of human subjects and ended with the description of the methods that were used to obtain informed consent/assent for the middle school adolescent's participation in the study.

### *Data Collection Procedures*

This section describes the sources of data collection and the procedures that were used during data collection. This discussion addresses the strategies used to schedule the interviews and collect interview data. The Young Adolescent Interview Form (Appendix G) describes the questions used during the interview process.

### *Data Sources*

The nurse researcher collected data from these following sources (a) information received during meetings with the school nurse, (b) the interview with the adolescent; including artistic and literary works, and (c) observations during the interview. Information from the school nurse and parent/guardian identified each participant's

level of asthma severity. While interviewing the informant, the nurse researcher documented her observations of the participant's facial expression, voice tone and pitch, body movements, and silence.

### *The Interview*

The following procedures were used to arrange the interviews. During conversations with the nurse researcher, the parent/guardian, and the informant selected the date, time, and place of the interview. The interview was rescheduled by mutual agreement if the participant was hospitalized or otherwise ill.

The nurse researcher interviewed each participant in a location of his/her choice; however, the parent/guardian's approval was required. All interviews were scheduled after school or on the weekend as not to interfere with the participant's school day. Each participant selected their home, where privacy was afforded but both the participant and nurse researcher is clearly visible to others.

The planned interview session consisted of two parts. Approximately 45 minutes to one hour was allocated for each informant, however it was anticipated that each interview would take less time. The first part of the interview was used to collect demographic information and social epidemiological information (Appendix G). The informant gave his/her name, age, school grade level, school achievements, school activities and clubs associations, extra-curricular activities, favorite activity, favorite subject, least favorite subject, and future plans for college or vocational school. The informant then briefly described characteristics about himself/herself and his/her family.

This information was completed prior to the one-to-one oral interview to allow the maximum amount of time for the interview.

Each informant or parent/guardian was asked to identify the number of missed school days related to asthma for the current and immediate past school year. The informant was asked to identify the number of times that he or she received treatment in the emergency (ER) and the hospital because of asthma within the six-month interval prior to the interview. Each family member; “father,” “mother,” “grandmother,” “brother,” and “sister” in the household was identified by the informant. The informant was asked to identify his/her primary caregiver.

The nurse researcher audio-taped the second part of the interview; each informant told his/her lived experience by responding to the statements and questions that are identified in Appendix G. Each informant was allowed to supplement his or her oral interview with an artistic work or literary work if so desired.

In order to ensure accurateness of documentation of the informant’s experience, two additional strategies were employed. The nurse researcher asked the informant to clarify aspects of his/her account that may not be clear. At the end of a particular account, the nurse researcher briefly summarized its crucial points and validated with the informant whether the researcher’s perceptions were correct. The need for a second interview caused by interruption or malfunctioning equipment was considered on an individual basis.

Data collection ended when the data showed evidence of saturation. The data were considered saturated when it contains a sufficient amount of repetition in the



informants' account and provided an inclusive description of their lived experience with asthma (Cohen, et al., 2000; Lincoln & Guba, 1985). Qualitative researchers state that fifteen interviews can provide sufficient amounts of data in phenomenological studies (Sandelowski, 1995; Van Kaam, 1959).

### *Summary*

This section discussed the methods that were used to collect data that describes the lived experience of middle school African-American adolescents with asthma who reside in inner city communities. The discussion included a description of the planned sources of data collection and the procedures that were used to conduct each interview. The discussion briefly covered the types of data that were obtained during the interview process and the decision to conclude data collection.

### *Data Analysis and Presentation of Data*

Data analysis will be discussed in this section. This discussion provides a description of the van Manen's (1990) approach of hermeneutic phenomenology data analysis and the application to the text of each transcribed interview. The procedures that will be used to minimize researcher bias during data analysis and the audit trail will conclude this discussion.

### *Van Manen's Human Science Approach*

The hermeneutic phenomenological human science approach advocated by van Manen (2001) is used in this current study. The phenomenological aspects of van Manen are ingrained within the philosophical traditions of Husserl's and Heidegger's philosophy (Plager, 1994). According to the work of van Manen, scholarly inquiry is

best attentive to the lived experience. Moreover, van Manen proposes that experience will speak for itself and that a study of experience should be completed in a pre-reflective manner without conceptualization or classification. It is imperative that the researcher's focus is upon the nature of the meaning of experience: What is the essence of the experience?

A form of human science, derived from the work of Dilthey (1985), the aim of phenomenology as described by van Manen (1990) is to translate lived experience into textual expression of its essence, the essential truths. The subject matter of human science is the human world. This world is personified by mind, thought, consciousness, roles, feelings, emotions, actions, and purposes. Furthermore, the human world is objectified in language, beliefs, arts, and institutions. All of these explicate the structures of meaning of the lived world. This seems to be an appropriate approach to utilize when the informants are children or adolescents and their interactions are with adults including parents, teachers, and healthcare professional. As noted by van Manen, hermeneutic phenomenology "edifies personal insights, contributing to ones' thoughtfulness and ability to act towards others, adults, children or adolescents with tact or tactfulness," which is the purpose for the undertaking of this study (Plager, 1994; van Manen).

The works of van Manen (1990) place emphasis on the orientation of the researcher to the phenomenon of concern as well as to the narrative form of the lived experience. It is through self-reflection that the researcher gains a better understanding of the personal experience and thus able to interpret the lived experience. It is through

this self-reflection that the researcher brings to life the lived experience through linguistic transformation. This involves creating a more phenomenological sensitive text from the isolated thematic statements in the words of the researcher. In this methodology, research and writing are intimately entwined.

Lastly the interpretative or hermeneutic elements of van Manen's (1990) methodological approach were also derived from Dilthey (1985). It is through the narrative text the meanings of the lived experience are expressed. These meanings, expressed in textual form bring about an element of interpretation, thus the hermeneutic element. As the researcher selects appropriate verbiage for an untainted expression of the experience within the narrative text, the interpretation of the experience is rooted in the selection of text. The interpretation of lived experience occurs through the reflection of existentials from the life world (a) spatiality (lived space), (b) corporeality (lived body), (c) temporality (lived time), and (d) rationality (lived human relation).

#### *Rationale for Method Selection*

Numerous researchers have attempted to understand the effects of a chronic illness such as asthma on children and adolescents. Most of these studies assume an outcome-based focus by studying the incidence of physical discomforts, the ability to perform the activities of daily living, the achievement of developmental milestones including psychosocial developments, and the cost effectiveness of healthcare. Quantitative designed research is most frequently used in chronic illness studies (Cabana, Slish, Lewis, Brown, Nan, Lin et al., 2004; Castro, Zimmermann, Crocker, Bradley, Leven, & Schechtman, 2003; Docherty & Sandelowski, 1999; Magid, Houry,

Ellis, Lyons, & Rumsfeld, 2004; Silverstein, Mair, Katusic, Wollan, O'Connell, Yunginger, 2001; Weil et al., 1999). These studies are conducted from the perspective of the researcher rather than the informant.

The hermeneutic phenomenological research design is well suited as it looks at life experiences and their meanings from the perspective of the individual experiencing it. This method permits the researcher to give the informant the opportunity to unreservedly express their feelings and values. This freedom results in richer narrative descriptions. Van Manen's (1990) use of diverse data sources such as art, literature, music, and poetry make this design a suitable match for the young adolescents. Today's adolescents are often able to express themselves easier through various media forms. This also opens the interpretation process for the researcher to gain new and difference insights in the adolescent's lived experience with this method.

#### *Preparation of the Data for Analysis*

The following strategies were used to document the interview data. Immediately following each interview, this researcher transcribed verbatim the interview audiotape, checked for accuracy, and analyzed the content of the interview dialogue. This process also allowed the researcher to focus in the experiences of the adolescents. The researcher analyzed each interview before a subsequent interview was completed. This allowed for revision of interview questions, and wording and/or sequencing in order to obtain a better understanding each informant's lived experience with asthma.

The text was initially read to obtain a general sense of the information. This researcher analyzed the data and identified themes within the text. After all interviews

were analyzed, themes were compared with previously analyzed interviews. The fundamental themes that had a common thread throughout all of the interviews and any variations on these themes were identified. All other sources of data, artistic and literary expressions, were analyzed in a similar manner and compared with the data from the audio-taped interviews. Following this, the researcher determined if the data sources supported the fundamental themes.

After a thorough analysis of each interview, the original audiotape, transcript analysis, and interpretive analysis, the researcher composed a rich descriptive account of the adolescent's lived experience with asthma. This narrative reflects what the experience was like for the adolescent.

All study materials including audiotapes, transcripts, field notes, analyses, and literary and artistic works are secured in a locked file cabinet in the researcher's home, accessible only to the researcher. All materials will be destroyed according to the policy set by the University of San Diego, Institutional Review Board.

### *Data Analysis*

The process for analysis of the data involved the construction of themes. These themes were constructed through the six activities of van Manen's (1990) human science approach. The activities include (a) turning to a phenomenon that interests the researcher and commits the researcher to the world, (b) investigating experience as we live it rather than as we conceptualize it, (c) reflecting on the essential themes that characterize the phenomenon, (d) describing the phenomenon through the art of writing and re-writing, (e) maintaining a strong and oriented pedagogical relation to the

phenomenon, and lastly, (f) balancing the research context by considering parts and whole.

Van Manen (1990) describes these themes not as objects or generalizations but more like strongholds in the webs of our experiences, around which certain lived experiences are spun and thus lived through as meaningful wholes. The themes are like the stars that comprise the universes of meaning that we live through. By the light of these themes we can navigate and explore such universes. These themes have phenomenological power when they agree to our proceeding with phenomenological descriptions. Thus the process of discovering themes provides guidance; it also allows one to arrive at a deeper, richer, more comprehensive understanding of the world (van Manen).

The construction of themes allows the researcher to focus on the significant dynamics within the data relative to the research question. As van Manen (1990) clarifies, a theme is the “experience of meaning, a simplification of the summary of the significant factor” (p. 87). Van Manen suggests the use of one of three approaches for discovering or isolating thematic aspects of a phenomenon (a) the holistic or sententious approach, (b) the selective or highlighting approach, and (c) the detailed or line-by-line approach. (van Manen, 1990).

This study utilized the highlighting approach to analyze the data. This approach was selected because of the possibility of this nurse researcher having to transcribe the audiotape recordings. Selecting and/or highlighting are an effective method in which to construct thematic formulations. In this approach the researcher listened to and read the

text several times while attempting to discover which statements or phases were most essential or revealing about the phenomenon. These statements were then selected or highlighted (van Manen, 1990).

Analyzing the essence of the lived experience from the themes necessitates another step. Formulating the essential themes is different from discovering a theme(s); for that reason, because a meaning is echoed does not indicate its uniqueness to the phenomenon. Van Manen (1990) states that in determining the essential characteristic of a theme the researcher's concern is to discover what qualities make the phenomenon or without what qualities the phenomenon would not exist (van Manen).

To determine the qualities that make the phenomenon what it is van Manen (1990) offers the method of free imaginative variation in order to make the distinction between essential and incidental phenomenon. This process entails subsequent questions for the researcher to ask while listening to or reading the interview texts, journals, and field notes from the observations made. These questions include (a) if we were to imaginatively change or omit this theme from the phenomenon, will the phenomenon be the same? and (b) without the theme, does the phenomenon lose its fundamental meaning?

After reflection, sections of the responses that stand out were selected or highlighted as the starting point in the construction of thematic units. The audio-taped interviews were listened to and transcripts were read and re-read to extract and highlight the significant statements. It is through these highlighted statements, themes were uncovered. A theme is the experience of meaning, thus simplifying and creating a

summary of the significant factor(s) (van Manen, 1990). As stated earlier, free imaginative variation takes place during the reflection phase of data analysis.

### *Phenomenological Writing*

As the process of free imaginative variation occurs and is created, the phenomenological writings can begin. This process includes attending to the spoken language, varying the examples, writing, and rewriting. This final step requires sensitivity to the spoken words, the articulation of those words, including the tonalities of the words, unspoken/nonverbal language, and the context in which the dialogue occurs (van Manen, 1990).

### *Summary*

This section discussed the method to be used for data analysis. The discussion explained the application of the van Manen's (1990) approach to the texts of the audio-taped interviews.

### Trustworthiness

For quantitative research, there are standardized methods to ensure the validity and reliability of the research instrument and the research findings. In contrast, for qualitative inquires, the researcher is often the instrument of data collection and can influence data analysis. The researcher's personal attitudes, feelings values, interest, and even knowledge and experience may influence data collection and data analysis. The research audit trail addressed the issues of researcher bias and rigor, and thoroughness of the research process (Lincoln & Guba, 1985).



### *Researcher Bias*

Laying aside beliefs, judgments, knowledge, and experience related to the phenomenon that the nurse researcher may possess is known as “bracketing.” According to Cohen et al. (2000) bracketing is a necessary process that enables the researcher to control biases. One way to accomplish this is for the researcher to document beliefs, feelings, and thoughts about the phenomenon in a journal. For example, impressions formed by previous clinical experiences and literature readings of African-American children with asthma have indicated that the devastating affects of asthma decrease with appropriate medication. Thus, at the beginning of the existential investigation, to ensure trustworthiness, bracketing of this researcher’s assumptions, thoughts, and expectations about successful treatment with medication was initiated. To enhance the audit trail, additional measures were employed to decrease the nurse researcher’s bias and to determine whether the interpretations of the data are trustworthy.

### *Rigor*

The audit trail continues with the demonstration of whether the study meets the criteria for trustworthiness. Credibility, dependability, confirmability, and dependability provide a technique to support rigor (Guba, 1981). Credibility, the first of these techniques, addresses any action that may positively affect the reliability or integrity of the study findings. Establishing credibility occurs through the immersion of oneself in the research for extended periods of time, validating or authenticating data collection and data analysis with study informants. As data collection occurs, the analysis of data

began. Establishing credibility consisted of an intense period of interviewing, reflecting, and writing, thus creating for this nurse researcher extended time periods of being immersed in the data. This immersion occurs by listening and re-listening to the audio-taped interviews, recording field note entries, and discussions of data findings with other research colleagues.

Related to credibility, dependability is the second technique used to establish trustworthiness in qualitative research. The validity, reliability, and stability of the research findings were addressed through the establishment of dependability (Lincoln & Guba, 1985). This aspect of the audit trail assists the nurse researcher to determine whether the interpretations of the data are dependable through the support of tangible data that are consistent over time. Dependability is based on interpretations that are rooted in data that repeatedly explain certain behaviors or responses within the sample (Lincoln & Guba, 1985).

Thirdly, confirmability refers to the ability of another researcher to replicate the study. Confirmability involves auditability; requiring the researcher to record and document the research activities over time. This documentation must also include the decision trail involved in making interpretations and conclusions (Lincoln & Guba, 1985).

Lastly, transferability or fittingness states the meaning and value of the research study's findings to others. Transferability is the degree to which the findings of one study with a particular group of informants and a specific context are applicable in other

contexts or with other informants (Lincoln & Guba, 1985). This technique is related to the potential research consumer and reader rather than to the original researcher.

To enhance fittingness, triangulation is used. Triangulation involves the use of multiple methods, such as interviews, art, and literary works to collect or interpret data about the phenomenon. This converges of data portrays a more accurate representation of the lived experience, and enhances rigor (Polit, Beck, & Hungler, 2001).

### *Summary*

This section described the measures that were used to minimize the researcher's bias. The audit trail will support the nurse researcher's interpretations of the data by offering evidence of the sources of data.

### *Conclusions*

Chapter Three explains the methods that were utilized during sample selection and data collection. The discussion includes procedures that were used to (a) analyze and describe the data and (b) reduce the nurse researcher bias. The approach supported by van Manen (1990), selective or highlighting approach, was defined as the method of data analysis used. This method was used to analyze data describing lived experiences related to chronic illness (van Manen). In this study, the nurse researcher applied the van Manen's selective or highlighted approach to interpret the lived experience of inner city African-American young adolescents with asthma.

## CHAPTER FOUR

### Data Findings and Analysis

#### *Introduction*

The purpose of this study was to investigate and describe the subjective lived experience of inner city African-American adolescents with asthma using a phenomenological approach. Data was gathered through audio-taped interviews that were subsequently transcribed by this nurse researcher. This chapter describes the sample population, documents the participants' responses, and categorizes the study findings into themes with supportive study subject documentation.

#### *The Sample*

This purposive sample was comprised of 13 African-American adolescents with asthma. All resided in an inner city community in Los Angeles County. Six females and seven males were interviewed to obtain their perceptions of living with asthma as a resident of an inner city community.

The discussion begins with descriptions of the adolescents' age, gender, grade level in school, and extracurricular activities along with future professional and vocational aspirations. Additional data identified family and extended family members within the adolescents' household. Table 1 lists each adolescent's age, gender, and grade level in school. This section also addresses gender differences in the number of illnesses and the frequency of acute asthma-related episodes and healthcare facility use

among the adolescents (Table 2). Thirteen middle-school African-American adolescents with asthma who live in an inner city community participated in the study. Two of the participants are siblings. A randomly selected number replaces the participants' names.

Table 1

## Participants' Demographic Information

Participants' Number	Age	Gender	Grade
101	14	Female	8 <sup>th</sup>
102	15	Male	8 <sup>th</sup>
103	14	Female	8 <sup>th</sup>
104	12	Male	6 <sup>th</sup>
105	12	Female	6 <sup>th</sup>
106	12	Female	7 <sup>th</sup>
108	12	Male	6 <sup>th</sup>
110	12	Female	7 <sup>th</sup>
111	12	Male	6 <sup>th</sup>
112	12	Male	7 <sup>th</sup>
113	13	Male	7 <sup>th</sup>
114	12	Male	7 <sup>th</sup>
115	14	Female	7 <sup>th</sup>

The participants' ages ranged from 12 to 15 years, with 12.78 years identified as the mean age. Females were slightly older than their male counterparts; the mean age of the six female and seven male were 13 years and 12.57 years, respectively. The adolescents were involved in a limited range of extra-curricular activities that included mostly sport-related activities such as football or basketball. Although the females participated in sport-related extra-curricular activities, some were involved in other activities such as the youth choir at church and one was a member of the school's Step Team. Another enjoyed socializing with her friends.

During the first part of the interview, each participant was asked to complete a survey that described the family and extended family members in his/her home. Two (15.38%) lived with their parents, father and mother. Two of the participants lived with their father and stepmother (15.38%) and one lived with his/her mother and stepfather (7.6%). Seven of the participants lived in homes with only one parent; five (39.46%) lived with their mother and two (15.38%) lived with their grandmother. One (7.6%) participant lived with his/her father and great-grandmother. All of the participants had a stable home life with a concerned and knowledgeable caregiver.

The interview survey also queried participant regarding school absenteeism; full and partial days, hospital admissions, emergency/unscheduled health provider visits (ER), and wheezing episodes. Table 2 lists these results. Participant 102 could not offer a specific number of wheezing episodes and participant. Participant 111 stated that for him, wheezing episodes were often related to physical activity during Physical Education at school.

Table 2

## Acute Asthma Episode Related Characteristics

Participant	School Absences (# of days)	Hospital Admissions (# of days)	ER Visits	Wheezing Episodes
101	20	0	1	2
102	30	2	2	a lot
103	2	3	2	5
104	3	1	2	23
105	5	3	1	3
106	0	0	1	4
108	10-15	0	7	10-15
110	10-15	7+	10	10
111	0	0	3	N/A
112	1	0	2	2
113	3	0	0	7
114	5-10	0	1	5-10
115	2	0	2	4

Two of the participants could not give a specific number of wheezing episodes; “a lot” was their response. However, for another participant, the wheezing episodes were related to the physical activity (running) that is part of the physical education class

in school. It should be noted that for one of the participants, although his best recollection indicated 23 wheezing episodes, was receiving ongoing healthcare with his primary care provider and an asthma physician specialist. His was also following the prescribed medication regimen with both preventive or controller medications in addition to rescue (inhaler) medication.

It should be noted that nine (69.23%) of the participants have been prescribed both controller and rescue asthma medications; of the remaining four (30.76%), two were diagnosed within the past year and two were classified as mild, intermittent and were prescribed only rescue inhaler medication.

The male participants had 62 days of school absences, whereas the female participants had 44 days of school absences. Further data findings revealed the following: the total days of hospitalization were 16 with females having experienced more days than their male counterparts; 13 (81.25%) and 3 (18.75%) respectively. It should be noted that none of the female participants attributed asthma exacerbations to menstrual or hormonal influences. Both genders experienced the same number of unscheduled healthcare visits, which included emergency room, urgent care, or healthcare provider visits, 17 each for a total of 34. Finally, the total number of wheezing episodes for both genders was 115, with males experiencing twice as many episodes (80 episodes = 69.56%), than the females (35 = 30.43%). The timeframe for all asthma health related characteristics started at the beginning of the 2005-2006 school- year, which was in July, August, or September.



### *Summary*

This section described the participants' family, grade-level, extracurricular activity profile, demographic, health related history, and missed school days. According to the participants' reported information, some of the male participants had more missed school days than the female, but the female participants reported more days of hospitalization.

### *Data Analysis Process*

The data collection began with a demographic survey. After the completion of the demographic survey, the open-ended, unstructured audio-recorded interviews were conducted. All 13 interviews were conducted in a common area of the participant's home (living room or dining area). The participant's parent or guardian was present or within hearing distance of the interview. Each interview lasted between 30 and 45 minutes. The time varied according to the extent of the information offered by the participant.

At the completion of the interview, each participant was asked if he/she had any questions for the nurse investigator. It was during this time that the nurse investigator informed the participants of her history of asthma. Two participants responded with inquiries for this nurse investigator, one participant "interviewed" this nurse investigator.

Each interview began with the question, "What can you tell me about asthma?" The nurse investigator employed an interview protocol that served as guide. Examples were given to bring clarification for the questions and probe questions were utilized to

encourage response elaboration from the participants. Probe questions, such as “How do you handle these situations?” “How would you describe the effects of asthma on your life at home, school, with your friends?” “Why do you feel that asthma has no effect on your life at home, school, with you friends?” This type of interview questions allowed the opportunity for the participants to describe their own reality (Kortesluoma, Hentinen, & Nikkonen, 2003). Immediately following each interview, the nurse investigator made reflective notations in the field notes that served as a memory aid for analysis purposes.

The participants wanted their “voice” to be heard. One male participant stated, “I just want to help.” A female participant did not know about the monetary gift until the end of the interview, like the male participant, she wanted to help; she also wanted her voice to be heard. Parents and guardians were equally willing for their adolescent to participant to assist in getting their “voices” heard. One parent made special arrangements for the interview time and one of the guardians stated that her adolescent “would be a good one to interview. Another parent, whose adolescent had previously been involved in several asthma related research studies, was eager for her adolescent to participate.

After each interview, the audio recording was transcribed and typed verbatim by the nurse investigator. After the transcription of each interview, an initial analysis was conducted utilizing van Manen’s (1990) analytic process. The text was initially read to acquire an overall sense and familiarity with the data. Subsequently, the nurse investigator analyzed the data and identified themes within the text. This process was

carried out with each interview and a comparison was done with each interview.

Essential themes common to all interviews and any variations were identified. The data analysis process of van Manen (2001) begins with an examination of the text to uncover the meanings. All three of the procedures recommended by van Manen to isolate thematic structures, as follows: “(1) holistic approach, (2) selective highlighting approach, (3) (detailed line-by- line approach,” (pp. 92-93) were used in the analysis of the interview data.

During the analysis, the audiotapes were listened to and the transcripts read several times to obtain a sense of the whole. Sections of the text were highlighted and coded using the language of the participant. And finally, each transcript was examined line by line to discover what each response revealed about the participant’s lived experience with asthma.

### *Rigor*

Rigor was achieved by utilizing the following strategies. In the seminal work of Lincoln and Guba (1985), the authors stated that hermeneutic phenomenological study may achieve rigor, however, such terms as validity and reliability were not appropriate. For naturalistic studies the appropriate terms were (a) credibility, (b) fittingness, (c) auditability, and (d) confirmability.

### *Credibility*

In an effort to establish credibility, the nurse investigator became oriented to the phenomenon of interest by identifying what was of personal interest about the phenomenon, subsequently; all preconceived suppositions about African-American

adolescents with asthma and life in the inner city were identified and set aside through the process of bracketing. This made it possible for the nurse investigator to avoid making preconceived judgments about the nature of the meaning of the phenomenon thus allowing the nurse investigator to learn about the African-American adolescent's world of asthma rather than the nurse investigator's perspective.

### *Fittingness*

The participants were purposively sampled from the communities within United States Census Bureau zip codes that ranked at or below national poverty levels (Department of Commerce, 2000). The sample population had demographic characteristics similar to those of inner city African-American adolescents in the United States (U.S. Department of Health and Human Services (2000).

### *Auditability*

Specific details about the study were recorded to allow for another researcher to follow the decision trail. Written details of the research protocol were kept with the transcripts. Field notes, personal notes, and written transcriptions of the interviews were also kept. The method of van Manen (1990) was adhered to without variation.

### *Confirmability*

Confirmability was evidenced within the findings. When the reader is able to gain some understanding of the meaning of the inner city African-American adolescents' with asthma perspective of their lived experience, confirmability will be apparent.

### Research Findings

This study provides meaningful analysis with a core theme emerging from the data, *My Asthma, My Life*. The Essential Themes that was uncovered from the data are: (a) *My Asthma My Way*, which is an essential theme related to the adolescents' life journey with asthma which includes how each adolescent developed their individualized perspective of asthma in their world. The second essential theme, (b) *My Asthma, World*, addresses the inner city African-American adolescent with asthma and his/her relationship with family, peers, counter-peers, and academic achievement (Table 3). The major essential themes tell of the adolescents' resilience in living with asthma. The following section discussed these themes in more detail.

The phenomenological framework of van Manen (1990) supports the view that there is not one single lived reality. Experiences and perceptions are individualized and change according to circumstances, resources available, and maturity level. Utilizing the phenomenological framework, this nurse researcher took the transcripts and scrutinized the meaningful elements to extract meanings, categories, and their descriptive fundamentals from the subjective accounts of the participants. No two experiences were the same making many different meanings possible (Munhall & Oiler, 1986; Stringer & Genat, 2004).

This study illustrated that African-American adolescents residing in the inner city understood and had the ability to live productively with asthma by possessing an understanding of asthma that adapts to meet their cognitive and psychosocial needs. The adolescents in this study were equipped with the knowledge of asthma as reflected in

each of their responses. They were able to identify how their actions affected their individual asthma health status and triggered respiratory responses.

Table 3

Themes and Essential Themes

Essential Themes	Sub-Themes
Core Theme: My Asthma, My Way	
Themes:	
My Asthma, My Life	Learning of Diagnosis
	Description of Asthma
	Prevention and Treatment of Symptoms
	Self-Developed Strategies
My Asthma, My World	Life in the Inner City
	Self-Image
	Family and Home
	School and Asthma
	Peers
	Ethnic and Racial Peer Counterparts

The presentation of each theme is in the language of the participant (Cohen, et al., 2000), which explains the meaning of each theme by describing the experiences identified in the sub themes. In this data some words are italicized to represent an

emphasis that the nurse researcher heard or recognized in the body language, voice pitch, or tone of the participant during the interview.

### My Asthma, My Life

The adolescents' world was defined by their perception formulated through their present stage of cognitive development; what they have learned from living with asthma. It was defined by their own personal experiences related to the conditions and responses to the challenges that they have faced on a daily basis. These challenges have created an individualized perception of asthma phenomena. The four sub-themes of My Asthma, My Life consist of (a) Learning of the Diagnosis, (b) Description of Asthma (asthma in their own words) that detailed the adolescents' knowledge and impression of asthma, (c) Knowledge and Description of Asthma, and (d) Asthma Care Regimen including self-developed strategies. These sub-themes are part of what affects the adolescents' lived experience and thus their perspective of asthma. Except for the two adolescent who were diagnosed with asthma within the last year, these inner city African-American adolescents have had their lifetime to shape their perspective of the asthma, their live experience. And for the two adolescents who were recently diagnosed, their perspective of asthma and their lived experience is also being shaped by their current stage of cognitive and psychological development.

#### *Learning the Diagnosis*

Each adolescent participant reported that the memory of his/her experience with asthma is distressing. Ten of the adolescents were diagnosed with asthma during childhood and for them, the memories of living with asthma were vivid. Two of the

adolescents were diagnosed with asthma in the past year and for one the severity and frequency of acute wheezing and asthma episodes increased after he and his family moved to Southern California from rural central North Carolina. The past and present events that were interrupted because of a mild or acute wheezing episode came to life as they gave their description of learning about asthma for the first time.

Each adolescent could recall the childhood experience that helped him/her learn the diagnosis of asthma. For a 12 year-old male who learned of the diagnosis less than one year ago, the events that captured his attention were:

“The same age that I am now, it barely kicked in like last year, last year was when I started finding out that I have asthma and it was hard for me to breathe and *I had* shortness of breath and coughing and wheezing. When I start playing a lot and then when I get done playing or running a lap or five laps when I get done I have to sit down and catch my breath and take deep breaths to catch my breath and coughing and wheezing *while trying* to catch my breath.”

For a 14 year-old female the events that she remembered in learning about the diagnosis was when she was about 5 or 6 years old.

“One time I was outside playing in the front yard, and I collapsed on the front grass. I went to the hospital and then they put me on oxygen pump and put me on medicine.”



The memory of learning of the diagnosis of asthma was vivid for another 12 year-old male who first learned about the diagnosis at age 5 years.

“I just felt something hurt, I just felt my chest getting tight. I said ‘Mama I can’t breathe.’ And she said I got to take you to the hospital and she took me to the hospital and I was in the emergency room and the doctor said you got signs of asthma and they put me on the breathing treatment and my chest got better.”

And for some the learning of the diagnosis was from their parent.

“I think I was playing *a* game, Play Station®, I started breathing hard, and they (father) told me I got asthma.”

These adolescents learned about asthma after experiencing the effects. The ordeal is associated with emergency department visits, and the explanations about asthma were provided by their parents or the healthcare provider.

#### *Knowledge and Description of Asthma*

Each interview began with the question: “What can you tell me about asthma?” This question elicited responses related to the physiological aspects of the illness. The descriptions that the adolescents gave about their knowledge, explanation, and impressions of asthma indicated that they knew that the complications from asthma may cause death. They also had knowledge of the link between their actions and acute respiratory episodes. Two adolescent males, age 12 years, formed the following explanations of asthma:

“Well when you are in the weather and its cold and like you, white thick stuff builds up in your lungs and cause you to have an asthma attack and like, when the weather change you can like wheeze too. It’s not good to be in the cold and when you are running a lot in the cold it like catching me and that white thick stuff make me start wheezing.”

“When you have an attack your chest gets really tight and it start to hurt, where sometimes it makes you want to cry. That you can sometimes get embarrass, but if you run to people, if you want them to know that you have it and that you really need it or something, then you have to go somewhere else and take it. Like if I’m having an attack and I need my inhaler and I’m around my friends and they might think of me different if I have asthma. So I have to go somewhere else or something.” (Probe: do your friends know that you have asthma?) “Most of them do. Yes.”

A 12 year-old female added these adolescents’ explanation of asthma with:

“Well, I’m always wheezing a lot and I use my asthma pump at home and at school and I have to take it on field trips. And in really hot weather I can’t run, I wheeze and it makes me gag a little bit.”

A 14 year-old female gives her concise description of asthma.

“What is it like? A chronic disease that closes the lungs.”

These adolescents, like most of the participants in this study, learned about asthma and developed their explanation of asthma after experiencing its effects and the explanation of those experiences were developed by them through their daily experiences of having asthma.

Some of the adolescents' explanation of their knowledge and impression of asthma indicated they knew that the complications from asthma could cause death. Two female expressed their knowledge about asthma and its deadly outcome. One 12 year-old stated:

"I know it is a lung disease and it can kill you."

A 14 year-old female stated simply:

"You can die from it."

The brother of an adolescent male had died from the complications of asthma and other medical complications. This same adolescent experienced a cardiac arrest at the age of 10 years, the day prior to his culmination ceremony from elementary school. These are his words.

"I was wheezing so I took my pump. I waited five minutes, I was not feeling better so I took it again, and I waited another five minutes. I still was not feeling better, so I took it again. I don't remember much after that. My mother told me that she heard me wheezing and having problems breathing in the next room, she was bringing me my mechanical nebulizer when she heard a thump, I had

fallen out. She told me later that my heart had stopped and she started CPR and called the paramedics.”

One aspect of some adolescents’ explanation and impression of asthma was the knowledge that the complications of asthma can threaten life. The adolescents’ thoughts of asthma more frequently were the expression of the realities they had learned about living with asthma than their actual life experience. All of these adolescents experienced the symptoms and complications of asthma before they learned of their diagnosis.

The adolescents’ expressions of asthma frequently described the realities that they had learned about living with asthma. Some of the adolescents understood the effects of asthma on the body. However, their knowledge and impression of asthma was still expressed and explained in the language familiar to them, such as “short of breath.” An adolescent male, 12 years old, said:

“When you have an attack your chest gets really tight and it start to hurt, where sometimes it makes you want to cry. That you can sometimes get embarrass, but if you run to people, if you want them to know that you have it and that you really need it or something, then you have to go somewhere else and take it. Like if I’m having an attack and I need my inhaler and I’m around my friends and they might think of me different if I have asthma. So I have to go somewhere else or something.”

This adolescent was concerned about living with the signs and symptoms of asthma, letting his friends know, and having to go to others for assistance when he is not able to control any breathing difficulties. Another adolescent male, 14 years old, expressed similar concerns.

“Uh, that you can’t breathe in dust, uh that I can’t uh since I got asthma I can’t always run, uh I try not to use my asthma pump too much.”

An adolescent female believed that “asthma was not a good thing to have” when she described its effects on her ability to participate in physical activities. Her description was that asthma affected her ability to participate in physical activities.

“That asthma is that you ought to have medication with you. That it is not a good thing to have. Because it stops you from doing a lot of activities. Cause like if you run or anything you got asthma you start wheezing a lot.”

Most noticed an increase in asthma related symptoms as they became older and entered into middle school with the introduction of daily structured physical education. However, a few of the adolescents thought that they would “outgrow it” and perceived that it was better because of less unscheduled health provider visits and hospitalizations. One adolescent, age 12 years, thought his asthma was getting better, by stating that “in elementary school it was worse, in elementary school, everything I do, especially when the weather changes, like when the weather change, I can’t breathe.” In opposing fashion, an adolescent female, thought that her asthma was getting worse:

“ . . . it is different because when I was smaller it didn’t affect me that bad. But now that I’m getting older in age it affecting that bad where sometimes I stumble over my tongue and I can’t speak that good and it affects my breathing. Or I could be just sitting in the house somewhere and I will just start coughing or wheezing.”

Yet another adolescent, a 12 year-old female commented:

“Now I go to the hospital a lot more than when I was younger. It is more severe now. I remember going to the hospital but not as much as now.”

A 13 year-old male responded by saying that he does what he would normally do. This adolescent’s impression of asthma is to manage and control the asthma without permitting the asthma to control his life. A female described her impression of asthma from lessons learned:

“I know what certain things to do, I know what certain things not to do, I know what triggers my asthma. I know what doesn’t trigger my asthma. I know more now than when I was in elementary.”

Her impression of asthma was formed from her knowledge and experience of the chronic ailment and not allowing it to control her. All of these adolescents’ description of asthma was determined by comparing the effects on his or her life before and after learning of the diagnosis.

*Treatment, Prevention, and Self-Developed Strategies*

The adolescents that participated in this study were receiving healthcare from their private healthcare provider. All had a prescribed prevention and treatment regimen. In addition to the prescribed regimen, each adolescent had formulated his or her own individualized intervention plan that incorporated the prescribed medical regimen.

These personalized plans helped the adolescent to alleviate symptoms of asthma. One adolescent said,

“I didn’t know how to control it like I do now. I know what medicine to take; I know what medicines not to take. I know what certain things to do, I know what certain things not to do, I know what triggers my asthma, I know what don’t trigger my asthma. I know more than when I was in elementary.”

This adolescent benefited from knowledge that caused her to be able to divert possible acute respiratory episodes. Another adolescent female expressed similar thoughts and intervention for effectively avoiding triggers and diverting respiratory distress. The adolescent was aware of triggers and what works best for her to control acute respiratory symptoms.

“At school when I’m doing class work I can’t be in a hot room. Or then I start to cough and gag and wheeze. At home, well like, playing outside on a warm day I can’t really play kickball or soccer or baseball.”

Rest and hydration were routine measures that some adolescents used to alleviate acute respiratory symptoms during physical activity. One female offered her measures of precautions before she begins her physical education class.

“Running fast on the track, playing baseball and doing gymnastics. Well, once I start running or playing I get dehydrated and I can’t breathe that good and I get like lazy I very tired fast.” She continues with:

“I drink a lot of cold water and after I drink my water I take two puffs of my asthma pump and then I start PE. I have one asthma pump in the nurse’s office and one in my backpack.”

An adolescent male stated:

“[I] take cold water and breath real slow.”

Adolescents used various methods to prevent respiratory distress included frequent rest periods, avoidance of potential triggers. For one male adolescent, his story continues with:

“When I wake up in the morning, I know that I have to take my treatment so that’s why I get up at five, because I take my treatment. I still have to, I get my clothes ready at night and stuff but after I take my treatment and my medicine and stuff, sometimes I get sleepy and I sit down for awhile and I fall to sleep. And I wake up late after taking my medicine.”



The adolescent had learned to manage his care while attempting to live a “normal life.” Another adolescent male described important lessons learned concerned maintaining control over asthma symptoms.

“When I play basketball, I can’t really breathe when I run down the court. I bring my inhaler and take it right before I start practicing. And I use my Advair, Predisone, and the pump; I forget, Albuterol. I take Advair everyday, twice a day, before I go to school. Before PE because I know I will start wheezing because I know we have to run and when I run my chest start getting tight, so I take two puffs and I start feeling better and my chest won’t be tight anymore.”

A female adolescent gives her regimen in maintaining a “normal life:”

“I drink a lot of cold water and after I drink my water I take two puffs of my asthma pump and then I start PE. I have one asthma pump in the nurse’s office and one in my backpack.”

The decisions and behaviors described by the African-American adolescents in this study were based on their knowledge and their experience with asthma and not from a healthcare practitioner or their parent/guardian. Their responses to the healthcare were a product of their previous experience when facing acute respiratory episodes. These adolescents have learned to recognize the conditions and situations that preclude

acute asthma episode. They have learned the importance of knowing about asthma and managing their own care was part of their efforts to live a normal life.

### *Summary*

*My Asthma, My Life* exposed the realities of asthma to this population of African-American adolescent that reside in an inner city community. Many learned their diagnosis and the changes that occurred in their day-to-day life. From the adolescents' perspective, the knowledge they acquired related to asthma influenced their impression of asthma and its complications and consequences. Through their knowledge and lived experience with asthma, these adolescents developed strategies to cope with their asthma.

### *My Asthma, My World*

There are many situations that arise and challenge the inner city African-American adolescent with asthma. The most challenging situations are often those that are associated with self-image, relationship with peers, and social situations that can make one vulnerable. The sub-themes that were uncovered from the adolescents' stories were self-image, peer relationships, ethnic counterparts, and asthma.

The African-American adolescents' perspective related to life in the inner city is a key part of the lived experience of the African-American adolescent phenomena. Some of the adolescents felt that there was no difference in the cause, care, and treatment of other adolescents with asthma. One female adolescent stated:

“I don't think it's different because it's a disease people get.”

A male adolescent responded by saying,

“I don’t think there is a difference. The kids who got bad asthma, yea.”

The following are the thoughts of a female adolescent who perceived that her life with asthma and living in the inner city was different from others:

“Like I live out here and they live in the suburbs or something like that? Uh, I think it’s very different because out here it like it’s not that clean out here, it’s dust and stuff out here and like germs.”

A male adolescent also associated a difference in his life with asthma was due to where he resided:

“Probably because I’m nearer the dust and mold and stuff and they are in a different place than where I am and it will effect me more because like Beverly Hill and stuff I know is a clean place and out here is a totally different place from that so out here and the weather will get to me and stuff. And would have more attack then I usually would.”

The adolescents in the two previous stories perceived that life with asthma was different based on one’s community of residence. The response of a female adolescent brings insight:

“They don’t go through what I go through and I have asthma. It’s different but it’s really not, I look at myself like everybody else except I got asthma. It is

different because they can do things that I can't do, because I know that my asthma will kick in. They can run without any problems, they can play without any problems."

In her view, life in the inner city with asthma brought limitations that had to be overcome.

Inner city African-American adolescents described their perception of life with asthma. Situations that challenged them were often related to school and their academic achievement. Their stories describe the affects of asthma on their daily life and their self-directed measures to maintain a normal life. The adolescents voiced their feelings and told of their strategies that helped them face each day.

### *Self Image*

Each participant described his or her self-image in contrast to his/her peers. Some adolescents, based on that comparison, did not believe that living with asthma prohibited them from identifying with their peers. For example, a 13 year-old male said:

"I do what I normally do." ... [I'm] one of the group"

A 12 year-old female used these words to describe herself:

"It doesn't keep me from doing nothing, because I do everything a normal person does. I carry my pump and whenever I feel like [I'm] I use my pump."

A male adolescent, 12 year-old, compared his physical abilities with his peers and said:

“It does not keep me from doing what I want to do.”

Another male adolescent comment:

“I would take my pump and it would slow me down from doing what I’m doing, and I keep going and stop, keep going and stop.”

Each adolescent’s self-image included daily experiences that enabled him/her to identify with their peers. However some adolescents believed that living with asthma made them different from their peers. Some believed that they had less physical stamina than their peers during physical activities and this was one of the defining factors of their self-image. According one 14 year-old female:

“They don’t go through what I go through and I have asthma. It’s different but it’s really not, I look at myself like everybody else except I got asthma. It is different because they can do things that I can’t do, because I know that my asthma will kick in. They can run without no problems, they can play without no problem.”

And a 12 year-old male responded by saying,

“When I start playing a lot and then when I get done playing or running a lap or five laps when I get done I have to sit down and catch my breath and take deep breaths to catch my breath and coughing and wheezing to catch my breath.”

He continues with:

“I sometimes feel upset because those sports I want to do I really can’t do. Because if I wanted play and if I get aggressive and start playing hard and aggressively then that’s when I start coughing and wheezing and start having shorten of breath. And it’s like hard for me to play sports like that.”

These adolescent were redefining their self-image related to their participation in physical activities both at school and home. One aspect of the inner city African-American adolescent’s lived experience with asthma that was influential in the adolescent developing positive self-image was school.

A female adolescent, age 14 years, describes her efforts in attempting to maintain a positive self-image due vulnerability related to asthma symptoms that prevents her from participating in a well-loved activity with friends:

“. . . cause I be wanting to do all kinds of stuff like double-dutch and it stops me cause when I do that I can’t do that a long time ‘cause I start breathing real hard. [and] Drill team.”

Another female, age 12 years continues with the following:

“Running fast on the track, playing baseball and doing gymnastics. Well, once I start running or playing I get dehydrated and I can’t breathe that good and I get like lazy I very tired fast.”

For the African-American adolescent with asthma, self-image is formulated around who they are at school and the curricular and extra curricular activities in which they participate. These adolescents have diligently put forth efforts to develop and maintain a positive self-image so that they may continue to be part of an established peer group. The adolescents’ self-image was based on their ability to interact with their peers.

#### *Family and Home*

The adolescents demonstrated an understanding of the effects that asthma can have on their daily life, including at home. These adolescents were expected to complete household chores and maintain their bedroom. They participated in family functions and contributed to the well being of the family. According to one female adolescent’s perception, “. . . on effect on my life at home.” Another female adolescent supports this statement by commenting, “It doesn’t affect me at home, I am more active at school than I am at home.” For this adolescent, physical activity was her link to acute asthma episodes.

The environmental properties of the inner city were another aspect of home and asthma. When probed regarding having a pet, particularly a dog or cat, one male adolescent voiced the sentiments of all of the adolescents:

“....no, I don’t have a pet, [I] probably [would have] a dog. My parents said ‘no’.”

His reason for not having a pet was not related to his asthma but the responsibility of caring for the pet.

One of the female adolescents connected the effects of asthma on her life at home with the physical environment of the inner city:

“It’s a big effect because it’s dusty outside. Like it be messing me up because it is dusty outside. Because dust be flying and it be making me wheeze.”

These adolescents are an integral member of the family. For most of them, asthma has been part of their life since they could remember, thus doctor’s visits, medication regimen, and the responsibility of the illness was part of the family’s daily routine. The adolescents did not identify or recognize any effect on their lives at home because this is the manner to which they had become accustomed. They lived the normal life of an adolescent with the responsibility of chores and homework.

### *School and Asthma*

The inner city African-American adolescent with asthma is confronted with many challenges at school. Often facing consequences that are associated with chronic absenteeism or frequent tardiness may present with significant challenges. For example, one adolescent male, who was one to two grade levels behind his same-aged peers partly due to excessive absences related to asthma.



Some adolescents' academic grades suffered because they had difficulty completing class assignments. An adolescent female gave an account of an ongoing situation she encounters when she tried to successfully complete a physical education assignment:

“ . . . at gym when run, I can't run that's when I get a bad grade.”

An adolescent male described his circumstance in trying to “keep on top of things,” as follows:

“When I'm doing a test and I'm having a test and I have an asthma attack and I have to go to the nurse and she won't let me leave until I stop wheezing completely. And I understand that but when I get back the day is almost over and the period is done and he is collecting the test and he'll tell me I can finish it tomorrow and then I have to make-up more homework after that. And stuff.”

He continues by adding:

“(PE [physical education], yea like when I'm running around and exercising it will bother me and I have to stop and get my pump, because I let my PE teacher hold it.”

Some adolescents who miss school or class time because of asthma receive a disheartening grade or become overwhelmed in efforts to make-up for missed class

time. Their stories illustrated various challenges that an adolescent with asthma at school.

In the past, medicine accessibility at school was a challenge. However, with recent changes in the educational law and school policy related to specified medications, students can carry their inhaler and self-administrator medication when necessary. Some parents and healthcare providers prefer the medication to remain in the school nurse's office. One male adolescent, who was diagnosed less than a year ago stated:

“At school, I have it [inhaler] with the nurse, so if I start having it [difficulty breathing] I go to the nurse and take it.” (*Instructional time is missed*).

An adolescent female, speaks of the accessibility of her inhaler:

“I drink a lot of cold water and after I drink my water I take two puffs of my asthma pump and then I start PE. I have one asthma pump in the nurse's office and one in my backpack.”

School presents the greatest challenge for the adolescent with asthma. The need for parents and the adolescents to assure that school personnel and teacher understand asthma is vital to the health and academic achievement of the adolescent.

### *Peers*

The adolescents did not perceive that having asthma prevented them from participating in peer-group activities; an essential part of adolescent growth and

development. One male adolescent said, “They call me asthma boy, but they help and take it easy on me when we are playing.” Some adolescents found ways to be with their friends without involvement in physical activity, for example one female adolescent had plans to go to the movies with her friends after the interview. For others, interactions with friends involved a combination of physical activity and social interactions, such as “hanging out.” One female adolescent told about such interaction:

“They are very helpful when it comes to that part. Like don’t run or something like that. Because you know how boys will be boys and play with girls and they say you don’t run and they just go and get them for me or something like that. And when I’m with my friends we just walk around and sit down sometimes.”

Although she would experience signs of acute respiratory distress at times, the support from her friends made her interaction with them more enjoyable.

Adolescents want to identify with their friends during peer-group activity. Both male and female participants had friends who were aware of the adolescents’ condition and were able to recognize the acute asthma symptoms. One male adolescent voiced his opinion of his peer-relationships:

“[My] friends know, [I] have friends with asthma.”

A female adolescent responded with:

“. . . Yeah because my friends like to run and play with people. I can’t run with them because I get tired [but they help me, when I get tired].”

The aspects of asthma were minimized with these adolescents because of their friends and the willingness to assist and modify activities. The majority of the adolescents' peer-relationship was not challenged because of asthma. However, one male adolescent gave a very different account of his peer-relationships:

“Like when I’m playing I’ll have an asthma attack in the middle of it so that I stop and but they keep going and I just want to play and my mom or my dad have to wait and I have to calm down and stop playing I miss all the fun they do, like go to the park I know I can’t go because I know they my asthma will start acting up and no grown-ups around. [I’m allergic to] grass, mold, and all that stuff.”

The previous story illustrated that living with asthma affected the adolescent's interaction with his friends. Nonetheless, he met the challenge by modifying some of the activities or replacing some with board games or computer games.

#### *Ethnic and Racial Peers Counterparts*

The question of lifestyle difference between the inner city African-American adolescents with asthma and their Latino and White counterparts with asthma conveyed mixed perceptions from the adolescents. Although the adolescents in this sample lived in neighborhoods with Latinos and attended school with them, peer interaction at school and home was with other African-American adolescents. In addition, interaction with other ethnic adolescents was quite limited, if at all, as with others from a different SES unless it was a relative or a family friend.

Some of the adolescents perceived that ethnicity or race had few or little effects on an adolescent with asthma. The words of an adolescent male described his impressions of asthma and other peer groups:

“I don’t think it is different, I think it’s all the same. I don’t think color counts; it’s just how you fell inside.”

A female adolescent expressed a similar opinion:

“I don’t know. No difference. It does not matter what race you are.”

Another male adolescent simply stated:

“I really wouldn’t think it would be different.”

Some of the adolescents had a differing perception and opinion regarding the phenomena of life with asthma of their Latino and White adolescent peers. One female adolescent voiced her perception by stating:

“Well, some Latino people sometimes they know they have asthma and they just keep playing and they think it is not a problem. When other people can’t breathe that have water and sit down and they are okay.”

These are the words of an adolescent female who was diagnosed with asthma less than a year ago:

“Yea [there is a difference] and then no [there is not a difference]. Yea, because we are all the same age. No [because a] white girl would not live out here. Mexicans, we would both have the same thing going on. [A] White [girl] would live in a cleaner neighborhood or something like that because I live on a busy street and she probably won’t. She probably would not have to deal with that much traffic and smoke or something like that.”

A male adolescent stated:

“I think there is a difference in the medicine, not in their life. I don’t see a lot a Latinos with asthma.”

The adolescents’ perception of their counterpart peers, both Latino and White adolescents with asthma, gave varying insight to the life of the inner city African-American adolescent with asthma. For the adolescent, race was not a factor but the life of an adolescent with asthma, however, environment and medication was associated with a difference in the life of adolescents of other races and ethnicities with asthma.

#### Development of a Model

The resultant data from the interviews of the participating inner city African-American adolescents with asthma in this study led to a contextual analysis of two essential themes: My Asthma, My Life, and My Asthma, My World. The two essential themes captured the context of the initial nine themes extracted from the interview data. The essential themes and their descriptive elements represent a continuum between My

Asthma, My Life (the adolescent's cognitive view of asthma) and My Asthma, My World (the adolescents' psychosocial view of their world with asthma) with My Asthma, My Way as the balance to being normal (the lived experience). These two essential themes illustrate the varying, yet similar ways these adolescents have made concerted effort to be normal, like their peers.

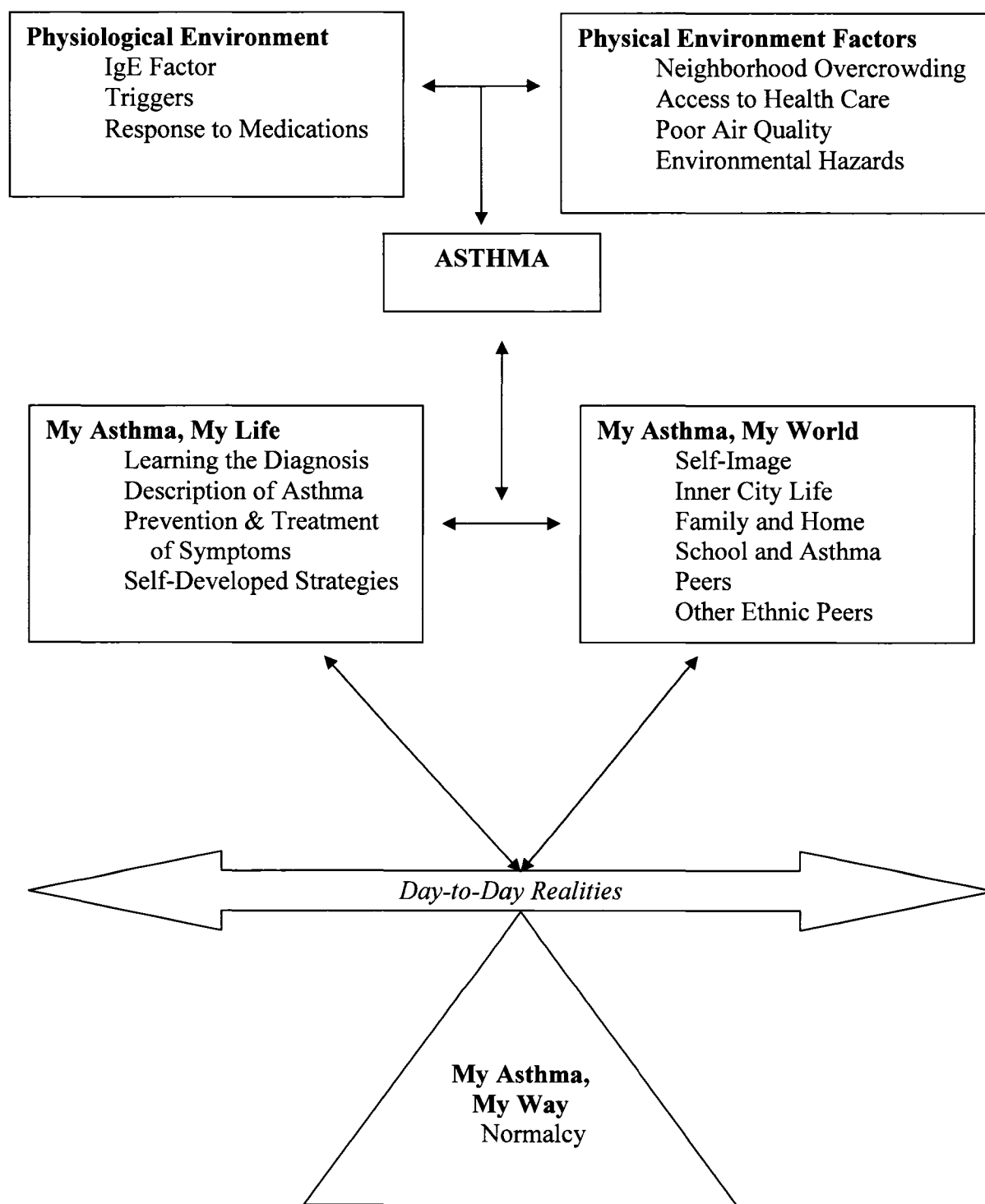
The core theme, My Asthma, My Way, summarizes the collective conceptualizations reflected in the adolescents' lived experience and perspective of asthma. There is constant interaction between My Asthma, My Life and My Asthma, My World, bringing the adolescents' life into back balance.

The inner city African-American adolescents' lived experience of the phenomenon of asthma was one of being normal, like his/her peers. The acquired knowledge and experience with asthma and self-developed strategies to decrease and resolve symptoms of asthma gave the adolescent a sense of control over the unpredictability of asthma. Despite the disruption that acute respiratory episodes caused in the adolescents' daily life, they continued to face life as normal adolescents, rather than surrender to asthma limitations.

The adolescent current stage of cognitive and psychosocial development shaped a more complex system of evaluating situations and symptoms producing a more positive or less traumatic outcome. The adolescents represented in this study are forming a stable and satisfying identify with a sense of direction that is based on consistent, personal, successful experiences and social acceptance and recognition. A representation of this conceptual occurrence is illustrated in Figure 1.

Figure 1

Model of Inner City African-American Adolescents with Asthma





Situations that frequently challenged the adolescent were related to school and their academic success such as absenteeism, missed instructional time, and at times, the inability to complete school assignments in a timely manner. The adolescents addressed this challenge by being prepared with prescribed and self-developed interventions. Friends provided a supportive network at school and home. These participants were determined to maintain their friends and be involved in peer activities. Finally, their perspective of others with asthma was limited, but with mixed views. Some voiced that their ethnic peer counterparts, the severity and treatment was different, others stated there was not a difference. For the participants of this study, their perspective of asthma is that asthma does not keep them from doing anything that they want to do.

The research findings reflect the perspective and views of the participants. Their perspective and views are based on their lived experience with asthma and is formulated through the cognitive and psychosocial stage of adolescent development.

#### Summary of Research Findings

The purpose of this phenomenological study was to explore the life experience of inner city African-American adolescents with asthma. The utilization of van Manen's (1990) method of qualitative analysis allowed this nurse researcher to examine the text of the transcribed interviews in a systemic manner. The analysis of the 13 transcribed interviews yielded themes that described the subjective lived experiences of adolescents aged 12 to 15 years with varying severities of asthma. The resulting synthesis revealed the adolescents' experience with asthma as a complex event. The core theme, *My Asthma, My Way*, formed the pendulum of which all the themes balanced. The two

major sub-themes of My Asthma, My Life and My Asthma, My World are related to and form the continuum of the core theme.

My Asthma, My Life describes the adolescents' memories of when they learned about the diagnosis of asthma, including their first memory of associating the disease with the symptoms and treatment. The description opened an understanding that each of the adolescent's knowledge and understanding of asthma is different and their explanation of asthma is likewise different. The African-American adolescent participants described their course of action when symptoms occurred and the methods they employed in an effort to avoid acute respiratory symptoms. They explained their self-strategies for home and school. Only two of the participants remember life without asthma. For those two participants, learning about asthma and how to manage it came quickly with experience. The adolescents' knowledge, explanation, and self-developed strategies were fashioned from their personal, lived experience with asthma.

The adolescents spoke of My Asthma, My World as asthma being about people, not a disorder. The sub-themes of self-image, life in the inner city, family and home, school and academic achievement, peer relations, and ethnic peer counterparts spoke of the world in which these inner city African-American adolescents live. Although their inner city communities may be isolated from others because of socioeconomic factors, these adolescents voiced their perspective about living with asthma and living a normal life. They spoke of their relationship with family and being responsible for chores. In accord, they all said that there were no changes in their relationship with their family

because of asthma. According to the adolescent participants, their parents' expectation of academic achievement remained the same.

## CHAPTER FIVE

### Discussion, Implications, and Summary

Chapter Five presents a discussion of the lived experience of inner city African-American adolescents with asthma. The discussion examines the study's finding in the context of the research literature describing the experiences of adolescents with chronic illness, the theories of cognitive maturity, psychosocial development, and Hoffman's Conservation of Resources (COR) theory. An examination of the challenges that confront the African-American adolescent with asthma is viewed from their perspective. Using Hoffman's COR theory, the discussion addresses self-image in the lives of inner city African-American adolescents with asthma. Piaget's theory of cognitive maturity and Erikson's (1963) theory of psychosocial are integrated throughout the discussion to maintain the contextual focus. The implications for nursing education, nursing practice and nursing research are discussed, as well as the limitations of the research and the conclusion.

### Discussion

The purpose of this study was to investigate the lived experience of inner city African-American adolescents with asthma. The investigation began by the adolescents answering the lead interview question: What is the lived experience of inner city African-American adolescents with asthma? Thirteen participants ranging in age from 12 to 15 years were asked eight open-ended questions along with completing a

demographic survey. The responses to the eight questions lead to the two essential themes: My Asthma, My Life and My Asthma, My World. The data told of the adolescents' quest to live a normal life by their rules and not the potential limiting affects of asthma. Thus emerged the core theme: My Asthma, My Way.

Adolescence is a time of transition and rapid physical changes. The adolescent undergoes major cognitive, emotional, and psychosocial maturity (Burns, Barber, Brady, & Dunn, 1996; Glasgow, Strycker, Toobert, & Eakin, 2000). An adolescent's cognitive and psychosocial development may be challenged when faced with a chronic disorder such as asthma. Clinicians generally rely on the physical and medical aspects of the asthma disorder to assess the illness and evaluate the treatment modalities along with the progression of the disorder. Although these reports are vital to positive outcomes, understating the disorder through the lenses of the adolescent cannot be discounted to ensuring appropriate care and treatment. Previously mentioned research studies have uncovered a genetic factor that influence the sensitivity response in African-American to various triggers. Other factors, however, may also influence positive outcomes.

Various factors may influence the adolescents' perspective of asthma, such as cognitive maturity. The factor of being an adolescent itself is a primary influence in the perspective of lived experience with asthma. Adolescents cognitively process information differently than adults (Bronson, 2000; Flower, & Saewyc, 2005; Piaget, 1928). The development of an asthma treatment plan without the input of the adolescent may not yield successful outcomes.

## My Asthma, My Life

### *Learning the Diagnosis*

The work of Kintner (1997) offers support for children and early adolescents in accepting their chronic health condition and the need for ongoing treatment. The event and age when the adolescent learned of the asthma diagnosis can be critical in the adolescents' cognitive maturity and psychosocial development (Dragone, 1990). The adolescents in the present study learned of the diagnosis during early or middle childhood except of two who were diagnosed within the past year.

The events that made the participants aware of his/her diagnosis of asthma were similar to events that helped children and other adolescents in a similar situation (Reid & Charache, 1995). The adolescents in this study remembered the tangible and sometimes traumatic event that occurred when they had an asthma-related acute respiratory episode during childhood or early adolescent years. The event informed the child or adolescent that they must take precautions during activities that their peers may not have to take. Similar to children with diabetes mellitus, sickle cell disease, and cystic fibrosis, some learning of the diagnosis came during an emergency department visit or an unscheduled hospitalization. One male participant tells of such an event when he learned of the diagnosis just prior to an unscheduled hospitalization (Christian & D'Auria, 1997). The work of Kintner (1997) related to adolescents with asthma supports the experience of adolescents in this study who learned of the diagnosis from their primary care provider and parent/guardian. The recall of this event that made the

adolescent aware of asthma was similar to those of adolescents with cystic fibrosis, sickle cell disease, diabetes mellitus, and other chronic disorders.

### *Knowledge and Description of Asthma*

The response the adolescents gave to the lead interview question: “What can you tell me about asthma?” shows evidence of the cognitive processing of information. The participants’ response ranged from their own definition of asthma to the effects of asthma on their personal life.

Each adolescent presented a description based upon his or her knowledge and lived experience with asthma, which was linked to his or her cognitive development. For the adolescent participants of this study, their description of asthma ranged from the simple to the complex. Their knowledge reflected information received from their healthcare provider and parent/guardian. They were able to associate the symptoms of acute asthma episodes with shortness of breath, airway constriction, mucus production, and wheezing. The adolescents understood that tightness in the chest and the coughing that were also acute respiratory symptoms. Using their own vernacular, each adolescent provided unique and individual descriptions of asthma. Their descriptions included phrases and words such as “make me gag,” “stumble over my tongue,” and one adolescent referred to mucus as “the milk.” These words demonstrate their perspective and knowledge including how the adolescent has come to accept the disorder of asthma without personification of the disorder.

The cause of acute symptoms varied for each adolescent. Some participants voiced that they experienced more frequent symptomatology during hot weather, for

others cold weather. One adolescent said that he could be sitting and have acute respiratory symptoms. All voiced their apprehension about the unpredictability of asthma acute symptomatology. It is vital that adolescents understand the physiology of asthma in their own terms to be effective in the control and treatment of the disorder.

The adolescent participants in this study understood and realized the seriousness of asthma disorder. Their comments such as “you can die from it,” “it’s not a good thing to have,” “I know it is a lung disease and it can kill you,” and “a chronic disease that closes the lungs,” attest to their perspective of the disorder. They all expressed their views differently, demonstrating varying stages of cognitive processing (Knight, 2005).

#### *Prevention, Treatment, and Self-Developed Strategies*

Adherence to prescribed prevention and treatment measures are crucial to the control and management of asthma. Except for two of the adolescents with only rescue medication, they all had a complement of asthma-related medications. They were able to demonstrate what medication is taken for what and when, but not necessarily the action of the medication. They understood the importance of following their asthma treatment plan. The adolescents voiced that their actions were vital in making the difference between them being “normal” like their friends or being different (Bursch, Schwankovsky, Gilbert, & Zeiger, 1999; Knight, 2005). This self-efficacy was evident in the development of their personalized self-development strategies. This finding is supported by the work of Ladebauche (1967). Adolescents in the present study accepted the responsibility of their asthma management. Moreover, the management strategies developed by each participant was based upon previous experiences in preventing and



controlling the onset of acute asthma symptoms (Velsor-Friedrich et al., 2004). The participants indicated that a series of interventions were attempted before seeking help. For most cases these interventions were successful in relieving the symptoms. The strategies these participants used included rest, keeping hydrated, avoiding triggers, and in some cases, finding other ways to interact with their friends. As one adolescent emphatically articulated

“I bring my inhaler and take it right before I start practicing, and I use my Advair, Predisone, and the pump – I forget Albuterol. I take the Advair everyday before PE because I know I will start wheezing because I know we have to run and when I run my chest start getting tight. So I take 2 puffs and I start feeling better and my chest won’t be tight anymore.”

Management of asthma during school hours presented the greatest challenge for the adolescent participants, including spending the majority of the day in school, introduction of structured physical education, navigation of a large school campus, plus multiple teachers can pose many challenges for this age group. This has led the adolescent to take a greater role in the responsibility of the management of asthma away from home through seeking appropriate support at the best time and developing a better understanding of their asthma. The research study of Flower and Saewyc (2005) provides evidence for adolescents aged 12 to 16 years shows cognitive capability of successfully managing asthma symptoms by safely self-carrying and self-administering their rescue medication with minimal supervision.

### My Asthma, My World

The psychosocial development of an adolescent is a passage across the lifespan with the rationale of solving eight crises, each with its own goal of achieving an intact personality. According to Erikson (1963) the crisis of adolescence concerns identity versus identity-confusion. During this passage, adolescents are attempting to achieve a stable and satisfying sense of identity and direction (Erikson). This is a time when the adolescent needs consistent personal experiences involving success and satisfactions combined with social acceptance and recognition. The critical issue during this stage of psychosocial development is for the adolescent to resolve the question, “Who am I?” This is a time when they have met many people, experience various situations, experimented with various identities, and now begin to integrate their previous and present identities into a meaningful sense of self. Nevertheless, they may have a sense of confusion about their identity or their role in society. *My Asthma, My World* is the lived example of adolescents attempting to develop a meaningful sense of self with an adversity, such as asthma. Family, friends, and healthcare professionals provide an important link to the adolescent with asthma.

#### *Self-Image, Family, and Peers*

Adolescence is a time of psychosocial development, a time of establishing one's identity through belief systems, attitudes, and values. As the adolescent transitions from childhood through adolescence, and into adulthood, the integration of past and present experiences forms the essence of one's sense of self. Successfully overcoming adversity, such as effectively managing a chronic illness like asthma, is dependent on

the adequacy and effectiveness of the adolescent's personal resources and social support systems (Dembo, 1994). Adolescents who are connected with family, peers, and other adults are considered to be resilient and able to develop a positive self-image. (Resnick, Bearman, & Blum, 1997).

The work of Sartor and Youniss (2002) has shown that this period of transition and exploration cannot occur successfully without the establishment of a secure foundation to which adolescents can return. As the adolescent struggles to achieve independence from their parents or caregiver they still depend on their parent or caregiver for support. During this transition period, parental support and involvement, and providing a secure foundation, is crucial to identity achievement and the development of a sense of self.

The adolescents in this study were developing a positive sense of self through the management of asthma and academic achievement with the support of parents/guardian and peers. According to Kyngäs (2004) support networks are vital to adolescent with a chronic disease. One female participant speaks of the effect of asthma on her life at home and with her friends stating, "It doesn't effect me at home" and that of her friends, "they are very helpful when it come to that part (asthma management)." Another participant learned about the diagnosis when he was five years old from his grandmother. He voiced a sense of accomplishment as he told of his daily medication regimen. All of the adolescents had the support of their parent/guardian who served as a secure haven as they continue to learn about and lived with asthma.

The findings of a study by Wirrell, Cheung, and Spier (2006) support the developing self-image of inner city African-American with asthma. The study concluded that asthma has a lesser impact on psychosocial functioning than other chronic illness (Calam, Simpson, Morris, Woodcock, & Custovic, 2003; McQuaid, Koppel, & Nassau, 2001). In the study, seven-year olds reported difficulty with exercise, making physical activity one of the most important modalities of social interaction in the age group. In contrast, adolescents felt that this potential limitation does not impact their social functioning, including popularity.

### *Inner City*

Inner city life was identified by the adolescent participants of this study to be not the cause of their asthma but as a factor in the symptomatology. As one female adolescent stated, her life with asthma in the inner city is different from someone that lived in the suburbs because she lived on a busy street. Other also talked about the dust and pollution in the inner city. The adolescents voiced an overall environmental health risk of living in the inner city.

None of the adolescents articulated the poor economic outlook of inner city America as an issue relative to their health. A male participant stated that he believed that others living in other communities received that same level of asthma care and treatment. The adolescents spoke of professional and vocational aspirations but none spoke of specifically leaving the inner city or the health link between the inner city environment and asthma. This fact could be attributed to the adolescent's stage of development as well as the various SES of their family.

Access to healthcare was not a perceived issue to the adolescent. Regular medical appointments were maintained. All of the participants had health insurance. Medication prescriptions were refilled as needed and any additional equipment, such as mechanical nebulizers, were paid by the health insurance. This research presented contrary findings to research stating that access to healthcare is a factor in the usually high morbidity and mortality rate related to asthma in this population. All of the adolescents were able to present their medication regimen and tells the basic function of the medication.

#### *School and Asthma*

Adolescents spend approximately one-third of their day and approximately one-half of their waking hours in school. School presented the greatest challenge for these adolescents. During this stage of psychosocial development the adolescent acquires increasing responsibility for and management of their own chronic disorder (Kygäs, 2003), which may also posed challenges in the school setting. The accessibility of one's medication created challenges. Adolescents in this study spoke of leaving an inhaler with the teacher during physical education or having to go to the nurses' office for symptom relief. With permission and approval from the adolescent's healthcare provider and parent/guardian, an adolescent can carry his or her inhaler and self-medicate, however, some parents/guardians prefer their adolescent to go to the school nurse for assistance.

Another challenge with school occurs with missed instructional time. One adolescent stated that he could be just sitting and have an acute episode. Another

adolescent voiced her concern when in a classroom was too hot, she had breathing difficulties. The adolescent's home physical environment could be controlled but it is often difficult to control the school's physical environment because of very limited funds (Bartholomew, Sockrider, Abramson, Swank, Czyzewski, Tortolero, et al., 2006). Programs such as Tool for Schools™ are designed for classroom mitigation of various asthma related triggers, however to implement the program in middle school would be costly and time consuming.

Acute respiratory episode often resulted in missed instructional time thereby affecting academic achievement. Adolescents gave their account of the frustration of missing instruction and attempting to make-up missed class work while keeping up with current class assignments. Moonie, Sterling, Figgs, and Castro (2006) suggest further studies related to missed instructional time because this does not always result in an absence, but affects adolescent achievement and self-image. The adolescents' perspective of missed school days ranged from zero to "a lot," however the adolescents were not queried as to how much instructional time was missed, specifically time spend in the health office only and not released to go home.

#### *Other Ethnic Peers*

Even though the adolescents in this study attended school with adolescents of other ethnic origins, according to their responses, interaction outside of the classroom was limited. Culture and language differences created a natural partition. In response to the interview question: "How do you think your life, as an African-American is different than a White or Latino adolescent with asthma?" their responses varied from

life being the same when referring to Latino adolescents with asthma but different for White adolescents with asthma. One adolescent stated, “I think there is a difference in the medicine, not in their life. I don’t see a lot of Latinos with asthma.” Another stated, “I don’t know. I think it is the same, but I can’t tell because I don’t know a White person with asthma.” Still another voiced, “Different medicine, better medicine.” One final comment was the consensus of several of the adolescent participants of this study:

“Probably (*is different from others*) because I’m nearer the dust and mold and stuff and they are in a different place than where I am and it will effect me more because like Beverly Hills and stuff I know is a clean place and out here (*inner city*) is a totally different place.”

### *Limitations of the Study*

The findings of this study represent the lived experience of asthma from 13 African-American adolescents who reside in an inner city community. The limitations identified in this study are related to the interview process, brevity of the interviews, adolescent vernacular, and the inexperience of the researcher.

The interview process posed one limitation on the findings. Adolescents can be difficult to interview because they may attempt to make an impression with the interviewer with their quality of knowledge of the subject matter or not be willing to speak freely fearing that they not have the knowledge base expected. To address this, the researcher prefaced each interview with instructing participants that there were no

right or wrong answers. The interview was “about them” and how they lived with asthma day-to-day.

Another limitation was related to the brevity of some of the interviews. Although most of the adolescents spoke openly and were very willing to share their story, it was difficult of the researcher not to take the lead. Probe questions were used to have the participant expand on a topic. In conjunction with the brevity of some of the interviews, adolescent vernacular created a challenge in understanding their story. Some the phrases used to refer to the participant’s aspect of life with asthma were personal which made it difficult to translate and comprehend.

The inexperience of the researcher presented another limitation. The researcher became more confident with subsequent interviews, being able to better observe the participant’s verbal and non-verbal language.

### Theoretical Framework

Adolescence is a time of rapid physical, cognitive, and psychological change (Sturdevant & Spear, 2002). The psychosocial tasks of adolescence are multifaceted and include attainment of cognitive maturity, morals and values development, and are a time that African-American adolescents establish their own identity. This period of transition, with the loss and acquisition of intrapersonal, extrapersonal, and interpersonal resources is characterized by accumulated stress, tension, and at times inadequate coping mechanisms (Ayers, Sandler, & Twohey, 1998; Rudolph, 2002). Family and other social support systems are critical to the adolescent’s successful transition into adulthood (Eisenberg, Neumark-Sztainer, & Perry, 2003; Espeland,



1998; Moos, 2002). The relationship between stress, social support, and the obtainment, retainment, and protection of the aforementioned resources is delineated in the theoretical perspective, the COR framework (Hobfoll, 1988).

Within this framework are the concepts of one's perspective of personal control, stress, adaptation, personal resources, and resilience. A change in the quality or quantity of resources affects the perspective of one's level of control in a particular situation, thereby influencing the perspective of stress and the stress response. This control can have control-promoting and control-inhibiting variables (Spitzer, Bar-Tal, & Golaner, 1995).

Control-promoting variables are those intrapersonal, extrapersonal, and interpersonal resources that promote a sense of control, reduce stress, and promote adaptation. Control-inhibiting variables are the lack of these resources, therefore, increasing stress and reducing adaptation (Hobfoll, 1988). The premise of COR framework is that individuals have both an innate and a learned desire to conserve and renew their resources so as to successfully cope with stressful situations (Spitzer, et al., 1995).

In essence, the COR framework is based on the principle that individuals strive to obtain, retain, and protect their resources thereby effecting their perspective and lived experience. Resources, in turn, are defined as those things that are highly valued by individuals or serve as a means of obtaining those things that are highly valued. The three major classes of resources identified include (a) intrapersonal resources (cognitive ability, self-esteem, self-efficacy, and physical and mental health); (b) extrapersonal

resources (social, work, environmental resources such as home, clothing, money, food, job, health/job access, safety, and security); and (c) interpersonal resources (relationships and connections with others, support systems). Given that individuals are motivated to obtain, retain, and protect resources, it follows that stress occurs when there is a threat of resource loss, an actual resource loss, or an investment of resource without a resource gain. These situations produce a net loss of resources since more resources were lost in the process of investment than were gained as an outcome of investment (Hobfoll, Dunahoo, & Monnier, 1995). Within this framework, the concept of resilience exists.

According to Dyer and McGuinness (1996) resilience is the process a person employs to bounce back from adversity and continue on with their lives. Resilience is the modification of the person's response to a risk situation (Rutter, 1987). As a self-motivated process, intrapersonal, extrapersonal, and interpersonal resilience is influenced by protective factors and competencies that reflect the resources identified in the COR framework.

The relationship between the COR framework and the phenomenon of the inner city African-American with asthma is the premise that the adolescents is confronted with the perceived loss of health resulting in limited physical functioning, that is, the loss of control of his/her health status. Being able to manage asthma successfully and maintain a "normal" life is a mean for the adolescent to engage support systems and therefore develop a positive self-image. This framework considers social interactions to be the key source for resource acquisition and protection as well as for significant cost

(resource depletion). An adolescent who perceives himself or herself as loved and supported is likely to conclude that they have the ability and skills that bring support (Spitzer et al., 1995). This inference has a direct impact on the adolescent's resilience and self-perception of their ability to be in control of and cope with a chronic illness. In previous studies researchers reported that individuals with a positive self-image perceive themselves as highly supported and with a substantial degree of control over their lives also displayed high levels of health and well-being. Therefore, Hobfoll (1988) suggested the impact of social support on effective coping mechanisms or adaptation need to be studied in the context of other variables that promote a sense of control, such as economic status, education, and the amount of information the person holds regarding the stressful event. For the adolescent, the context of these variables is the sense of control and its relationship to cognitive development, physical development, role expectation, social organization, and coping mechanisms, which all lead to the development of adolescent resilience influencing their lived experience with asthma.

### Summary

The lived experience of 13 African-American adolescents, ages 12 to 15 years, with asthma that reside in an inner city community was investigated utilizing the qualitative hermeneutic phenomenological human science approach advocated by van Manen (2001). Purposive sampling was used to collect data from five middle schools in a southern area of Los Angeles County. Inclusion criteria included (a) medical diagnosis of asthma; (b) African-American ethnic origin; (c) residing within an inner

city community; (d) 11 to 13 years of age; (e) attending middle/junior/intermediate school within the inner city; (d) assent to participate; and (f) parental consent to participate.

Approval from the University of San Diego's Institutional Review Board, Los Angeles Unified School District's Program Evaluation and Research Branch, the Los Angeles Unified School District's Director of School Nursing Services, and the site administrator (principal) of the middle schools involved in this study was secured prior to data collection. Support from each school nurse assigned to the middle school involved was also sought for potential participant selection. Participation in this study was voluntary and all participants, including the parent/guardian were provided with essential information for assent to participate and informed consent to participate in this study. Demographic data were collected prior to the start of the oral interview. During the analysis and reporting of the findings, participants were assigned and referred to by a randomly selected number, such as 101, 102, 103.

The interview protocol consisted of semi-structured open-ended questions and field notes for data collection. The interview process began with the question: "What can you tell me about asthma?" Probe questions were used throughout the interview process to elicit greater information and understanding, for example, "Tell me about your daily routine." "What is your view on that?" The audio-taped interviews, field notes, and the verbatim transcriptions were analyzed using the van Manen (1990) method.

The phenomenological framework of van Manen (1990) supports the view that there is not one single lived reality. Experiences and perceptions are individualized and change according to circumstances, resources available, and maturity level. Utilizing the phenomenological framework, this nurse researcher took the transcripts and scrutinized the significant elements to extract meanings, categories, and their descriptive fundamentals from the subjective accounts of the participants. No two experiences were the same making many different meanings possible (Munhall & Oiler, 1986; Stringer & Genat, 2004).

This study illustrated that African-American adolescents residing in the inner city understood and had the ability to live productively with asthma by possessing an understanding of asthma that is personalized to meet their cognitive and psychosocial needs. The adolescents in this study were equipped with the knowledge of asthma as reflected in each of their responses. They were able to identify how their actions affected their individual asthma health status and triggered respiratory responses. The findings of McNabb, Pessano, and Jacobs (1986) supports the findings of this current study by identifying those self-care competencies were viewed as important in the management of asthma.

The “voices of African-American adolescents” ages 12 through 15 with asthma from an inner city community were heard as described in the Data Analysis of Chapter Four. The physical implications of asthma, such as learning of the diagnosis, individual knowledge of asthma, explanation of asthma, and the treatment, prevention, and self-developed strategies were uncovered in this sample. The four sub-themes together

comprised the essential theme of My Asthma, My Life as viewed from the daily life of an African-American adolescent with asthma encompassing cognitive development.

The complementing essential theme that emerged from the data is My Asthma, My World. This documents the African-American adolescent's day-to-day interactions within an inner city community, self-image, family and home, school, peers, same ethnicity and racial counter-peers. This sub-theme speaks of the psychosocial aspects of adolescents with asthma.

The two essential themes formulated the core theme of My Asthma, My Way, the lived experience of inner city African-American adolescent with asthma. The adolescents in this study learned to balance the medical/physical aspects of asthma with the cognitive and psychosocial elements creating a "normal" life with asthma despite adversity related to societal and environmental issues.

### Implications

This study of inner city African-Americans adolescents with asthma has a number of implications for nurses working with this population of clients. The implications of this qualitative research validates the necessity that the line of inquiry for nurses and other healthcare professionals should allow for the assessment of not only the physical measurement of asthma but the daily experience held by the African-American adolescent. The findings of this research serve to inform nursing of the rationalization of conducting holistic assessments that include attending to the perspective of the African-American adolescent with asthma including their vernacular, opinions, and personal insights. This information assists in giving credence to the

foundation of the relationship we as nurses form with our “client.” We must remain cognizant of the fact that an adolescent’s perceptions may and oftentimes differ from their parent/guardian’s. Nursings’ relationship with the adolescent client is based on our understanding of the importance of establishing respect and trust, thus creating an unhindered surrounding that puts aside personal bias and agendas, and by establishing a line of inquiry that assesses the lived experience and meaning of asthma in the African-American adolescent clientele population.

The implications of the study surfaced as a result of the methodological investigation, which occurred. The findings help to support the suggestions for the inclusion of qualitative methods in the practice and education of nursing. In this line of inquiry, the client participant is the expert; the search of answers from this vantage point gives the nurse an opportunity to adapt the assessment to the distinctive cognitive maturity, psychosocial development, and cultural perspectives of the client.

The value of qualitative research extends beyond the realm of clinical practice. The implications of this study transcends to nursing education to inform us of the necessity of educating future nurses at all levels of preparations of the holistic practice of nursing. The value of qualitative research continues in the arena of clinical practice by demonstrating ways to improve client/patient care and enhance nursing practice. Finally, the implications of this study guides nursing back to research, again opening the line of inquiry between qualitative and quantitative research with nursing clinical practice.

*Nursing Education*

All nursing curriculum includes some level of research both instructional or implementation of quantitative and qualitative research. Implication of this study implores nursing educators to integrate and implement research into the curriculum. Application of this research would open dialogue related by using a more dynamic and effectual approach.

Nursing curriculum includes components of communication skills, adolescent growth and development, and cultural diversity as tools in health assessments and practice. The implications of the study suggest however, that these components must be taught to reflect and enhance the objective of research and standards of nursing practice. These tools should improve the line of inquiry of all clients, but specifically African-American adolescents with asthma. Methods for formulating the appropriate questions as well as methods for asking the questions should be included in the nursing curricula.

In addition, the findings of this study suggest the need for specialized nursing education components to prepare school nurses, as well as advance practice nurses (APN) whose practice serves a diverse adolescent population. It is not uncommon for the school nurse to be considered by the parent/guardian as the adolescent's primary healthcare provider, thereby being poised to meet the asthma healthcare needs of this population. Expanding the education of the school nurse would provide accessibility to a more informed and knowledgeable health practitioner. This positions nursing, particularly school nursing, to create and implement programs such as the Power Breathing™ Program, to help the adolescent facilitate appropriate self-management of



asthma, in addition to being key in the development and implementation of other asthma health related measures. The school nurse and the APN could advise and guide health curricula ensuring its congruence and positive outcomes.

### *Nursing Clinical Practice*

Research findings of this study provide insight into the essence of how asthma is experienced by African-American adolescents living in inner city communities. As shown by the findings of this study and supported by literature, healthcare providers must not take for granted the perspective of their clients, particularly their African-American adolescent clients. Respect and trust must be honored for open communication to begin. Lines of inquiry that attend to the verbal communication articulated must be asked to elicit insight. Measurements of the adolescent's perspective must be obtained and put into context of the answers given along with the adolescent's cognitive maturity and psychosocial developmental stage. This provides opportunity for a more comprehensive assessment, affording nursing to deliver effective and efficient care relative to the African-American adolescent's needs. Having insight into the African-American adolescent's perspective of asthma will help facilitate the appropriate treatment and management plan. Nursing needs to advocate for the natural order within the context of health.

Highlighting critical information such as general healthcare along with asthma management and linking both to adolescent development would be valued. The adolescent participants of this study, as well as numerous other research studies, support the case for timely reinforcement of knowledge as it relates to health and asthma health.

Nurses could be instrumental in reinforcing asthma related education with a thorough assessment of the adolescent's perspective in order to provide more effective, efficient, and personalized learning.

The African-American adolescent is at the age of cognitive and psychosocial maturity to assume responsibility for the daily management of asthma. Although the role of the parent/guardian is changing from primary caregiver, the parent/guardian still provides support to the adolescent. Again, school nurses are in a unique position to help with this transitional role of the parent/guardian. Assessment and interventions should take place individually with the adolescent and parent/guardian and with both together for a greater understanding of the lived experience and achieving better outcomes.

The need to understand the lived experience of African-American adolescent with asthma is evident in this study. The perspective of the inner city African-American adolescent with asthma can be vital in closing the related health disparities gap in this population (Guthrie & Low, 2006; Monsen, 2006). However, to uncover their perspective, a relationship of respect and trust must be established and time given to develop two-way dialogue. Because this may be time consuming, research encourages nursing to investigate innovative ways to effectively and efficiently uncover the lived experience of being an adolescent of color with a chronic illness.

The clinical role of the school nurse is primed to address the implications that became apparent from this study relative to practice. The unique role of the school nurse allows for an emphasis on asthma care and treatment. The unique professional relationship between school nurse and adolescent student is in a setting that is non-

threatening and is built upon respect and trust. In considering the implications of the finding of this study, the school nurse is in a key position to monitor the changes in the lived experience of asthma for this population. Relative to the inaccessibility of healthcare providers in the inner city that are able to meet the specialized needs of this population, supporting and expanding the role of school nurses is and would be of value to nursing clinical practice.

### *Research*

The Nursing's Social Policy Statement speaks clearly about the commitment of nursing to social relevance and scientific advancement (AACN, 1999), which is the foundation for the goals of the nursing profession. The standards set by these goals encourage nursing to include qualitative data in patient assessments. Providing relevant, holistic, and comprehensive data permits a more realistic and accurate assessment. A more accurate assessment such as that of the lived experience affords one to provide a more effective and efficient intervention: e.g., one based on the perspective of the patient rather than on assumptions and biases of the researcher. The integration of qualitative research into practice would allow nursing to ask relevant questions complementing quantitative data with a relevant context.

Previous quantitative research findings measured asthma health indicators. This study finding serves to inform health professionals of the benefits of qualitative research, specifically the lived experience of inner city African-American adolescents with asthma. Additional qualitative research into the lived experience of inner city African-American adolescents (ages 12 to 15 years) with asthma is needed. An

exploration of African-American adolescents from urban, suburban, and rural communities including those of other SES and of biracial ethnicity would be advantageous in understanding the lived experience of asthma in these various populations. The participants in this study had health insurance and access to medical care, however an investigation of African-American adolescent's without health insurance would be of value as their lived experience may be quite different. Conducting a similar study with older adolescents and children, even African-American adult populations would lend insight and depth not provided in strictly quantitative research studies.

### Conclusion

This study investigated the lived experience of inner city African-American adolescents with asthma. The adolescents presented aspects of their lived experience that have not been described in the research literature. The inner city African-American adolescents with asthma described positive impressions of self and the challenges faced with asthma on a daily basis. The present study suggests evidence that health disparity related to asthma that is at epidemic proportion in the African-American adolescent populations maybe the result of factors other than non-compliance in asthma management.

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Appendix A  
Recruitment Poster



## *Recruitment Poster*

Would you like to part of a study that looks at African-American young adolescent boys and girls with asthma?

I am a nursing student who is doing a research study on the day to day life of young African-American adolescents with asthma and I would like to interview you.

If you are 12, 13, or 14 years old, have asthma and attend one of the following middle schools:

Bethune Middle School  
 Drew Middle School  
 Edison Middle School  
 Gompers Middle School  
 Markham Middle School

and are willing to share your story and experiences of living with asthma please get the **Asthma Study Flyer** from the school nurse or you may contact me at

323-770-4054

Othello Childress, PhD(c), RN

All that are selected and complete the interview process will be given \$25.00 for their time

Appendix B  
Asthma Study



# ASTHMA STUDY

**Othello Childress, RN  
 Doctoral Student  
 University of San Diego  
 Hahn School of Nursing and Health Science**

- ◆ Are you 12, 13, or 14 years old?
- ◆ Are you in grade: 7 or 8?
- ◆ Are you of African –American heritage?

I am a nurse and would like to talk with you about how asthma is affecting your day-to-day life with your family, friends, and school.

It will take about 1 hour and I will talk with you after school or on the weekend  
 At the end of our talk I will give you \$25.00 for your time spent talking with me.

This research study may help doctors, nurses, and other health care providers to better understand you, a young African-American adolescent with asthma.

Please share this information with your parent or guardian if you would like to be a part of this research study.

Have your parent or guardian complete the information below and return tear off to your school nurse by April 28, 2006 or call (323) 770-4054 (evenings) for more information

---

Tear off here

Name \_\_\_\_\_ Age \_\_\_\_\_

School \_\_\_\_\_ Grade \_\_\_\_\_

Parent/Guardian \_\_\_\_\_

Phone # \_\_\_\_\_ Best time to call \_\_\_\_\_

\_\_\_ Yes, my adolescent may take part in this research study

\_\_\_ Please call me, I would like more information

## Appendix C

### Parental Informed Consent for Research Participants

**University of San Diego**  
**Parental Informed Consent for Research Participant**

What Are They Saying?

Lived Experience of Inner City African-American Adolescents with Asthma

Othello Childress is a doctoral student in nursing at the University of San Diego, Hahn School of Nursing and Health Science. She is exploring how adolescents with asthma live and understand asthma. Your teenager aged 12, 13, or 14 years, enrolled in the seventh or eighth grade, residing in an inner city community is invited to participate in this research study.

The research study will involve one interview lasting approximately 45 to 60 minutes. Additionally, a second interview or telephone call may be necessary to clarify the interview information. Your teenager will be asked questions about his/her thoughts and feelings associated with having asthma, attending middle/junior high school and living in an inner city community. The interview will be held in a location that is convenient for you and your teenager, but where Ms Childress may speak privately with your teenager. This may be in your home, at a public library or in a local park.

The interviews will be audio-recorded, written, coded, and studied in a way that will protect your and your teenager's identity. All information that you and your teenager provide will remain confidential. The information will be kept in a locked file cabinet in the nurse researcher's home for five (5) years.

The results of the research study may be made public and information quoted in journal publications, however all individual information will remain confidential. A pseudonym (made-up name) will be used instead of your name.

The interviews are entirely voluntary and after the interview begins, you and your teenager may refuse to answer any question and/or withdraw at any time without any effect on the services your teenager receives at their doctor, clinic, or school.

If at any time during the interview your teenager tells the nurse researcher that someone is hurting him/her, the nurse researcher is legally required to report this to proper authorities.

Although risk is minimal, your teenager may become tired or fatigued during the interview. If this occurs, the interview will be stopped and resumed at a later date.

Your teenager may experience feeling of anxiety or other discomfort when talking about his/her experience with asthma. If you or your teenager would like to speak to someone about these feelings after the interview, you can call the Los Angeles County Department of Health Services (323-563-4053), the Teen Line (800-852-8336), or your teenager's private physician. Any expenses for such services will be the responsibility of the parent/guardian, not that of the nurse researcher or the University of San Diego.

The benefits of your teenager participating will be in knowing that your teenager has talked with someone about his/her experience with asthma and the satisfaction of contributing to the body of nursing knowledge. Your teenager will be given \$25.00 for his/her time spent for the interview.

**Questions**

Before you sign this form, please ask questions on any aspect of the research study if it is at all unclear to you and your teenager. If you or your teenager has any additional questions during this research study, please contact Othello Childress at (323) 770-4054 or Othello Childress' research advisor, Dr. Anita Hunter at (619) 260-4550.

You will be given a copy of this form to keep for your records.

**YOUR ARE MAKING A DECISION WHETHER OR NOT TO ALLOW YOUR  
TEENAGE SON/DAUGHTER TO PARTICIPATE. YOUR SIGNATURE  
INDICATES THAT YOU HAVE DECIDED TO ALLOW HIM/HER TO  
PARTICIPATE HAVING READ THE INFORMATION PROVIDED ABOVE.**

Date \_\_\_\_\_

Signature \_\_\_\_\_

Print Name \_\_\_\_\_

Relationship to Teenager \_\_\_\_\_

Name of teenager \_\_\_\_\_

Signature of Witness \_\_\_\_\_

Signature of Investigator \_\_\_\_\_

Appendix D  
Human Subjects Assent for Participation

**University of San Diego**  
**Human Subjects Assent for Participation**

What Are They Saying?

Lived Experience of Inner City African-American Adolescents with Asthma

You are being asked to participate in a research study that will explore how African-American early adolescents who reside in an inner city community live and understand asthma. You fit the qualities necessary for the study: you are aged 12, 13, or 14; live in an inner city community; and attend seventh or eighth grade. Before you agree to participate in this study, it is important that you read and understand the following description of this study along with the scheduled interview. If you have any questions about the study or your rights as a participant, be sure they are answered before you agree to participate.

The purpose of this study is to find out how African-American early adolescents living in an inner city community live with asthma. It will consist of performing at least one 45 to 60 minute interview.

The questions will be asked in a way that involves more than a yes or no answer. You may wish to draw a picture, write a poem, or make a video recording to help explain about how you live with asthma. Additional interviews will clarify answers that you give as well as pattern of answers heard from all study participants.

The results of these interviews will be analyzed and documented for partial fulfillment of the requirements for the Doctorate of Philosophy, University of San Diego: Hahn School of Nursing and Health Science. The results of the study may be made public and information quoted, but all individual information will be kept confidential.

As stated, the research study will consist of a 45 to 60 minute interview. If you choose not to answer a question will move on to the next question. If you agree to participate in this study, you and I will meet in a quiet, public place that affords privacy. This place may be your home or in a public place such as the local library.

Our conversation will be private, in-person, and will be audio tape-recorded. Once the conversation is completed, I, the researcher, will write out our conversation (I will transcribe the audio-tapes). All of the audiotapes, field notes and transcripts will be kept in a locked file cabinet in my home for five (5) years. Any information such as your name or other people mentioned in the interview will be removed and a pseudonym (a made-up name) will be used. The only exception to this requirement is in the case that you tell me that you would hurt yourself, someone or that someone is hurting you. In that case, I will have to notify proper authorities.

It is possible that in discussing the experience of asthma, you might discover something about yourself or about your life that causes you to feel sad or uncomfortable. If this occurs and you would like to talk with someone about these feelings after the interview you may call the Los Angeles County Department of Health Service (323-563-4053), the Teen Line (800-852-8336), or your private physician.

Many people find that sharing their thoughts and experience to be a good thing. It is possible that you will feel positive about your talk. You could also feel more committed to taking care of your asthma. In addition, you could feel good about contributing to the study itself. However, no guarantees or promises are made that you will receive any benefits from this study.

Everyone willing to participate in this study will be compensated with \$25.00 for your time after the completion of the interview.

Your participation in this study is voluntary. Your refusal to participate or withdraw from the study will not have a negative effect on you.

Before you sign this form, please ask questions on any aspect of the study that is at all unclear to you. If you have any questions during this study, please contact: Othello Childress at (323) 770-4054 or Othello Childress' research advisor, Dr. Anita Hunter at (619) 260-4550.

You will be given a copy of this form to keep for your records.

YOUR ARE MAKING A DECISION WHETHER OR NOT TO ALLOW YOUR  
TEENAGE SON/DAUGHTER TO PARTICIPATE. YOUR SIGNATURE  
INDICATES THAT YOU HAVE DECIDED TO ALLOW HIM/HER TO  
PARTICIPATE HAVING READ THE INFORMATION PROVIDED ABOVE.

Date \_\_\_\_\_

Signature of Parent/Guardian \_\_\_\_\_

Print Name \_\_\_\_\_

Relationship to Teenager \_\_\_\_\_

Name of teenager \_\_\_\_\_

Signature of Teenager \_\_\_\_\_

Signature of Witness \_\_\_\_\_

Signature of Investigator \_\_\_\_\_

## Appendix E

### Anonymous Consent to Use Literary or Artistic Work



### **Anonymous Consent to Use Literary or Artistic Work**

#### **Part One: Participant Consent/Assent:**

I, \_\_\_\_\_ creator of this literary/artistic work give Othello Childress, Doctoral Student; principal investigator permission to use my work in the study entitled “What Are They Saying? Voices from the Inner City.” I understand that when the study is published or presented in some other public manner, no identifying information will be connected to the literary/artistic work **unless I explicitly direct Othello Childress to do so.** I understand that submission of this work means I am giving consent for Othello Childress to use the work in her study, presentations, and publications.

#### **Part Two: Parent/Legal Guardian Permission**

I \_\_\_\_\_ parent/legal guardian of \_\_\_\_\_ give Othello Childress, Doctoral Student, principal investigator permission to use my adolescent’s literary/artistic work in the study entitled “What Are They Saying? Voices from the Inner City”. I understand that when the study is published or presented in some other public manner, no identifying information will be connected to the literary/artistic work **unless I and my adolescent explicitly directs Othello Childress to do so.** My adolescent and I understand that submission of this work means I am giving consent for Othello Childress to use the work in her study, presentations, and publications.

---

Signature of Parent/Legal Guardian

---

Date

Questions or concerns may be directed to:  
 Othello Childress, Ph.D.(c), R.N.  
 (323) 770-4054 home

## Appendix F

### Consent to Use Literary or Artistic Work

## Consent to Use Literary or Artistic Work

### **Part One: Participant Consent/Assent:**

I, \_\_\_\_\_ creator of this literary/artistic work give Othello Childress, Doctoral Student, principal investigator permission to use my work in the study entitled “What Are They Saying? Voices from the Inner City”. I understand that when the study is published or presented in some other public manner, no identifying information will be connected to the literary/artistic work **unless I explicitly direct Othello Childress to do so**. I understand that submission of this work means I am giving consent for Othello Childress to use the work in her study, presentations, and publications.

Please include my name with my work \_\_\_\_\_

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

### **Part Two: Parent/Legal Guardian Permission**

I \_\_\_\_\_ parent/legal guardian of \_\_\_\_\_ give Othello Childress, Doctoral Student, principal investigator permission to use my adolescent’s literary/artistic work in the study entitled “What Are They Saying? Voices from the Inner City”. I understand that when the study is published or presented in some other public manner, no identifying information will be connected to the literary/artistic work **unless I and my adolescent explicitly directs Othello Childress to do so**. My adolescent and I understand that submission of this work means I am giving consent for Othello Childress to use the work in her study, presentations, and publications.

\_\_\_\_\_  
Signature of Parent/Legal Guardian

\_\_\_\_\_  
Date

Questions or concerns may be directed to:  
Othello Childress, Ph.D.(c), R.N.  
(323) 770-4054 home

Appendix G  
Interview Guide and Questionnaire

**Interview Guide  
Part One**

Code Number \_\_\_\_\_

**Demographic and Social Epidemiological Data:****Participant's Code Number** \_\_\_\_\_

Age \_\_\_\_\_      DOB \_\_\_\_\_      Grade \_\_\_\_\_

Middle School \_\_\_\_\_

Favorite school activity \_\_\_\_\_

Favorite after-school activity \_\_\_\_\_

Favorite school subject \_\_\_\_\_

Future plans \_\_\_\_\_

Number of full or partial school days missed this school year related to  
asthma \_\_\_\_\_

Number of days in the hospital last year (2005) \_\_\_\_\_

Number of unscheduled healthcare visits during this school year (emergency room,  
clinic, urgent care) \_\_\_\_\_Number of times your had wheezing or other asthma complications in the last 6 months  
(June 1, 2005 to December 31, 2005) \_\_\_\_\_

Who lives with you? \_\_\_\_\_

**Interview Questions**  
**Part Two**

1. What can you tell me about asthma?
2. How old were you when you first learned that you had asthma?
3. What do you remember about the time when you first learned that you have asthma?
4. Does living with asthma ever keep you from doing something that you want to do?
  - Probe: participating in school activities, spending time with friends, playing sports? If yes, how do you handle these situations?
5. Does asthma have any effect on your life at home, school, with your friends?
  - Yes: how would you describe the effects of asthma on your life at home, school, with your friends?
  - No: why do you feel that asthma has no effect on your life at home, school, with your friends?
6. How do you think your life, living in the inner city, with asthma is different than any other adolescent with asthma?
7. How does your perception of asthma differ now than when you were younger?
  - Probe: when you first learned that you have asthma or when you were in elementary school.
8. How do you think your life, as an African-American is different than a White or Latin adolescents with asthma?

## Appendix H

Letter from Anita Hunter, APRN, PhD



University of San Diego

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Hahn School of Nursing and Health Science

Los Angeles Unified School District  
Program Evaluation and Research Branch  
333 S Beaudry St  
Los Angeles, CA 90017

To Whom It May Concern,

As Chair of Othello Childress's doctoral dissertation committee, at the University of San Diego, I would like to submit my support for Othello's research project related to asthma in African-American adolescents. This will be a qualitative exploration of the perceptions these children and their parents have about their asthma and the effect it has had on their lives. The results of this research could improve the health care these children receive from their health care providers by making such care more culturally appropriate and safe. Should there be any questions, please feel free to contact me at 619-260-7609.  
Respectfully,

Anita Hunter, APRN, PhD  
Associate Professor  
University of San Diego

5998 Alcalá Park, San Diego, CA 92110-2492 619/260-4548 Fax: 619/260-6814



Appendix I

Support Letter from Karen Maiorca, RN



**LOS ANGELES UNIFIED SCHOOL  
DISTRICT**

**Student Health and Human Services Division  
District Nursing Services  
644 West 17<sup>th</sup> Street, Bungalow B  
Los Angeles, CA 90015**

Phone: (213) 763-8374 Fax: (213) 763-8382

**Roy Romer**  
Superintendent of Schools

**Rowena Lagrosa**  
Deputy Superintendent

**Michelle King**  
Assistant Superintendent

**Karen Maiorca**  
Director

February 7, 2006

University of San Diego University  
Institutional Review Board 5998  
Alcala Park San Diego, CA 92110

IRB Committee Members,

This letter is in regard to the study proposed by Othello Childress RN, MSN. As part of her Doctoral Research she is investigating the experiences of young African-American adolescent students with asthma who reside within an inner city community.

I have reviewed the contents of the study with Ms. Childress and believe that this study will provide us with invaluable information regarding the adolescent prospective of their chronic illness. For your review, Othello Childress has my approval to select a sample of adolescent students in the designated area of the Los Angeles Unified School District for this purpose. Her involvement will be through questionnaires or surveys and she will obtain the necessary permission from the students' parents. She will also interact with the School Nurses assigned to designated middle school sites who will assist with identifying students and families that may wish to participate. Subjects will be recruited in a manner that is ethically and administratively consistent with all guidelines as established by our Program Evaluation and Review Board.

Karen Maiorca, RN  
Director, School Nursing Services  
Los Angeles Unified School District

## Appendix J

### LAUSD Program Evaluation and Research Branch Approval

Los Angeles Unified School District  
Program Evaluation and Research Branch

January 27, 2006

Othello Childress  
Central West Support  
Unit School Nursing  
Services Local District 7

Dear Ms. Childress,

The Committee on Research Studies has approved your request to begin your study entitled "What Are They Saying? The Lived Experience of Inner City African-American Adolescents with Asthma" in Los Angeles Unified School District.

This approval by the committee is in no way a requirement for district personnel to participate. All participation must be completely voluntary. The anonymity of all data sources must be maintained.

At the conclusion of your study, please send an abstract of your findings to my attention. Sincerely,

Glenn Daley  
Program Evaluation and Research Coordinator  
Chair, Committee on Research Studies  
[glenn.daley@lausd.net](mailto:glenn.daley@lausd.net)

Program Evaluation and Research Branch  
333 South Beaudry Avenue, 23<sup>rd</sup> Floor  
Los Angeles, CA 90017  
Phone: 213.241.6476 - Fax: 213.241.8426