

**The Effect of Barriers on Health Related Quality of Life (HRQL) and Compliance in Adult
Asthmatics who are followed in an Urban Community Health Care Facility**

by

Rosemary L. Hoffmann

BSN, University of Pittsburgh, 1977

MSN, University of Pittsburgh, 1983

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School of Health & Rehabilitation Sciences

This dissertation was presented

By

Rosemary L. Hoffmann

It was defended on

July 17, 2006

and approved by

Wesley M. Rohrer III, PhD, Assistant Professor

Jeannette E. South-Paul MD, Professor

Ray Burdett, PhD, PT, Associate Professor

Valerie J.M. Watzlaf, PhD, RHIA, Associate Professor

Dissertation Advisor: Wesley M. Rohrer III, PhD, Assistant Professor

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Rosemary L. Hoffmann, RN, BSN, MSN, PhD,

University of Pittsburgh, 2006

This cross sectional descriptive study sought to identify perceived barriers to follow-up care for adult asthmatics who are followed in two community health care facilities. A second purpose of the study was to determine the effect of any barriers to Health Related Quality of Life (HRQL) and compliance in the sample. Thirty-four adults who receive follow-up care for asthma at either Bloomfield-Garfield (BG) or Latterman Family Health Care Center (LFHC) completed a demographic and health status survey, the MiniAQLQ and the EWash Access to Health Care Survey. “Long waiting time in provider’s office,” “someone had to miss work,” “cost of care too much,” and “long wait for an appointment” were the most prevalent perceived barriers in the sample. “Lack of transportation” was significantly associated with study participants who receive health care at LFHC or who stated the emergency room as their usual place of care. “Someone had to miss work” was significantly correlated with the following variables: employment, a higher annual household income, 1-2 daily medications for asthma, no overnight hospitalizations for asthma and no psychological co-morbidities. A higher reported quality of life was significantly correlated with study participants whose medical care needs were met and found access to local health care services. The only perceived barrier that was significantly correlated with compliance was study participants who “sometimes” had to reschedule an appointment with a health care provider due to “lack of transportation.” The present study suggests that strategies designed to decrease the perceived barriers of lack of transportation, a patient or family member missing work, long wait for an appointment, and inconvenient office hours may improve follow-up care in this population. Such strategies would operate primarily (or even exclusively) through improving access and thus fostering asthma care in the community where it can be effectively managed. A program that limits barriers might improve compliance with the treatment regime, thus decreasing costs, absenteeism, and lack of continuity.

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PREFACE

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1.0 INTRODUCTION

Asthma is a major public health problem in the United States. According to the 2001 National Health Interview Survey, approximately 31.3 million people have been diagnosed with asthma and the disease is not limited to age, ethnic origin, or socioeconomic status (National Heart Lung and Blood Institute [nhlbi] n.d.). In addition, an estimated 12 million people reported an asthma attack within the past 12 months (nhlbi n.d.). The disease has been associated with familial, infectious, allergenic, socioeconomic, psychosocial, and environmental factors (Mannino, et al., 2002). Asthma is responsible for approximately 10 million physician office visits, over 100 million days of restricted activity, and total annual costs of over \$11 billion (Action Against Asthma, 2000). Findings from the Asthma in America Study revealed over 100,000 people in the total population in the Pittsburgh, Pennsylvania area experience asthma (Asthma in America 1997-2004). The study also revealed that at least 21% of adult patients with asthma missed school or work in the past year and 33% were treated in emergency rooms or required urgent care. The report noted that a communication gap exists between asthma patients and their healthcare providers. Although 70% of the doctors surveyed said they prepared a written action plan for their patients, only 27% of patients said their doctors developed one for them (Asthma in America, 1997-2004).

The impact of socioeconomic status on health care and use of medical services has been studied with a variety of chronic disease states including asthma (Chang, Marmot, Failey, &

Poulter, 2002; Eisner, Katz, Yelin, Shiboski, & Blanc, 2001; Lacey & Walters, 2003; Perry & Rocella, 1998;). Additional studies have shown that insurance coverage, in and of itself, do not guarantee use of timely and appropriate medical care (Haas, 1994; Newacheek, McManus, Fox, Hung, & Halfon, 2000; Pappas, Queen, Hadden, & Fisher, 1993; Riportela-Muller, et al., 1996;). Some health system organizational obstacles, other than financial reimbursement, faced by asthma sufferers include difficulty scheduling follow-up appointments, lack of continuity in provider, long waiting times in a health care facility and cultural insensitivity (Bender, 2002; Crain, 1998; Kerr, 1993; Mansour, 2000; Rask, 1994). Bender (2002) identified prolonged or complex treatment regimens as a treatment related barrier to asthma care. Some patient-specific barriers to asthma follow-up care include dysfunctional social or home environments, educational deficits, language barriers, transportation, and child care responsibilities (Bender, 2002). If these structural, treatment, and patient-specific factors are significant barriers, they may result in delays in follow-up care and adverse health outcomes independent of health insurance (Weissman, 1991). Since asthma is a chronic disease that can be successfully managed in a community setting, it is important to ascertain the barriers that influence the patient's ability to receive quality health care in the community.

1.1 PURPOSE

The purpose of this study is to determine self reported barriers for follow-up care among adult asthmatic patients receiving care from urban community health care facilities. Two secondary purposes are to determine what effect these barriers have on the adult patient's health related quality of life and compliance with follow-up health care management.

1.1.1 Specific aims

The aims of this study are:

1. To identify the perceived barriers related to follow-up health care for adult asthmatic patients who are receiving care in an urban community health care facility.
2. To determine whether a relationship exists between perceived barriers and selected demographic characteristics of adult asthmatic patients in an urban community health care facility.
3. To determine whether a relationship exists between perceived barriers and selected health status characteristics of adult asthmatic patients in an urban community health care facility.
4. To determine whether a relationship exists between perceived barriers and health related quality of life for adult asthmatic patients in an urban community health care facility.
5. To determine whether a relationship exists between perceived barriers and compliance for adult asthmatic patients who are receiving care in an urban community health care facility.

1.1.2 Research Questions

The following research questions will be addressed in this study:

1. What are the perceived barriers reported by adult asthmatic patients who are followed in an urban community health care facility?

2. What is the relationship between perceived barriers and selected demographic characteristics of adult asthmatic patients in an urban community health care facility?
3. What is the relationship between perceived barriers and selected health status characteristics of adult asthmatic patients in an urban community health care facility?
4. What is the relationship between perceived barriers and health related quality of life of adult asthmatic patients in an urban community health care facility?
5. Which of the following variables (subscales on the EWash; medical care needs, prescription drug needs, satisfaction with care, health insurance, health insurance coverage, out of pocket expenses, local availability of services, barriers to obtaining care, concerns related to health care, health of members of household, or sources of health care) are best associated with health related quality of life in the adult asthmatic patient in an urban community health care facility?
6. What is the relationship between perceived barriers and compliance with follow-up care for adult asthmatic patients in an urban community health care facility?

2.0 LITERATURE REVIEW

As a major public health problem in the United States, asthma affects all individuals across the life span from infants to senior citizens (≥ 65 years). Furthermore, the disease does not show preference for race, socioeconomic status, or gender. In 1998, 26.3 million people in 1998 were diagnosed with asthma (Trends in Asthma Morbidity and Mortality, 2001). Although pharmaceutical and clinical researchers continue to test and prescribe new medication and therapies for secondary prevention of asthma, it is important for health team members to recognize the importance of comprehensive outpatient management of this disease. According to recent findings, asthma accounts for an annual economic impact to our nation of approximately \$12.7 billion in direct and indirect costs (Trends in Asthma Morbidity and Mortality, 2001). Even though the number of hospital discharges have stabilized since 1998, the number of office-based physician visits have increased to approximately 11.3 million in 2001 and the number of outpatient department visits exceeded 1.3 million in 2001 (National Center for Health Statistics, 2003, www.cdc.gov). In Allegheny County alone, there are over 70,000 adults with asthma (American Lung Association Action Network, 2001).

As a result of these statistics, the Center for Disease Control and Prevention developed its National Asthma Control Program to fund programs that study three basic public health principles related to asthma. These principles include tracking asthma's occurrence, developing interventions to reduce its burden, and evaluating partnerships with stakeholders in local asthma

control programs (National Asthma Control Program, 2002, in www.cdc.gov). In addition, Healthy People 2010 has identified several objectives related to asthma, including reducing asthma deaths, hospitalizations, emergency department visits, activity limitations, and school/work days missed (Healthy People 2010 in www.healthypeople.gov). More important, since asthma is considered a public health problem, Healthy People 2010 has identified an additional goal related to managing asthma in the primary care settings. Simply stated, this goal is to increase, as an essential part of disease management, formal patient education about community and self-help resources (Healthy People 2010).

Asthma is a chronic illness; therefore, the majority of its medical management can be successfully managed in the community. In this setting, costs will be reduced, quality of life improved, and continuity of care enhanced by decreasing episodic treatment in the emergency room. These measures will only be successful if health care professionals have a better understanding of issues that effect access to quality outpatient care. This review of the literature will provide an overview of the following relevant issues related to asthma management in the community. Literature related to barriers for adult asthmatics and families will be reviewed. These include potential demographic barriers such as gender, years of formal education, patient education, and ethnicity. Other economic barriers, besides a lack of adequate insurance coverage, that hinder outpatient asthma management include transportation and child care or caregiver needs will be considered. Other factors associated with organization of healthcare, such as appointment schedules, characteristics of the health care providers and continuity of care will be discussed as they relate to barriers of outpatient management of adult asthmatics. Finally, the effects of these barriers on health related quality of life (HRQL) will be discussed.

2.1 CONCEPTUAL FRAMEWORK

Both economic and noneconomic factors affect access to health care services. Numerous suggestions have been introduced by policy makers to balance equity of access for health and medical care in the United States. Some policy programs suggest increasing the buying power of the public through national health insurance programs. Other suggestions include increasing the availability of services through health maintenance organizations (HMOs) and community health facilities. According to Aday and Andersen, (1975) access to care is complex and multidimensional. One method to study access to care is through health service research (HSR).

The Institute of Medicine defines HSR as:

“a multidisciplinary field of inquiry, both basic and applied, that examines the use, cost, quality, accessibility, and delivery, organization, financing, and outcomes of health care services to increase knowledge and understanding of the structure, processes, and effects of health services for individuals and populations” (1995, p. 17).

Aday and Anderson, (1974) believe the key issue is whether “those persons actually in need of medical care receive it” (p. 210). Furthermore, equity in care is said to exist “when services are distributed on the basis of people’s need for them...Inequity is suggested, however, if services are distributed on the basis of demographic variables, such as race, family income, or place of residence, rather than need” (Aday, 1980). Bodenheimer (1970) emphasizes that access is demonstrated when services are available whenever and wherever the patient needs them and that the mechanism to obtain these services are clearly stated to the consumer. Donabedian (1973) elaborates upon access and includes both a socio-organizational and geographic consideration. Socio-organizational factors includes all the attributes or resources of the health care institution that either facilitate or hinder the client in obtaining care, while geographical

accessibility refers to issues of time and physical distance that must be traversed to receive care (Donabedian, 1973). As a result of the complexity of factors involved in health care utilization, Aday and Anderson (1974) developed a framework for the study of access (see figure 1), based on a behavioral model of determinants of families' utilization of health services (Andersen, 1968). The framework can be applied to analyze data both at a national and local level. The framework includes interrelationships among five domains: (1) health policy, (2) characteristics of the health delivery system, (3) characteristics of the populations at risk, (4) utilization of health services, and (5) consumer satisfaction (see Figure 1).

Health policy is the starting point for consideration of access. It influences characteristics of the health delivery system and the population it serves either at the federal, state, or local level. The characteristics of the health delivery system include resources and organizational factors. Included within this domain are labor, health personnel, technology, materials, and the mix and coordination of services (Aday & Andersen, 1975). In addition, this domain includes barriers to entry into the system, such as travel and waiting time, and what happens to the client once entry into the system is achieved (Aday & Andersen, 1975). Characteristics of the population at risk include predisposing, enabling and need components. Predisposing components exist prior to entry into the health care system and include such things as age, race, religion, and values concerning health care (Aday & Andersen, 1975). Enabling components describe the personal and family resources individuals have available for utilizing services, such as family income, insurance and attributes of the community (Aday & Andersen, 1975). The need component refers to the illness level, such as primary, acute or rehabilitative and is usually the immediate cause of seeking health care.

Utilization of health services are characterized by type, site, purpose or time interval of use (Aday & Andersen, 1975). Researchers analyzing this domain would seek to identify the kind of service received, the place where care was received, frequency/duration, and who provided it. Finally, cognitive and affective consumer satisfaction refers to the feelings and satisfaction achieved when in contact with the health care delivery system (Aday & Andersen, 1975). Factors to consider when analyzing data in this domain include satisfaction with convenience of care, its coordination, the courtesy of the providers, health care information obtained, and the quality of care the consumer received. The research by Kahn and Bhardqaj (1994) expanded this category to include perceptions of factors important when seeking care and barriers to care. The circular pattern in the framework illustrates that the domains feed back into health care policy decisions that is the starting point for consideration of the access concept (Aday & Andersen 1975).

The conceptual framework by Aday and Andersen (1975) will be used in this study. Many, but not all, of the factors described in the different domains will be analyzed to determine the barriers to outpatient asthma care in the community. Findings from this study will be shared with health team members at the community health facilities. The health team members at community facilities expressed a desire to obtain any information that addresses access to care from a consumer perspective. Interventions may need to be developed from a health care policy/planning perspective based upon the findings of the study

Some relevant characteristics of the health delivery system are resources, especially staffing and organization. Some additional examples include travel and waiting time, number and type of providers, and the availability of services. Furthermore, the process of entry into the system and the barriers to utilize services will be studied.

Characteristics of the population at risk that include predisposing, enabling, and other variables about the population will be identified. Predisposing factors include but are not limited to age, family size, employment and educational level. Enabling factors refer to the means by which clients utilize services in the community. Finally, need is defined as the perceived value an individual associates with health. The need for services usually initiates the first exposure into the health care setting, whether that is primary, secondary, or tertiary levels of care.

Utilization of health services will focus on resources available within the community setting and organization of services provided. Studies have found that continuity and having a regular source of care are associated with compliance to the treatment plan (DiMatteo, et al. 1993). Study participants will respond to questions related to the type of health care services used to obtain health information and the setting in which services were delivered.

Finally, consumer satisfaction entails satisfaction with the complete experience associated with the medical care received. This section will be expanded to include health related quality of life (HRQL). Andersen (1994) states that findings from HSR can shape national health policy by considering community and delivery system factors that influence HRQL. Furthermore, HSR can influence researchers to be more aware of factors other than medical interventions that affect a patient's well being (Andersen, 1994). Consequently, HSR can provide theoretical and empirical support for multiple outcome measures in asthma, such as a decrease in length of stay (Johnson, Blaisdell, Walker, & Eggleston, 2000), utilization, satisfaction, and cost (Bodenheimer, Wagner, & Grumbach, 2002; Eisner, Ackerson, Chi, Kalkbrenner, Buchner, et al. 2002,). Furthermore, studies have found that if health services are perceived as congruent with client needs, adherence to the treatment plan improves, thus

improving HRQL (Renzi, Picardi, Abaeni, & Agostini, 2002; Safran, et al., 1998; Thom, Kravitz, Bell, Krupar, & Azari, 2002;).

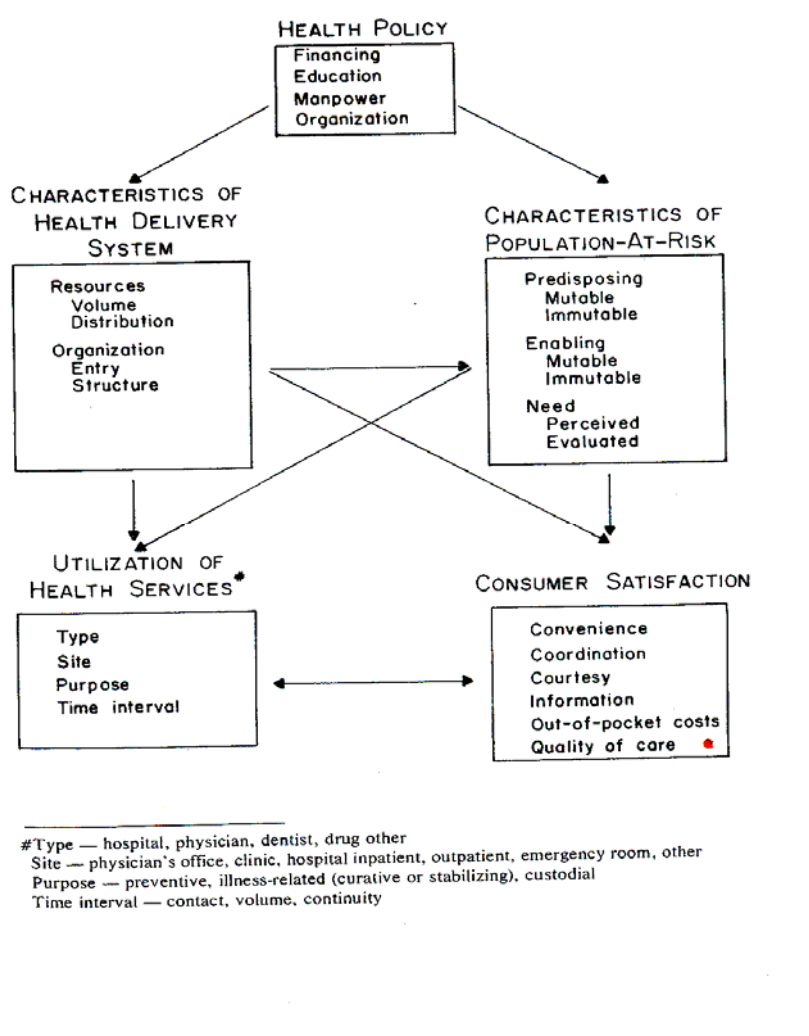


Figure 1: Conceptual Model

2.2 BARRIERS TO OUTPATIENT CARE IN THE ADULT

2.2.1 Demographic Barriers

2.2.1.1 Gender

Barriers to asthma follow-up care have been studied in pediatric clients and caregivers, but relatively few studies exist in the adult population (Crain, Kerckmar, Weiss, Mitchell, & Lynn 1998; Davidson, Klein, Settupane, & Alario, 1994; Diette et al., 2001; Hartert, 2003; Leickly et al., 1998; Mansour, Lanphear, & DeWitt, 2000; Spurrier et al., 2003) Recent studies have shown that insurance coverage alone does not guarantee use of timely and appropriate medical care (Adler, Boyce, Chesney Gorkman, & Syme, 1993; Eisner et al., 2001; Field & Briggs, 2000; Pappas et al., 1993). There are many noneconomic factors that affect the access of appropriate medical care, one of which includes being female (Barr, Somer, Speizer, & Camargo, 2002; Diette et al., 2002;). Gender differences, related to the use of technological services and referrals to another physician, have been documented (Ayanian & Epstein, 1991; Verbrugge & Steiner 1981). In addition, Barr, Somers, Speizer and Camargo (2002) found that asthma was undertreated among older women. Although the use of invasive services may be more prominent in men, several studies have shown women are more likely to seek out health services in the community, receive definite follow-up appointments and obtain continuity of care (Adams & Benson, 1992; Ballard et al., 1988; Verbrugge & Steiner, 1981;). In a study by Singh, Cydulka, Stahmer, Woodruff, and Camargo (1999) women were more likely to be admitted to an emergency room and report ongoing exacerbations during follow-up care. This was evident even though women were insured and had a primary care provider. Since asthma is a major healthcare issue that is not gender specific and can be successfully managed in a community

health care facility, more studies are needed to determine the effects of gender on barriers to management with this chronic condition.

2.2.1.2 Inadequate patient education

The effect of health education on positive health care outcomes has been well established (George et al., 1999; Smith, Highstein, Jaffe, Fisher, & Strunk, 2002). Some positive outcomes of a well informed consumer include compliance with the treatment plan (Diette et al., 2002), improved health status (Blanc et al., 2003), and increased primary prevention (Kennedy, Stone, & Rachelsfshky, 2003). Yet, inadequate health education, from the prospective of both the consumer and educator of health services, has been cited to a barrier to asthma care. For example, a study by Taylor, Auble, Calhoun, and Mosesso (1999) found that the outpatient management of most asthma patients, who presented to a large urban tertiary emergency room, did not comply with the International Consensus Report on the Diagnosis and Management of Asthma. Despite the availability of these guidelines, studies have found that patients fail to use peak flow meters, underuse preventive medications, and over use symptom relief agents (Friedhoff, & Togias, 1996; Hartert, Windom, Peebles,). Furthermore, according to the Asthma in America Survey, there is a disparity between what physicians say to patients and what patients believe they are told by their health care provider regarding lung function tests, treatments, and written action plans (Asthma in America Home Page, 1997-2003). Asthma in America researchers believe there is a large knowledge deficit related to the cause and treatment of asthma within the population (Asthma in America Home Page 1997-2003). The researchers found that approximately 71% of asthmatic patients surveyed believe there is a strong need for additional education about their disease in the areas of causes of exacerbation and prevention (Asthma in America Home Page, 1997-2003). Additional interviews conducted with people in

the Pittsburgh metropolitan area reveal some of the same findings. More than half (59%) of the asthma patients interviewed believed it was possible to treat only asthma attacks and symptoms, not the underlying cause (www.asthmainamerica.com/cities/pittsburgh, accessed June 11, 2003). In addition, although 70% of doctors in the Pittsburgh metropolitan area say they prepare a written action plan for their patients, only 27% of patients say their doctor developed one for them (www.asthmainamerica.com/cities/pittsburgh, accessed June 11, 2003). Consequently, a barrier exists for asthmatics whose physicians are not following the national guidelines or who believe they receive inadequate patient education.

All asthma patients and their family members should recognize the symptoms of asthma and triggers of asthma exacerbations and be able to initiate an action plan when symptoms worsen. Furthermore, patients need to be taught their prescribed medications, peak expiratory flow rates, and environmental control strategies. Yet, studies have shown that the patients' lack of knowledge of the disease and its treatment is a barrier to appropriate asthma care (Davidson, Klein, Settupane & Alario, 1994; Fish & Lung, 2001; Janson & Becker, 1998; Kerr & Siu, 1993). Munro, Haire-Joshu, Fisher, and Wedner (1996) found that the lack of available patient education material and well-articulated information a barrier to low-income emergency care recipients who presented with asthma symptoms. Mansour, Lanphear, and DeWitt (2000) found that one of the key barriers for parents of asthmatic children was a lack of knowledge related to asthma management, warning signs, and medication. The lack of knowledge related to either the treatment regime or action plan was also cited by Bender (2002) as one patient-related barrier to asthma treatment.

2.2.1.3 Formal education

Likely correlated with a set of socioeconomic variables, a lack of formal education has been cited as a barrier to appropriate asthma care. A study by Pappas, Queen, Hadden, and Fisher (1993) found that an inverse relationship existed between mortality and education that persisted over a 25 year period. In a study by Rask, Williams, Parker, and McNagny, approximately 43% of patients surveyed had less than a high school education and listed this as an obstacle to medical care. Haas, Clerary, Guadagnoli, Fanta, and Epsein, (1994) found that adults with asthma who had less education were more likely to receive less continuity of care and post discharge instructions.

Within the past decade, technology has broadened the patient's awareness of health, illness, prevention, and treatment of many disease states, including asthma. Although asthma is a chronic disease, its treatment regimen can be successfully managed by all age groups. Whether it is a lack of understandable patient education material or limited formal education, researchers need to assess learning needs as barriers in outpatient asthma management. Only through effective communication can asthmatics continue to regulate and control their health state. Additional studies will substantiate education as a barrier to asthma care in the community.

2.2.1.4 Cultural factors

Other health care delivery system barriers that hinder asthma care in the community include the culture within the health care setting and attitudes of non physician personnel. This includes the lack of multi-cultural awareness, a hectic or otherwise stressful uncomfortable clinic environment, or indifference or ambivalence about addressing the needs of the patient/ caregiver (Crain et al., 1998; Higgs, Bayne, & Murphy, 2001; Mansour et al., 2000; Munro, Haire-Joshu, Fisher, & Wedner, 1996; Rose & Garwick, 2003;). Bender (2002) stated that one of the main

clinician-related barriers to adherence in adults may be staff or physician disinterest and limited time to answer specific questions related to the treatment regime. Other researchers found that patients complained that health care providers did not take a holistic approach to managing asthma (Mansour et al., 2000). Traditionally, American healthcare has consistently focused on individuals and their health problems, yet have failed to recognize cultural differences, including beliefs, symbolism and interpretation of illness. Therefore, health care professionals must recognize and appreciate the influence of these cultural differences, beliefs, symbolism, and interpretation of illness on patients and their families in order to facilitate holistic care. This is increasingly important for patients with asthma since this chronic disease is not restrictive to age, sex, gender or ethnicity. Studies are needed that determine which aspects of the outpatient health care environment are most important for adults in order to manage their treatment regime effectively. These aspects need to be related to quality of life so that positive patient outcomes can be achieved.

The literature has found some evidence that gender, inconsistencies with standards of practice, limited patient education regarding treatment of asthma and a lack of formal education as barriers in the adult asthmatic population as discussed above. In addition, limited research exists that identify cultural factors as a barrier. Researchers are recognizing the importance of cultural factors of patients from two perspectives; responsiveness to a diverse patient population and the positive work experience that exists with a culturally diverse workplace. Unfortunately, much of the research has been conducted with acute care facilities. Therefore, additional research needs to verify these findings in a community health care facility where the majority of ongoing asthma management occurs.

2.2.2 Economic Barriers

2.2.2.1 Transportation

There are other economic obstacles, besides insurance coverage, that have been cited as barriers to asthma care. Some examples include insufficient sick leave, child care costs, limited or inadequate transportation to the care provider's site of care and out-of-pocket medical expenses, such as medication and treatment co-payments (Davidson et al., 1994; Kiefe, & Harrison, 1993; Mansour et al., 2000; Riportella-Muller et al., 1996). Lack of transportation to a health care facility was a theme in a study of low income asthma patients during focus group data collection (Munro et al., 1996). Although lack of funds to pay for medication or treatments was not identified as a barrier, transportation to the pharmacy or health care facility was an obstacle for over half of the study participants (Munro et al., 1996). Some adult asthmatics in this study had to rely on family members or friends for transportation for follow-up care. These patients must coordinate PCP appointments or prescription refills around their access to transportation. As one subject stated, "I had to wait several days for transportation to pick up my medicine because my mom only got a car last year. If you don't have access, you have to go to the emergency room." (Munro et al., 1996). Similar findings were found by Higgs, Bayne and Murphy (2001) among 475 residents in an urban county in the state of Washington. Transportation, out of pocket costs, and missing work were some variables cited by the study population as barriers that limited the ability to obtain services when needed. Supporting the notion is one study by Baren, Shofer, Iven, Reinhard, DeGus, et al., (2001) which demonstrated that providing transportation vouchers and a 48-hour telephone reminder to make an appointment increased the likelihood that patients discharged with asthma from an emergency room obtained primary care provider (PCP) follow-

up care. This study showed that 46% of the intervention patients received follow-up while only 29% of the control group received follow-up care (Baren et al., 2001).

Transportation barriers were not limited to adult asthmatics. Parents and caregivers of asthmatic children also cited transportation issues as a barrier to follow-up care in the community. Crain, Kerscmar, Weiss, et al. (1998) reported that almost 43% of the respondents identified needing child care and lacking transportation as a barrier to follow-up care. However, over 96% of the parents reported that having a usual place for care and insurance was not a significant barrier to follow-up care. Similar findings were cited by Rose and Garwick (2003) when studying family caregivers of urban American Indian children with asthma. They cited lack of transportation to the PCP as one of the most frequently identified demographic barriers to care for their child.

2.2.2.2 Child care

Asthma is a family problem. Although the disease may be prevalent in one member of the family, due to the chronic nature of the disease, other siblings and adults are involved, either with providing child care, taking leave from work, arranging physician appointments, or implementing treatment plans. Child care needs are very important to consider with either the adult, who may be experiencing an acute exacerbation of asthma, or the caregiver of an asthmatic child. Not surprisingly, the need for child care has been found to be a barrier to follow-up care. One of the most frequently reported barriers to short-term care by patients with asthmatic children in an inner city was finding affordable child care for other siblings. This finding was reported for both acute episodes and follow-up care (Crain et al. 1998). Rose and Garwick (2003) also reported that family caregivers of children with asthma reported difficulty with childcare as a barrier to management. Health care researchers need to be cognizant of the

complexity of care that is required with this chronic disease state. The care extends beyond medical and pharmaceutical interventions, but also the impact to the family associated with providing daily emotional support to siblings and other adults residing in the household. Additional studies are needed that verify the significance of this barrier so that interventions can be developed that address caregiver needs.

Available research suggests that other economic barriers, besides insurance coverage, hinder outpatient asthma management. Transportation has been cited with both adults and parents of asthmatic children as a barrier to follow-up care. In addition to finding a means to travel to the health care facility, patients and their family members must also find safe child care for other siblings. Some studies suggest that if transportation to a PCP is a barrier to appropriate follow-up care, an effective intervention might include actions which improve transportation access or availability. Studies that also substantiate the importance of child care concerns are needed so that interventions are developed that address this major caregiver concern.

2.2.3 Healthcare Organizational Barriers

2.2.3.1 Appointment scheduling

Characteristics of the health care delivery system may influence access to asthma care in the community. They include organizational factors such as ease of entry into the service setting, the availability of services, and the time required for services to be delivered. It may also include characteristics of service providers. One finding that has been stated as a barrier to care is scheduling follow-up appointments or the length of time waiting in the service setting. Consumers have stated that it is often difficult to schedule a follow-up appointment with a health care provider in a community facility that is congruent with their schedule (Bender, 2002;

Davidson et al., 1994; Higgs, Bayne, & Murphy, 2001; Munro et al., 1996). When office hours are available, they may not be convenient for many adult asthmatics, especially if they work during the day, have limited sick time, or other responsibilities such as child or elder care. Munro et al., (1996) reinforced this finding during focus group discussion, and cited lack of convenient office hours, especially in the evening, as a barrier. The inconvenient office hours, or an extended delay in follow-up appointments, were also cited as key obstacles for consumers in a large urban community (Higgs et al., 2001). On a scale of importance, related to potential barriers for seeking health care, from 0-100 (100 extremely important) a long wait for an appointment and inconvenient office hours were rated as 80 and 70 respectively (Higgs, et al. 2001).

A lack of a flexible PCP schedule was a barrier cited among parents or caregivers of children with asthma. Davidson et al., (1994) reported that patients with Medicaid were less likely to call their physician prior to presenting to the emergency room with their children due to a lack of physician availability. Crain et al., (1998) found that although 96% of caregivers reported a usual place for follow-up care, 53% had difficulty obtaining follow-up care and 18% had difficulty getting appointments. In addition, almost 20% felt they had to wait too long to see the physician at their appointment time (Crain et al., 1998). These figures are noteworthy since asthma management in the United States is focused on prevention and outpatient management. Consequently, the researchers believe that although access in the United States may be adequate for some socioeconomic groups, health care delivery system barriers are frequently reported, leading to poor patient outcomes.

2.2.3.2 Characteristics of healthcare providers

However, when patients have a satisfying, ongoing relationship with a specific PCP, positive outcomes, including compliance, are promoted (Onyirimba et al., 2003). The key to establishing such relationships is open communications, attentiveness, giving both verbal and nonverbal encouragement, and having interactive communications with the patient and family. Clark and Partridge (2002) argue that to reduce barriers to effectively manage asthma, clinicians, office and clinic staff need to be involved in the educational process that builds on the strengths of each member. Core messages are introduced by the physician and reinforced by other clinicians in a coordinated, synergistic manner (Clark & Partridge, 2002). Furthermore, although patients preferred clinicians to assume the major role in most decisions about their management, they wished to remain in control when seeking care and initiating changes in medication use (Adams, Smith, & Rufflin, 2000). These measures facilitated a more collaborative relationship with the health care provider, thus limiting perceived barriers.

Positive interaction with health care providers leads to adherence in the treatment plan, more open communication to discuss problems, and better outcomes. This finding was supported by a two-year longitudinal study of 186 physicians and their patients being treated for diabetes, hypertension, and heart disease in which the influence of the physicians' attributes and practice style on patients' adherence to treatment was analyzed. Several physician attributes that were predictors of increased patient adherence were an understanding of the patient, effective communication styles, and scheduling a follow-up appointment (DiMatteo et al., 1993).

2.2.3.3 Continuity of care

Continuity of care with primary care providers helps to establish an advantageous doctor-patient relationship. Unfortunately, with the large volume of adult patients utilizing diverse outpatient

facilities, follow-up care with a specific primary care provider may be difficult. The need for dependable follow-up care is especially important with asthmatics because of the chronic nature of the disease. A patient may not have the energy, patience, or time to repeat a long medical history to new practitioners during an exacerbation. Patients need to feel secure and comfortable that their PCP is familiar with their needs during all phases of care. The lack of continuity, with a specific provider, has been cited as a barrier with adult asthmatics in several studies (Bender, 2002; Davidson et al., 1994; Kerr & Siu, 1992; Munro et al., 1996;). Although subjects in one study could cite a primary provider at one month, this was not evident at subsequent appointments (Keer & Siu, 1992; Rose & Garwick, 2003). Some family members described the lack of continuity with providers in a busy clinic hindered their ability to understand the treatment plan for their child (Rose & Garwick, 2003). Higg, Bayne, and Murphy (2001) also found that staff knowledge of patient needs was ranked high (79 out of 100; 100 being extremely important) in a study of factors related to seeking health care in a large urban community health care setting. In the same study, feeling uncomfortable with a provider was cited as a barrier to seeking health care by over half of the study population (Higgs et al., 2001). In addition, Rask et al., (1994) reported that over 20% of the patients in her study reported that the lack of continuity of care, outside of a public hospital, was an obstacle to seeking follow-up medical care.

Healthcare organizational barriers are often cited as a hindrance to seeking care for follow-up asthma management. Some research suggests that barriers such as a lack of continuity in care or inconvenient office hours are barriers outside the emergency room. There is some evidence that these barriers can be decreased with continuity in health care providers, willingness of the physician to discuss the treatment regime, and availability of the PCP. While some of these barriers have been identified in the pediatric asthma population, additional research is

needed with adult asthmatics in a community setting. Findings may lead to directives that facilitate follow-up asthma care.

2.3 HEALTH RELATED QUALITY OF LIFE IN ADULTS WITH ASTHMA

Health related quality of life (HRQL) has been increasingly used to measure outcomes with many chronic diseases, especially asthma (Eisner et al., 2002; Erickson, Christian, Kirking, & Halman, 2002; Onyirimba et al., 2003). HRQL is a multidimensional factor with domains encompassing physical, social, and psychological functioning (Guyatt, Feeny, Patrick, 1993; Testa, & Simonson, 1996). In asthma, HRQL has been associated with traditional measures of physiologic impairment, such as forced expiratory volume in one second (FEV₁) (Juniper, Guyatt, Ferrie, Griffith, 1993), physical symptoms (Rutten-van Molken et al., 1995), psychological symptoms (Mancuso, Rincon, McCulloch, & Charleson, 2001) and aggregate measures (Viramontes, & O'Brien, 1994). Psychological factors, such as altered coping and low self esteem have been associated with greater psychological morbidity in adults with asthma and a lower HRQL (Katz, Yelin, Eisner, & Blanc, 2002; Mancuso, Rincon, McCulloch, & Charlson, 2001; Miles, Garden, Tunnecliffe, Clayton, & Ayres, 1997;).

HRQL, along with physiological health, are key components in the health service research (HSR) paradigm. This is important with many chronic diseases, but especially asthma, since the treatment is mainly on an outpatient basis and encompasses physical, social, and psychological domains. Consequently, it is important to assess outcomes relevant to this population of patients, including aspects of HRQL (Richards & Hemstreet, 1994). More

importantly, the patients' perspective is foremost in this evaluation as a mechanism of not only measuring outcomes, but improving care.

When studying HRQL in populations, such as those in an outpatient facility, one needs to consider the influence of patient, disease, treatment, and characteristics of the health care delivery system. Other variables, such as education, socioeconomic factors, gender, insurance, and organizational dynamics of the delivery system, such as transportation, attitudes of the professional and nonprofessional personnel, and appointment schedules may influence HRQL. Researchers in health services need to examine which variables are most influential to an individual's HRQL. From this empirical data, interventions can be developed that promote positive health care outcomes.

Although the relationship between HRQL and asthma has been studied from a treatment regime, little research exists that examine the effects of barriers and/or facilitators on HRQL (Jacobs, van de Lisdonk, Smeele, van Weel, & Grol, 2001; Pinnock et al., 2003; Thoonen et al., 2003). Erickson, Christian, Kirking, and Halman (2002) examined the relationships between patient and disease characteristics and HRQL in adults with asthma. Data from 603 subjects in one managed care organization was collected using the Asthma Quality of Life Questionnaire, SF-36, and the Model of Health Services Utilization. They found that barriers related to health care and beliefs (for example "I do not understand everything I have been told to do to control my asthma) showed a consistently significant relationship with each domain and summary score on the Asthma Quality of Life Questionnaire (Erickson et al., 2002). Furthermore, perceived accessibility of the health care provider was a major contributor to the SF-36 Physical Functioning domain (Erickson et al., 2002). The researchers conclude that one must examine the

influence of patient variables, in addition to disease, when evaluating HRQL in a specific population.

Health care utilization, and its relationship to HRQL, has been studied in the adult asthma population. One study found that better baseline asthma specific HRQL was associated with a decreased risk of future all-cause hospitalization and asthma-related health costs (Eisner et al., 2002). Another study with urban African Americans found that although the majority of subjects reported their overall health as “good to fair” they indicated impairment in asthma-related quality of life (Blixen, Tiley, Havstad, & Zoratti, 1997). In the same study, even though 71% of the subjects identified a physician outside of the emergency room they saw for asthma, 54% had not spoken to either a physician or nurse and 46% had not had an office visit within the prior three months (Blixen et al., 1997). The researchers’ findings were inconclusive as to whether the behavior reflected the effects of barriers with health care utilization in this population.

Socioeconomic status has been related to HRQL in adults with asthma in several studies (Abdulwadud, Abramson, Forbes, & Walters, 2001; Aper, Reisine, Affleck, Barrows, & ZuWallack 1999; Erickson, et al., 2002;). Other studies have found that consultation with a physician (Jacobs et al., 2001), follow-up telephone calls (Pinnock et al., 2003), therapeutic treatments by an allergist (Kanter et al., 2002) or behavioral interventions that promote self management (Thoonen et al., 2003) have an effect of HRQL. However, little research exists that identifies the barriers and/or facilitators of follow-up asthma care in community and its effect on HRQL. As a result of the chronic nature of the disease, the potential for life-threatening exacerbations, and the burden of day-to-day management, it is imperative that researchers identify those specific barriers that hinder care so that effective interventions and congruent health policies are developed.

3.0 METHODS

This study was conducted at two outpatient health facilities of the University of Pittsburgh Medical Center (UPMC) Health System. UPMC Health System has 12 outpatient community facilities serving the Greater Pittsburgh and Allegheny County area. The two outpatient health care facilities conveniently selected for this study were Bloomfield-Garfield (BG) and Latterman Family Health Center (LFHC) in McKeesport. BG serves a population of approximately 15,500 while LFHC population exceeds 30,000. Patients who seek care at Harrison and Crawford Health Care offices were also asked to participate. Harrison and Crawford are two subsidized housing facilities under the McKeesport Housing Authority. Harrison and Crawford offices often refer patients to LFHC for more complex issues, such as asthma. The population of Harrison and Crawford increase LFHC's service population to over 36,000.

UPMC Health System primarily serves residents of Allegheny County, a population comprised of Caucasians, (84.3%), African Americans (12.4%), and Asians, (1.7%), and other (1%). Of this population, 86% are high school graduates or equivalent, and nearly 18% of the population is greater than 65 years of age (2002 U.S.Census data). The median income of Allegheny County is approximately \$38,300 while greater than 13% of the population is below the federal poverty limit (2002 U.S. Census data). The two community health care facilities patient populated in this study have patient populations similar to demographics of Allegheny County.

3.1 SAMPLE

Study participants were recruited who met the following inclusion criteria,: 1) ability to read and speak and comprehend English (needed for instrument completion), 2) attained 18 years of age or older, 3) have been told by a physician or health care provider that they had asthma, 4) show no evidence of cognitive disorders that would interfere with data collection, and 5) utilize one of the two selected urban community health care facilities for routine health care on a regular basis.

Exclusion criteria included: 1) inability to speak or comprehend English, 2) less than 18 years of age, 3) history of other chronic diseases of the respiratory system (ex. emphysema, chronic obstructive pulmonary disease, pulmonary fibrosis, bronchiectasis) 4) evidence of cognitive disease that would interfere with data collection and 5) were not seen regularly by the medical staff at one of the two urban community health care facilities.

3.2 SAMPLE SIZE JUSTIFICATION

A sample size of approximately 50 participants was needed to achieve statistical power of 0.80.

3.3 STUDY DESIGN

This study was a descriptive cross-sectional design. All adults with asthma currently seen in either BG or LFHC community health facilities were eligible to participate. The cross-sectional design allows for examination of the effects related to differences in socioeconomic status, age, and ethnicity on the outcomes measured. A description of the characteristics of both sites can be

found in Table 1. Data was analyzed to identify barriers to follow-up health care for adult asthmatic patients who are followed in an urban community health care facility and their effects on compliance with outpatient asthma management. Furthermore, data was analyzed to determine which barrier affect health related quality of life (HRQL) for the adult asthmatic patients in the community.

Table 1: Demographic Data of Study Sites

Site	Total Population	Total White	% White	Total Black	% Black	Total Other	% Other	% Below Poverty	Per Capita Income	% H.S. Grad or higher
Allegheny County	1,281,000	1,080,000	84%	159,000	12.4%	27,400	3%	13%	\$38,300	86%
BG	15512	7499	48.3%	6951	44.8%	1062	6.8%	27.5%	\$16,457	80%
LFHC	30875	26125	84.6%	4004	13.0%	746	2.4%	17.8%	\$15,296	80%
Harrison	1589	609	38.3%	931	58.6%	49	3.1%	57.3%	\$11,245	58.3%
Crawford	4399	2874	65.3%	1342	30.5%	183	4.2%	29.6%	\$11,925	81%

3.4 STUDY VARIABLES

3.4.1 Descriptive data

3.4.1.1 Sociodemographic characteristics

Demographic data was obtained from subjects using an investigator developed questionnaire that identifies age, gender, employment status (outside the home), socioeconomic status, education, race, marital status, and number of dependents (See Appendix A).

3.4.1.2 Health status characteristics

Health status data was obtained from subjects using an investigator developed questionnaire that identifies number of asthma medications prescribed, number of emergency room visits within the last 12 months, years with asthma, number of community health visits to a primary care provider (PCP) within the last 12 months, number of physiologic and/or psychologic comorbidities, and compliance with the treatment regime (See Appendix B).

3.4.2 Dependent variables

3.4.2.1 Mini Asthma Quality of Life Questionnaire (MiniAQLQ)

The MiniAQLQ is an asthma specific, 15 item self-administered questionnaire developed by Juniper, Guyatt, Ferrie, and Griffith (1999). Scores in four domains; activity limitations, symptoms, emotional function, and exposure to environment stimuli and a summary score, are obtained. Eleven out of the 15 questions use a Likert scale ranging from 1 (all of the time) to 7 (none of the time). The last four questions refer to limitations in activity and use a Likert scale ranging from 1 (totally limited) to 7 (not at all limited). The MiniAQLQ was developed for greater efficiency, group patient monitoring, and large survey data collection. The MiniAQLQ was tested with symptomatic asthma patients. Patients completed the MiniAQLA, the Asthma Quality of Life Questionnaire (AQLQ) and the Short Form (SF)-36. Reliability was acceptable for the MiniAQLQ (interclass correlation coefficient =0.83) and responsiveness was good ($p=0.0007$) (Juniper et al., 1999). Construct validity was strong and criterion validity showed there was no bias ($p=0.61$) and a high correlation ($r=0.90$) between instruments (Juniper et al., 1999). Although both tools were developed in Canada, Leidy and Coughlin (1998) found that

the AQLQ can be a useful outcome measure for clinical trials conducted in the United States (See Appendix C).

3.4.2.2 Eastern Washington Access to Health Care Consumer Survey 2001

The Eastern Washington Access to Health Care Consumer Survey 2001 (EWash) was developed by Higgs, Bayne and Murphy to assess the perceptions of health care access and satisfaction with health care in the Spokane Washington area (2001). The original tool consists of 90 items with scores ranging from “not at all” (0) to “totally” (100) for each item. Subscales of the instrument include the perceived degree to which the need for services are met in relation to medical, dental, and mental health services. In addition, items regarding current source of care, the degree to which medical, dental, mental health services, and prescriptions were covered by insurance; factors perceived as important when seeking health care; barriers to care; and overall satisfaction with medical, dental, and mental health care received are measured (Higgs et al., 2001). Cronbach alpha reliability coefficients ranged from 0.72 to 0.96 for subscales (Higgs et al., 2001). As a result of the need to obtain information related to the above categories, a revised Eastern Washington Access to Health Care Survey was developed by Bayne, Higgs and Gruber (2001) (phone conversation with Z. Higgs, February 19, 2004). For the purpose of the present study, the revised Eastern Washington Access to Health Care Consumer Survey was used. The revised tool consists of 170 questions. Participants were asked to rate the degree to which access to health care was met for all members in the household using a five point Likert scale. Responses can range from 0 (NA) to 5 (Always). Content validity for the revised tool was based on the literature and the theoretical framework on access to health care (phone conversation with Z. Higgs, February 19, 2004). Since certain subscales on the EWash do not pertain to the present study, the tool was modified with permission from the developer. The EWash for this study

consist of the following subscales: medical care need, prescription drug needs, satisfaction with care, health insurance, health insurance coverage, health care costs not covered, local availability of services, barriers to obtaining health care, concerns related to health care, health of the members of your household, and sources of health care and health information for a total of 10 subscales. There are 66 total questions in the subscales. Responses are recorded using either a five or six point Likert scale. The final two open ended questions relate to health information for a total of 68 questions in the tool (See Appendix D).

3.5 DATA COLLECTION/RECRUITMENT

The research study was introduced to potential subjects by either of the following methods.

- 1) A poster and brochure was placed prominently in the waiting rooms of both BG and LFHC health care facilities (See Appendix E: Poster and Appendix F: Brochure) If the patient expressed interest in participation in the study, the patient was instructed to contact a member of the research team directly or the administrator of the community health care facility for additional information. If the patient called a member of the research team directly for additional information, eligibility for study participation was determined (see Appendix G: Screening Tool).
- 2) A member of the medical/nursing staff who by virtue of his/her position had access to the potential subject's health information. The medical/nursing staff member was not a study investigator. If the patient met entry criteria, the medical/nursing staff asked the potential subject if she/he was interested in

study participation. If the subject expressed interest in participating, the patient was asked if a member of the research team might contact him/her directly to provide more information about the study.

- 3) A member of the medical/nursing staff who by virtue of his/her position had access to the potential subject's health information. If the patient met study criteria and was interested in participating, the medical/nursing staff member gave the subject a packet containing a cover letter (See Appendix H) explaining the purpose of the study, a consent form to sign, instructions for completing the questionnaires, the questionnaires, and a pre-postage paid return envelope. Subjects were instructed to return all completed forms to the primary investigator. A reminder postcard was sent one week after the initial packet to these subjects, followed approximately one week later by a second questionnaire packet to all non-respondents. Once all completed questionnaires were returned to the primary investigator, a \$25.00 gift certificate was mailed to each study participant.
- 4) All completed forms were stored in a locked cabinet accessible only to members of the research team. Any identifiable information was stored separately from the completed forms and accessible only to members of the research team.

3.6 DATA ANALYSIS

To answer the research questions, several statistical approaches were used. To answer researcher question #1 “What are the perceived barriers reported by adult asthmatic patients who are followed in an urban community health care facility?” descriptive statistics were used. This format allowed the researcher to characterize the perceptions of the sample population about the extent to which needs for health care were being met, whether or not the care was covered by insurance, and whether or not the services received were satisfactory. Analysis of items from the tool allowed the researcher to examine the subject’s usual source of care, interest in obtaining care if available, importance of concerns related to seeking care, and barriers to care.

Demographic and health status characteristics were analyzed by utilizing measures of descriptive statistics including central tendency and variation. Several statistical methods were used to analyze research questions #2; “What is the relationship between perceived barriers and selected demographic characteristics of adult asthmatic patients in an urban community health care facility?” and research question #3; “What is the relationship between perceived barriers and selected health status characteristics of adult asthmatic patients in an urban community health care facility?” The t-test was used to assess whether the means of two groups were statistically different from each other. This analysis was appropriate whenever the researcher wanted to compare the means of two groups (Trochin, 2002). ANOVA was used to test hypotheses about differences between two or more means. ANOVA was used to test differences among several means for significance without increasing the Type I error rate (Lane, 2004). The

Mann-Whitney U-test was used instead of the t-test when normalcy of data could not be assumed (Conover, 1980). The Kruskal-Wallis test was used to compare three or more independent groups of sampled data when assumptions about normalcy of data could not be assumed. Research question #4 “What is the relationship between perceived barriers and health related quality of life of adult asthmatic patients in an urban community health care facility?” was analyzed using the Pearson Product Moment correlation coefficient. Multiple regression was the statistical approach used to analyze research question #5, “Which variables (subscales on the EWash) are best associated with health related quality of life in the adult asthmatic patient in a community health care facility?” Multiple regression is commonly used to determine which variables best predict the probability of a particular outcome. In this research question, the researcher sought to identify which domain of the independent variable (subscales on the EWash) or combination of these are most likely associated with quality of life (dependent variable). It is also frequently used to determine the value of all independent variables, when put together, predict the dependent variable any better than if individually tested (Menard, 1995).

Several statistical procedures were used to analyze research question #6, “What is the relationship between perceived barriers and compliance with follow-up care for adult asthmatic patients in an urban community health care facility?” The t-test was used to assess whether the means of two groups were statistically different from each other. ANOVA was used to test hypotheses about differences between two or more means. The Mann-Whitney U-test was used instead of the t-test when normalcy of data could not be assumed. The Kruskal-Wallis test was used to compare three or more independent groups of sampled data when assumptions about normalcy of data could not be assumed. Statistical significance for all tests was set at $p < 0.05$.

3.6.1 Informed consent

Screening Waiver: Because I asked potential subjects to contact the research team directly regarding further interest in the study, I requested a waiver of the requirement to obtain signed informed consent for the screening process. I believe this study design met the following criteria: 1) the respective research study procedures presented no more than minimal risk of harm to the involved subjects; and 2) the information obtained during the screening phone call is routine for patients utilizing an outpatient health care facility, i.e., identification of asthma by a health team professional and over 18 years of age. (See Appendix G for the screening script and screening tool that was utilized.) If the subject did not meet inclusion criteria, all information collected during the screening process was destroyed. A member of the research team obtained written informed consent prior to the administration of the survey instruments.

4.0 RESULTS

The main results of this study are summarized in three parts: Part A is a description of the sample, Part B is a description of the subjects in relation to the health status questionnaire, MiniAQLQ and EWASH tools and Part C presents results associated with the research questions.

4.1 DESCRIPTION OF THE SAMPLE

Approximately 85 study packets were distributed between the two sites, BG and LFHC. Thirty-five packets were returned. One participant did not meet the study criteria and was eliminated from data analysis. The remaining 34 packets constituted the study sample. This represented a 41% return rate. Mean response rates to mailed surveys published in medical journals has been cited at 59% +/- 20% (median 59%) (Asch, Jedrziwski, & Christakis, 1997). Staff at each outpatient facility were asked to record the name of every patient to whom they distributed a study packet. BG would supply either a phone number or address of the patient for follow-up but LFHC would not give any follow-up information to the researcher. If surveys distributed at BG were not returned to the researcher within one week, follow-up phone calls or postcards were sent. This was repeated in another week if the surveys were not returned. All but three of the study

participants received their health care from either BG or LFHC. These three study participants saw information related to the study in the waiting room while family members were seen by a doctor at the outpatient facility. Staff members distributed a study packet to these participants. Since the number was small and they met all study criteria except receiving health care at one of the two outpatient facilities, they were included in data analysis. Missing data is minimal and any missing data is marked in the respective tables. All data was analyzed using both parametric and non parametric statistical programs. Data for all research questions is reported using parametric statistics since no difference was found with comparable non parametric programs.

Ninety-four percent (94%) of the sample was female. In 2004, Allegheny County reported the percentage of women with asthma as 11% compared to 7% for men (Allegheny County News [www.county.allegheny.pa.us/news/241027.asp] n.d.). The age groups of 35-44 and 45-54 comprise 20.6% and 26.5% of the total sample surveyed respectively. Those 55 years and older constitute only 11.8% of the total sample. Over 90% of the sample had at least a high school education or GED while at least 70% were single or never married (Table 2).

Table 2: Demographic Characteristics of the Sample

Age	Frequency	Percent
18-24 years	3	8.8
25-34 years	11	32.4
35-44 years	7	20.6
45-54 years	9	26.5
55-74 years	2	5.9
75 + years	2	5.9
Educational Level		
Educational Level	Frequency	Percent
8th grade or less	1	2.9
Some high school	2	5.9
High school or GED	9	26.5
Voc/technical school	3	8.8
Some college	9	26.5
College graduate or beyond	10	29.2
Marital Status		
Marital Status	Frequency	Percent
Never married	14	41.2
Currently married	7	20.6
Live with partner	3	8.8
Single	10	29.4

In terms of employment, 36.2% reported full-time employment which comprised the largest portion of the sample. Disabled, unable to work, homemaker, and retired responses comprised 20.6%, 17.7% and 17.7% of the sample respectively. Asthma was not a hindrance to work as reported by 61.7% of the sample. Annual household income ranged from 47% for those earning less than \$19,999, 41.2% between \$20,000 and \$49,999 and 8.8% greater than \$50,000 (Table 3). The lowest income bracket exceeds the U.S. Census report in Allegheny County of 22% below \$19,999 (www.census.gov/press/release [n.d.]). Even though these numbers exceed the U.S. Census report, only 10 subjects (29.4%) perceived a great deal of difficulty paying for basic needs (Table 3).

Religion was reported as either Catholic, Jewish, Protestant, including Baptist and American Zion, other, or no religious preference. Other consisted of Christian, Salvationist or Jehovah Witness. The “other” category represented 17.6% of the sample while the next largest group was Catholics at 29.4%. Protestants comprised the largest religious group representing 41.1% of the sample. Over half of the sample felt religion was extremely important to them (52.9%). African Americans and White were the two largest ethnic groups representing 50% and 35.3% respectively. It is noted that the sample included of one male American Indian. This is interesting considering only 0.1% of Allegheny County reported their ethnicity as American Indian (www.census.gov/press/release [n.d.]). When asked to report the importance of ethnicity in their daily lives, 64.7% of subjects perceived it as somewhat or very important, yet only 8.8% perceived their providers to have no understanding of their ethnic background (Table 4).

Table 3: Demographic Characteristics of Participants Related to Health Care Facility, Employment, Annual Household Income, Work Hindrance Related to Asthma and Perception of Difficulty Paying for Basic Needs

Health Care Facility	Frequency	Percent
Bloomfield-Garfield	15	44.1
Latterman Family Health Care	16	47.1
Other	3	8.8
Employment Status	Frequency	Percent
Full time	13	36.2
Laid off/retired	6	17.7
Disabled	7	20.6
Homemaker/student	6	17.7
Never employed	2	5.8
Annual Household Income	Frequency	Percent
Less than \$10,000	8	23.5
\$10,000-\$19,999	8	23.5
\$20,000-\$49,999	14	41.2
\$50,000 +	3	8.8
Total for annual income	33	97.1
Work Hindrance	Frequency	Percent
Yes, due to physical demand	10	29.4
Yes, due to mental demands	1	2.9
Yes, for other reasons	2	5.9
No	21	61.7
Difficulty Paying Basic Needs	Frequency	Percent
No difficulty	9	26.5
Somewhat difficult	15	44.1
A great deal of difficulty	10	29.4

Table 4: Religion and Ethnicity of Participants and their Perception of Importance

Religion	Frequency	Percent
Catholic	10	29.4
Jewish	1	2.9
Protestant	16	41.1
Other	5	14.7
No religion	4	11.6
Importance of Religion	Frequency	Percent
Not at all important	8	23.5
Somewhat important	8	23.5
Extremely important	18	52.9
Ethnicity	Frequency	Percent
White	12	35.3
African American	17	50
American Indian	1	2.9
Mixed	2	5.9
Other	2	5.9
Importance of Ethnicity	Frequency	Percent
Not at all important	11	32.4
Somewhat important	8	23.5
Very important	14	41.2
Participant's Perception of Provider's understanding of ethnicity (1 missing data)	Frequency	Percent
Not at all	3	8.8
Somewhat understand	16	47.1
Understand a lot	13	36.2

4.2 DESCRIPTION OF THE SAMPLE IN RELATION TO HEALTH STATUS, QUALITY OF LIFE AND EWASH

4.2.1 Health Status Questionnaire

Half of the sample receive medical care for their asthma at one of the outpatient health care facilities while 11 (32.4%) go to a private physician office while only 8.8% utilize an emergency room. One or two pharmacologic agents were prescribed for 70.5% of the sample with metered dose inhalers and long acting beta agonists the most common medications. (Table 5)

Over half of the sample (66.7%) saw their primary care physician for asthma related health care issues two times or fewer within the last year. The maximum number of times was 10, as stated by one sample participant and 2 visits was the modal number. Sixty percent (60%) of the sample stated zero visits to the emergency room within the last year for an asthmatic attack and only 21% were treated once in the emergency room. Furthermore, only 8.8% of the sample necessitated an overnight hospital admission (Table 6). Asthma is not the only medical condition that warranted physician's care for many sample participants. Fifty-eight percent (58%) of the sample has a variety of other co-morbidities with hypertension, diabetes, and high cholesterol reported by eight, four, and four sample subjects respectively. Depression was the most common psychological condition reported by 29% of the sample (Table 7).

Table 5: Location of Participants' Asthma Health Care, Number and Type of Prescribed Pharmaceutical Agents

Location	Frequency	Percent
Private Physician office	11	32.4
At one of the two clinics	17	50.0
Emergency Room	3	8.8
Other	3	8.8
Number of Medications	Frequency	Percent
0	1	2.9
1	6	17.6
2	18	52.9
3-7	9	26.3
Type of Medication	Frequency	Percent
Steroids	5	6.6
Metered dose inhalers	21	28
Long Acting Beta ₂ Agonists	21	28
Mast Cell Stabilizers	7	9.3
Leukotriene antagonist	6	8
Anticholinergics	0	0
Short acting beta ₂ agonists	14	18.6
Methylxantine	1	1.3

Table 6: Number of Visits to Primary Care Provider/Emergency Room or Overnight Hospitalizations within the Past Twelve Months for Asthma

Number of Visits	Frequency	Percent
Zero	5	14.7 %
1 visit	6	17.6 %
2 visits	11	32.4 %
3 visits	3	8.8 %
4-5 visits	2	5.9 %
6-7 visits	4	11.8 %
9-10 visits	2	5.8 %
Missing -1		
Emergency Room visits	Frequency	Percent
Zero	20	58.8
Once	7	20.5
2-3 times	2	5.9
4-7 times	3	8.8
> 7 times	1	2.9
Missing-1		
Overnight hospitalizations	Frequency	Percent
Zero	27	79.4
Once	3	8.8
2-4 times	1	2.9
5-6 times	2	5.9
Missing -1		

Overall, 58.8% of the sample reported occasional difficulty avoiding irritants that exacerbate asthma. The home and/or outdoor environments (35.3% for both groups) contain irritants that trigger asthma exacerbations. Unfortunately, 29.4% of the sample report smoking either cigarettes, cigars, or a pipe and 23.5% have members of their household who smoke (Table 8).

Table 7: Pathological and Psychological Co-Morbidity Factors of Participants

Number of Participants under physician care for medical conditions	Frequency	Percent
Yes	30	58.8
No	14	41.2
Medical condition	Frequency	
High blood pressure	8	
Diabetes mellitus	4	
High blood cholesterol	4	
Arthritis	3	
Degenerative disc disorder	3	
Heart condition	2	
Acid reflux disease	2	
Pregnancy	2	
The following conditions were cited once	Fibromygia, gout, anemia, thyroid disease, sleep apnea, cardiovascular accident, blood dyscrasia, multiple sclerosis, seizure disorder, smoking cessation	
Number of Participants under physician care for psychological conditions	Frequency	Percent
Yes	10	26.5
No	25	73.5
Psychological condition	Frequency	
Depression	9	
The following conditions were cited once	Mood and antisocial	

Table 8: Perception of Difficulty Avoiding Asthma Triggers

Perception	Frequency	Percent
Frequently	9	26.5
Occasionally	20	58.8
Never	5	14.7
Perceived Precipitating Factors	Frequency	Percent
Home environment	12	35.3
Work environment	4	11.8
Outdoor environment	12	35.3
Exercise	3	8.8
Social situations	1	2.9
Other	2	5.9
Participant Smoking History	Frequency	Percent
Do not smoke	24	70.6
Light smoker	6	17.6
Heavy smoker	4	11.8
Household members' smoking history	Frequency	Percent
Yes	8	23.5
No	26	76.5

4.2.2 MiniAQLQ

The MiniAQLQ is divided into two sections. The first section consists of 11 questions related to symptoms experienced within the last two weeks related to the participant's asthma. Questions are recorded on a Likert scale from "all of the time" to "none of the time." The last four questions relate to limitations in activities within the last two weeks as a result of asthma. These responses are also recorded on a Likert scale from "totally limited" to "not at all limited." Data was available for all questions except three subjects did not answer question 15 "Work related activities (tasks you have to do at work)." Consequently data was analyzed for 31 subjects for this question only.

The first 11 question responses were coded 1 through 7. A value of 1 represented “all of the time,” 2 “most of the time,” 3 “a good bit of the time,” 4 “some of the time,” 5 “a little bit of the time,” 6 “hardly any of the time,” and 7 “none of the time.” A higher score coincides with a better quality of life. Mean scores ranged from 3.4 for “Feel bothered by or have to avoid cigarette smoke in the environment” to 4.6 for “Feel bothered by or have to avoid going outside because of weather or air pollution.” Eight of the 11 questions had a mean score above 4, which represents “some of the time.” The three questions which subjects scored between “a good bit of the time” and “some of the time” were “Feel bothered by or have to avoid dust in the environment,” “Feel bothered by coughing,” and “Feel bothered by cigarette smoke,” at 3.8, 3.7 and 3.4 respectively (Table 9).

Means for the last four questions related to activity limitations ranged from a high of 5.3 for “Work related activities (tasks you have to do at work) to 3.9 for “Strenuous activities (such as hurrying, exercising, running up stairs, sports)”. Except for the question on strenuous activities, the subjects reported only a moderate or less limitation in activities such as walking, housework, climbing steps, talking, playing with peers or visiting friends (Table 10).

4.2.3 EWASH

The EWASH surveyed participants regarding their perceptions of access to health care for them and all members of their household. Participants were told that their responses would provide useful information on planning future health care services. Unless stated otherwise, study participants completed every question on the survey.. One initial

question asked the participant to identify their source of health care insurance. All but one study participant reported at least one form of insurance while 30% stated two different forms of insurance coverage. Medicare was identified by 24% of the sample followed by UPMC, Gateway, Medicaid, BlueCross/Highmark at 21%, 15%, 12% and 12% respectively. Table 9 profiles the variety of health insurance coverage in the sample. Although only three participants stated their age as greater than 64 years, eight participants marked NA in response to the question “Overall, to what degree does insurance cover most of the medical care needs of the following members of your household: Adults 65 and over?” Of the remaining sample participants 69% responded that insurance covers most of the medical care needs of the adults in the household 19-64 years of age “nearly always or always.”

Table 9: Insurance Coverage of Participants

Insurance Form	Frequency/Percent
Medicare	8/ 19,5%
UPMC	7/ 17%
Gateway	5/ 12%
Medicaid	4/ 9.7%
BlueCross/Blue Shield	4/ 9.7%
Private	3/ 7.3%
Welfare	2/ 4.8%
SSI	2/ 4.8%
Medplus	1/ 2.44%
Access	1/ 2.4%
Veteran's	1/ 2.4%
Security Blue	1/ 2.4%
NALC	1/ 2.4%
None	1/ 2.4%

Local availability of services was assessed using a Likert scale of 1 (N/A) to 6 (strongly agree). Sample subjects were asked to state whether or not they perceived the availability of nine different services in their local area. A higher mean score indicated agreement that services were available. Mean scores ranged from a high of 4.67 to a low of 3.85. High mean scores were evident in the sample's perception of sufficient access to ambulance/emergency transportation and pharmacies/drug stores. A score of 4.67 fell between the values of "neutral" and "agree." On the other hand, the sample's perception of sufficient home health care services (such as visiting nurse or home health aids) and health and safety education programs fell between "disagree" and "neutral." Overall, the sample rated local availability of services with a mean score of 4.30, a value between "neutral" and "agree." (Table 11)

Table 10: MiniAQLQ Survey Results

Question	Response Category														Mean
	All of the time-1		Most of the time-2		A good bit of the time-3		Some of the time-4		A little of the time-5		Nearly any of the time-6		None of the time-7		
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	
Feel short of breath	1	2.9	2	5.9	6	17.6	6	17.6	8	23.5	7	20.6	4	11.8	4.61
Feel bothered by dust	5	14.7	3	8.8	5	14.7	11	32.4	2	5.9	7	20.6	1	2.9	3.79
Feel frustrated	4	11.6	1	2.9	4	11.8	7	20.6	7	20.6	7	20.6	4	11.8	4.44
Feel bothered by coughing	4	11.8	7	20.6	6	17.6	4	11.8	6	17.6	6	17.6	1	2.9	3.67
Feel afraid of not having medication	4	11.6	3	8.8	2	5.9	9	26.5	5	14.7	5	14.7	6	17.6	4.38
Feel chest tightness	2	5.9	3	8.8	3	8.8	9	26.5	9	26.5	5	14.7	3	8.8	4.38
Feel bothered by cigarette smoke	8	23.5	8	23.5	2	5.9	5	14.7	5	14.7	3	8.8	3	8.8	3.35
Have difficulty sleeping	2	5.9	4	11.8	3	8.8	8	23.5	6	17.6	9	26.5	2	5.9	4.38
Feel concerned	7	20.6	1	2.9	4	11.8	8	23.5	2	5.9	9	26.5	3	8.8	4.05
Experience wheeze in chest	3	8.8	3	8.8	6	17.6	8	23.5	5	14.7	7	20.6	2	5.9	4.11
Feel bothered by weather or air pollution	2	5.9	3	8.8	4	11.6	7	20.6	5	14.7	6	17.6	7	20.6	4.64
	Totally limited-1		Extremely limited-2		Very limited -3		Moderate limitation-4		Some limitations-5		A little limitation-6		Not at all limited-7		
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	
Strenuous Activities	4	11.8	6	17.6	3	8.8	7	20.6	6	17.6	8	23.5	0	0	3.85
Moderate Activities	1	2.9	4	11.8	4	11.8	8	23.5	5	14.7	6	17.6	6	17.6	4.58
Social Activities	2	5.9	3	8.8	1	2.9	5	14.7	5	14.7	6	17.6	12	35.3	5.17
Work related activities (3 missing data)	1	2.9	2	5.9	1	2.9	2	5.9	2	5.9	8	23.5	15	44.1	5.32

Domain mean scores:

Symptoms: 4.23

Emotional function: 4.29

Environmental stimuli: 3.92

Overall MiniAQLQ score: 4.31

Activity limitation: 4.73

Table 11: Participants' Perception of Local Availability of Services

Services	N/A-1		Strongly Disagree-2		Disagree-3		Neutral-4		Agree-5		Strongly Agree-6		Mean
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	
Ambulance	0	0	1	2.9	4	11.9	5	14.7	19	55.9	5	14.7	4.67
Dentist	1	2.9	2	5.9	6	17.6	7	20.6	15	44.1	3	8.8	4.23
Urgent Care	1	2.9	1	2.9	5	14.7	8	23.5	14	41.2	5	14.7	4.41
Health and Safety Education	2	5.9	3	8.8	9	26.5	7	20.6	10	29.4	3	8.8	3.85
Home Health Care	5	14.7	3	8.8	5	14.7	5	14.7	11	32.4	5	14.7	3.85
Pharmacies	1	2.9	2	5.9	4	11.8	2	5.9	16	47.1	9	26.5	4.67
Primary Care Physicians	1	2.9	2	5.9	4	11.8	2	5.9	16	47.1	9	26.5	4.67
Rehabilitation (PT?OT)	4	11.8	1	2.9	8	23.5	3	8.8	13	41.2	4	11.8	4.00
Specialty Physicians	1	2.9	6	17.6	15	44.1	1	2.9	5	14.7	4	11.8	4.41

Health care concerns are common with any chronic condition and asthma is no exception. It is imperative that health care providers comprehend the multiple health concerns of individuals under their care. Study participants were asked to rate their agreement with eight health care concerns experienced by members of the household within the last year. The same Likert scale was applied. A higher mean score indicated that the participant had experienced these concerns. Once again, there was no missing data in this section. The concern “a provider did not notify us of test results” achieved the highest mean score of 3.55, which is between the values of “disagree” and “neutral.” The lowest mean score of 2.70 reflected the concern “felt a provider did not take enough time to understand our race/ethnic background.” Therefore, this mean score falls between “strongly disagree” and “disagree” for the sample. No one in the sample strongly agreed that this was a concern in their household. The mean score of the sample for the eight concerns was 3.15, a value near “disagree” on the Likert scale. Table 12 identifies the eight concerns.

The sample was asked to estimate the number of times within the last year eight health care options were utilized. Alternative medicine and chiropractors were not used by 85% of the sample while health department clinics and urgent care/minor emergency center was not used by 77% and 62% of sample participants respectively. Although 21 out of 34 sample participants (62%) did not use a mental health counselor, 8.8% reported either 1-2, 3-5 or 6-8 visits within the last year help for counseling. Furthermore, 11.8% of the sample reported accessing a mental health counselor nine or more times within the past year. Ten sample participants used the community/neighborhood medical clinics nine times or more within the past year. The hospital emergency room was used once or twice by 35.3% of the sample while 29.4% were seen between 3-5 times. A private physician’s office was the most common site of health care for this

sample. Twenty-one sample subjects reported at least one visit to a private physician's office by a member of their household within the past year. The greatest percentage of the sample (26.5%) reported 6-8 visits to a private physician's office. (Table 13)

The next section on the EWASH asked sample participants to indicate what degree they or their household members would use low cost health care services (such as medical, dental, mental health) if available at an array of sites including community/neighborhood health clinic, hospital outpatient clinic for non-emergency care, mobile health van, public health department, and a school based clinic. Community/neighborhood health clinics would be used "nearly always" or "always" by 55.9% of the sample. In addition, 50% of the sample would "nearly always" or "always" utilize a hospital outpatient clinic for non-emergency care for low cost health care services. A mobile health van would seldom or never be used by 64.7% of the sample. Fourteen sample subjects reported children under the age of 18 residing in the household. Fifty-five percent (55%) of this cohort stated a school based clinic would either sometimes or always be used for medical, dental, or mental health care services. (Table 14)

The last section of the EWASH asked subjects to what degree they or members of their household use the following nine sources for health information and advice. The services include the child's school, a health care provider, health related books, neighbors/friends, newspaper/magazines, the public health department, radio, television or the World Wide Web. Participants rated the degree they obtain health information from each of these sources on a seven point Likert scale from "never" to "always." Half of the study participants with children under the age of 18 stated they "sometimes" or "nearly always" use the child's school as a source of health information and advice. A health care provider "nearly always" or "always" is the source for health care information and advice for 58.9% of the sample. Radio was cited to be a

health care source as “seldom” or less frequently by 58.9% of the sample. Conversely, 58.9% of the sample reported television to be a source “sometimes,” “nearly always,” or “always” (47%, 9%, and 3% respectively.) Health related books are “sometimes” to “always” a source of health care information for 67.6% of the sample. Newspapers/magazines were “nearly always” to “always” a source of health information for only 9% of the sample. Neighbors/friends would “never” or “seldom” be a source of health information for 55.1% of the sample. Five study participants marked N/A for the source World Wide Web. This might reflect a lack of access to the Internet. However, 51.5% of the remaining participants stated they or members of their household “sometimes” to “nearly always” use the World Wide Web as a source of health information. (Table 15).

Table 12: Participants' Perceptions of Concerns Related to Health Care

Concern	N/A-1		Strongly Disagree-2		Disagree-3		Neutral-4		Agree-5		Strongly Agree-6		Mean
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	
A provider did not notify me of test results	4	11.8	4	11.8	11	32.4	2	5.9	10	29.4	3	8.8	3.55
Could not get health care advice by phone	8	23.5	4	11.8	10	29.4	3	8.8	8	23.5	1	2.9	3.05
Felt a health care provider did not care enough	3	8.8	5	14.7	13	38.2	6	17.6	3	8.8	4	11.8	3.38
Felt a provider did not take enough time to understand our race/ethnic background	9	26.5	5	14.7	12	35.3	3	8.8	5	14.7	0	0	2.70
Felt a provider did not take enough time to understand our family situation	8	23.5	6	17.6	10	29.4	3	8.8	6	17.6	1	2.9	2.88
Felt a provider gave unclear or no health-related instructions	5	14.7	7	20.6	12	35.3	3	8.8	6	17.6	1	2.9	3.02
Felt uncomfortable with a health care provider	5	14.7	4	11.8	11	32.4	4	11.6	6	17.6	4	11.8	3.41
Office staff was not respectful	5	14.7	5	14.7	14	41.2	1	2.9	5	14.7	4	11.8	3.23

Table 13: Estimated Number of Times Participants Used the Following Health Care Sources and Information in the Last Year

Source	N/A (1)		1-2 (2)		3-5 (3)		6-8 (4)		9 or greater (5)	
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
Alternative Medicine	29	85.3	0	0	1	2.9	3	8.8	1	2.9
Chiropractor	29	85.3	2	5.9	1	2.9	2	5.9	0	0
Community neighborhood medical clinic	12	35.3	6	17.6	3	8.8	3	8.8	10	29.4
Health department clinic	26	76.5	4	11.8	1	2.9	2	5.9	1	2.9
Hospital emergency room	6	17.6	12	35.3	10	29.4	5	14.7	1	2.9
Mental health counselor	21	61.8	3	8.8	3	8.8	3	8.8	4	11.4
Private physician office	13	38.2	1	2.9	7	20.6	9	26.5	4	11.8
Urgent cre/minor emergency center	21	61.8	3	8.8	5	14.7	3	8.8	2	5.9

Table 14: Estimated Times Participants would use Low Cost Health Care if Available in the Following Sites

Service	N/A-1		Never-2		Seldom-3		Sometimes-4		Nearly Always 5		Always-6	
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
Community/neighborhood clinic	4	11.8	4	11.8	1	2.9	6	17.6	10	29.4	9	26.5
Hospital outpatient clinic for non emergency care	5	14.7	2	5.9	2	5.9	8	23.5	6	17.6	11	32.4
Mobile health van	10	29.4	10	29.4	2	5.9	4	11.8	5	14.7	3	8.8
Public health department	7	20.6	12	35.3	4	11.8	6	17.6	3	8.8	2	5.9
School based clinic	11	32.4	9	26.5	3	8.8	3	8.8	7	20.6	1	2.9

Table 15: Estimated Number of Times Participants Used the Following Sources to Obtain Health Care Information and Advice

Source	N/A-1		Never-2		Seldom-3		Sometimes-4		Nearly Always 5		Always-6	
	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%	Freq	%
Child's school	15	44.1	5	14.7	7	20.6	6	17.6	1	2.9	0	0
Health care provider	3	8.8	1	2.9	1	2.9	9	26.5	11	32.4	9	26.5
Health related books	3	8.8	4	11.8	4	11.8	16	47.1	6	17.6	1	2.9
Neighbors/friends	5	14.7	5	14.7	11	32.4	10	29.4	2	5.9	1	2.9
Newspaper/magazine	3	8.8	6	17.6	9	26.5	13	38.2	2	5.9	1	2.9
Public health department	4	11.8	11	32.4	10	29.4	7	20.5	2	5.9	0	0
Radio	2	5.9	9	26.5	9	26.5	12	36.3	2	5.8	0	0
Television	2	5.9	6	17.6	6	17.6	16	47.1	3	8.8	1	2.9
World wide web- Internet	5	14.7	8	23.5	6	17.6	8	23.5	5	14.7	2	5.9

4.3 RESEARCH QUESTIONS

4.3.1 What are the perceived barriers reported by adult asthmatics patients who are followed in an urban community health care facility?

One subscale on the EWASH asked subject participants whether or not during the last year any of the following health care barriers were experienced by a member of their household. There were 10 listed barriers. Agreement with the barriers was analyzed using a Likert scale. Scale answers were “N/A” “Strongly disagree,” “Disagree,” “Neutral,” “Agree” and “Strongly agree” using a 5 point Likert scale with 1=strongly disagree and 5 representing “strongly agree.” N/A answers were not included in the data analysis. A higher mean score indicated agreement that a member in the respondent’s household experienced the barrier within the past year. The sample participants perceived “long waiting time in the provider’s office” as the greatest barrier with a mean score of 3.2, which falls between “neutral” and “agree” on the Likert scale. Three study participants answered “N/A” for this barrier. The lowest mean score of 2.2 was recorded for the barrier “did not know where to go for services”. Eight study participants marked “N/A” for this barrier.

“Could not be seen by a provider during an emergency” was a barrier for which 67.8% of the study participants either as “strongly disagree” or “disagree.” One barrier that showed evidence of either “agree” or “strongly agree” was “too long to wait for an appointment.” The percentage of sample participants who either “agreed” or “strongly agreed” with this statement was 35.4%. Twelve study participants, or 46.2%, expressed

the same agreement with the barrier “someone had to miss work.” There were eight study participants who selected ‘N/A’ for this statement. Consequently, mean scores were derived for an n=28. The average mean for all barriers was 2.70, which falls between “disagree” and “neutral” on the Likert scale. Overall, none of the items indicated in the survey were perceived to be barriers to health care by the sample participants. Means and frequencies for the 10 potential barriers are reported in Table 16.

4.3.2 What is the relationship between perceived barriers and selected demographic characteristics of adult asthmatics patients in an urban community health care facility?

Study participants were grouped according to the site of health care, either BG or LFHC to compare the study participant’s perception of the 10 stated barriers. The three study participants who did not receive their asthma care at either site and those participants who marked “N/A” for the stated barrier were eliminated from this analysis. When comparing the two facilities, no statistical difference was found reflecting overall barriers to care based on site of care. Two barriers that had statistical significance between the two sites were “lack of transportation” and “poor quality of care by local providers” at $p=0.048$ and $p=0.013$ respectively. Study participants who received their asthma follow-up care at LFHC perceived lack of transportation and poor quality of care by local providers as more of a barrier than study participants who received their asthma follow-up care at BG. (Table 17)

The following demographic characteristics were analyzed in relation to perceived barriers. They include age, ethnicity, employment, educational level, religion, importance

of religion, annual household income, and difficulty paying for basic needs. All study participants, except those that marked “N/A” for the respective barrier were included in the analysis. T-tests were utilized to test for significance between ethnicity, employment and educational level. Oneway ANOVA was the statistic program for analysis of religious affiliation, importance of religion, and difficulty paying for basic needs and perceived barriers to health care. Pearson correlation was used to analyze barriers with age and annual household income. Ethnicity was coded as either white or non-white. Employment was coded either yes or no. The category yes included all occupations except homemaker. Education was coded as either high school/less or post-secondary. The barrier “office hours not convenient” was perceived as a significant barrier for white study participants but not for non-white respondents ($t=2.307$ $p=0.029$). If the study participant worked, they perceived “could not be seen by a provider during an emergency,” “cost of care too much,” and “someone had to miss work” as barriers to care ($p=0.03$, $p=0.00$, and $p=0.04$ respectively). Furthermore, a statistically significant difference was found between overall barriers and study participants who are currently employed ($p=0.008$). No statistical significance was found between levels of education and perceived barriers. (Table 18)

Religious affiliation was coded as either Catholic, Protestant, other or none. No statistically significant difference was found between religious affiliation and perceived barriers. This finding was also evident with importance of religion and perceived barriers (Table 19). The association between reporting difficulty paying for basic needs with any of the barriers or overall barriers to health care did not show significant association. Age was also not statistically associated with any of the perceived barriers. One demographic

variable that was significantly associated with the barrier “someone had to miss work” was household income ($p=0.008$). Consequently, the higher the income reported, the more study participants perceive “someone had to miss work” as a barrier. (Table 20)

Table 16: Means, Frequencies, and Percentages of Reported Barriers

Barrier	Response Category												Mean
	N/A		Strongly Disagree-1		Disagree-2		Neutral-3		Agree-4		Strongly Agree-5		
	Freq	Valid %	Freq	Valid %	Freq	Valid %	Freq	Valid %	Freq	Valid %	Freq	Valid %	
Could not be seen by a health care provider during an emergency	3		6	19.4	15	48.4	1	3.2	5	16.1	4	12.9	2.55
Cost of care too much	5		8	27.6	4	13.8	5	17.2	8	23.5	4	13.8	2.86
Did not know where to go for services	8		6	23.1	13	50.0	2	5.9	5	19.2	0	0	2.23
Lack of transportation	5		6	20.7	11	37.9	3	10.3	5	17.2	4	13.8	2.66
Long waiting time in the provider's office	3		3	9.7	8	25.8	7	22.6	9	29.0	4	12.9	3.10
No one was available to watch the children	17		6	35.3	5	29.4	2	11.8	4	23.5	0	0	2.24
Office hours are not convenient	4		5	16.7	14	46.7	3	10.0	4	13.3	4	13.3	2.60
Poor quality of care by local providers	3		8	25.8	11	35.5	4	12.9	6	19.4	2	6.5	2.45
Someone had to miss work	8		5	19.2	3	11.5	6	23.1	10	38.5	2	7.7	3.04
Too long to wait for an appointment	3		5	16.1	8	25.8	7	22.6	10	32.3	1	3.2	2.81

Table 17: Relationship between Health Care Facility and Perception of Barrier

Barrier	Health Care Facility/ N	t-test	Significance
Could not be seen by a provider during an emergency	BG- 13 LFHC- 15	0.28	0.78
Cost of care too much	BG- 12 LFHC- 14	-0.43	0.66
Did not know where to go for services	BG- 10 LFHC- 13	0.69	0.49
Lack of transportation	BG- 11 LFHC- 15	-2.08	0.04*
Long wait in provider's office	BG- 14 LFHC- 14	-0.61	0.54
No one available to watch children	BG- 7 LFHC- 9	-1.12	0.27
Office hours not convenient	BG- 12 LFHC- 15	-1.29	0.20
Poor quality of care by local providers	BG- 12 LFHC- 16	-2.67	0.01*
Someone had to miss work	BG- 9 LFHC- 15	-1.58	0.12
Too long to wait for an appointment	BG-13 LFHC- 15	-0.57	0.57
Overall barriers to health care	BG-15 LFHC-16	-1.62	0.11

*p<0.05

Table 18: Association between Ethnicity, Employment Status, Education Level and Perceived Barriers to Care

Barrier	Demographic Characteristic					
	Ethnicity		Employment		Education	
	t-test	Sig	t-test	Sig	t-test	Sig
Could not be seen by a provider during an emergency	1.72	0.09	2.22	0.03*	-0.00	0.99
Cost of care too much	1.47	0.15	3.27	0.00**	-1.25	0.22
Did not know where to go for services	0.26	0.79	1.24	0.22	0.26	0.79
Lack of transportation	-1.31	0.20	1.94	0.06	0.12	0.90
Long wait in provider's office	1.49	0.14	0.48	0.63	-0.62	0.53
No one available to watch children	-0.92	0.37	1.18	0.25	0.65	0.52
Office hours not convenient	2.30	0.02*	1.74	0.09	-0.75	0.45
Poor quality of care by local providers	-0.70	0.48	1.69	0.10	-0.28	0.77
Someone had to miss work	1.23	0.22	2.12	0.04*	-1.42	0.16
Too long to wait for appointment	0.41	0.68	1.54	0.13	-0.59	0.55
Overall Barriers to health care	0.73	0.47	2.80	0.00**	-0.77	0.44

*p<0.05

** p<0.01

Table 19: Association between Religion, Importance of Religion and Difficulty Paying for Basic Needs and Perceived Barriers to Care

Barrier	Demographic Characteristic					
	Religion		Importance of Religion		Difficulty Paying for Basic Needs	
	F	Sig	F	Sig	F	Sig
Could not be seen by a provider during an emergency	0.82	0.49	0.81	0.45	0.43	0.65
Cost of care too much	0.47	0.70	0.08	0.92	1.05	0.36
Did not know where to go for services	0.73	0.54	0.10	0.90	0.60	0.55
Lack of transportation	0.34	0.79	0.00	0.99	0.59	0.56
Long wait in provider's office	0.67	0.57	1.90	0.16	0.18	0.83
No one available to watch children	0.28	0.83	1.12	0.35	0.57	0.57
Office hours not convenient	1.37	0.27	0.61	0.54	1.89	0.17
Poor quality of care by local providers	0.44	0.72	0.10	0.90	1.21	0.31
Someone had to miss work	1.67	0.20	0.10	0.90	1.11	0.34
Too long to wait for appointment	0.69	0.56	0.17	0.84	1.44	0.25
Overall Barriers to health care	0.35	0.78	0.11	0.89	0.88	0.42

Table 20: Relationship between Age and Annual Household Income and Perceived Barriers to Care

Barrier	Demographic Characteristic			
	Age		Annual Household Income	
	r	Sig	r	Sig
Could not be seen by a provider during an emergency	-0.25	0.16	0.14	0.43
Cost of care too much	-0.13	0.47	0.26	0.17
Did not know where to go for services	0.02	0.91	0.21	0.30
Lack of transportation	-0.13	0.49	-0.12	0.89
Long wait in provider's office	-0.09	0.61	0.20	0.28
No one available to watch children	0.08	0.75	0.27	0.27
Office hours not convenient	-0.11	0.53	0.33	0.07
Poor quality of care by local provider	-0.00	0.96	0.23	0.19
Someone had to miss work	0.03	0.87	0.50	0.00**
Too long to wait for appointment	0.14	0.43	0.05	0.78
Overall barriers to health care	-0.10	0.54	0.26	0.13

** p<0.01

4.3.3 What is the relationship between perceived barriers and selected health status characteristics of adult asthmatic patients in an urban community health care facility?

The following health status characteristics were analyzed in relation to perceived barriers to care. They include usual place of asthma care, total number of daily medications for asthma, number of times primary care provider was seen for asthma within the past 12 months, number of times visited the emergency room for asthma within the past 12 months, number of times hospitalized overnight for asthma within the past 12 months, and whether or not the study participant is treated by a health care provider for other medical or psychological conditions. All study participants, except those who marked

“N/A” under the respective barrier were included in data analysis. One way ANOVA was the statistical method utilized to relate usual place of care to perceived barriers. Pearson correlation was utilized to measure the associations between each perceived barriers and each health status indicator. Finally, a t-test was used to determine whether or not being treated by a health care provider for other medical or psychological co-morbidities was significantly related to any of the perceived barriers.

Study participants who go to the emergency room for their usual place of asthma care perceive a lack of transportation as a barrier ($F= 3.96, p=0.02$) (see Table 21). No statistical significance was found between number of times study participants saw a primary care provider for asthma within the past 12 months and the number of emergency room visits within the past 12 months and any perceived barriers to health care. No significance was found in the association between overall barriers to health care and these two health care behaviors.. The health status variable “How often do you come back to the health center for checkups for asthma?” was recoded to eliminate study participants who answered “as needed” as a response, since this response is essentially ambiguous. The barrier “someone had to miss work” was perceived as a greater obstacle by study participants who came to the health care facility for asthma less often ($p=0.00$). Furthermore, study participants who took one or two daily medications for asthma perceived someone having to miss work as a barrier ($r=-0.51, p=0.01$). A significant relationship was also evident between missing work and the number of times study participants experienced an overnight hospitalization for asthma. Study participants who did not have an overnight stay for asthma perceived someone missing work as a greater barrier than participants who had two or more overnight hospitalizations ($r=-0.49,$

p=0.01). One possible explanation for this finding is that study participants who were more symptomatic as a result of their asthma were not currently working (Table 22)

Table 21: Relationship between Usual Place to Receive Asthma Care (Private Doctor Office, Clinic, Emergency Room, or Other) and Perceived Barriers to Care

Barrier	F	Sig
Could not be seen by a provider during an emergency	1.81	0.16
Cost of care too much	1.07	0.37
Did not know where to go for services	0.50	0.68
Lack of transportation	3.96	0.02*
Long wait in provider's office	0.46	0.70
No one available to watch children	0.16	0.91
Office hours not convenient	1.75	0.18
Poor quality of care by local providers	1.51	0.23
Someone had to miss work	1.28	0.30
Too long to wait for appointment	1.56	0.22
Overall barriers to health care	1.74	0.17

*p<0.05

The two health status characteristics, treatment for other medical or psychological conditions, were each coded as a binomial variable. No statistical significance was found between whether or not study participants were being treated for other medical conditions and individual or overall barriers to health care. Study participants who were not being treated for a psychological condition perceived “someone had to miss work” as a greater barrier to health care than participants currently under treatment by a health care provider for other psychological conditions (t=-4.08, p=0.00). No significant difference was found between overall barriers to health care and whether or not study participants reported treatment for other psychological conditions. (Table 23).

Table 22: Relationship between Total Number of Daily Medications For Asthma, Number of Times Participant saw Primary Care Provider/Visits to Emergency Room/Overnight Hospitalizations for Asthma, Frequency of Visits to Health Care Facility for Asthma and Perceive Barriers to Health Care

Barrier	Health Status Characteristic									
	Medications		PCP Visits		ER Visits		Overnight hospitalization		Freq Health Care Visits	
	r	Sig	r	Sig	r	Sig	r	Sig	r	Sig
Could not be seen by a provider during an emergency	0.00	1.00	0.02	0.90	0.12	0.52	-0.04	0.82	-0.15	0.43
Cost of care too much	-0.12	0.57	-0.19	0.31	-0.17	0.38	-0.23	0.22	-0.10	0.62
Did not know where to go for services	0.03	0.87	0.04	0.82	-0.06	0.76	-0.06	0.74	-0.01	0.94
Lack of transportation	0.02	0.92	0.08	0.68	0.18	0.33	0.04	0.80	0.05	0.80
Long wait in provider's office	0.00	0.96	0.11	0.55	-0.06	0.75	-0.13	0.49	-0.012	0.53
No one was available to watch children	-0.35	0.20	-0.03	0.88	-0.29	0.25	-0.27	0.28	0.21	0.43
Office hours not convenient	-0.32	0.11	0.09	0.60	-0.07	0.70	-0.06	0.72	-0.29	0.15
Poor quality of care by local providers	-0.14	0.49	-0.01	0.99	0.15	0.42	-0.04	0.79	-0.02	0.91
Someone had to miss work	-0.51	0.02*	-0.30	0.13	-0.33	0.09	-0.49	0.01*	-0.55	0.00**
Too long to wait for appointment	0.32	0.10	0.13	0.47	0.16	0.39	0.08	0.67	0.22	0.27
Overall barriers to health care	-0.06	0.73	-0.06	0.72	-0.05	0.76	-0.17	0.34	-0.13	0.49

*p<0.05

**p<0.01

Table 23: Relationship between Treatment by a Health Care Provider for either a Medical or Psychological Condition and Perceived Barriers to Health Care

Barrier	Health Status Characteristic			
	Medical Condition		Psychological Condition	
	t	Sig	t	Sig
Could not be seen by provider during an emergency	-0.08	0.93	-0.86	0.39
Cost of care too much	0.81	0.42	-1.11	0.27
Did not know where to go for services	0.00	1.00	0.82	0.41
Lack of transportation	0.95	0.34	-1.63	0.11
Long wait in provider's office	-0.18	0.85	0.68	0.49
No one available to watch children	0.66	0.51	-1.45	0.16
Office hours not convenient	-1.01	0.32	-1.92	0.06
Poor quality of care by local providers	-0.19	0.85	-1.90	0.06
Someone had to miss work	-0.16	0.87	-4.08	0.00**
Too long to wait for appointment	0.39	0.69	-0.42	0.60
Overall barriers to health care	0.47	0.63	-1.83	0.07

**p<0.01

4.3.4 What is the relationship between perceived barriers and health related quality of life of adult asthmatic patients in an urban community health care facility?

Questions on the MiniAQLQ are divided into four domains, plus an overall quality of life score. The four domains are symptoms, activity limitations, emotional functions, and environmental stimuli. All study participants, except those who marked “N/A” under the respective barrier were included in data analysis. Pearson correlation was used to analyze barriers with the four domains and overall quality of life. Study participants who stated agreement with the barrier “cost of care too much” perceived their environmental stimuli quality of life as poor (p=0.00). In addition, study participants who stated agreement with the barrier “did not know where to go for services” also perceived a lower quality of life

in the environmental domain ($p=0.02$). The environmental domain refers to stimuli, such as cigarette smoke, dust or air pollution that may trigger asthma exacerbations. Otherwise, the perceived barriers had no significant relationship with the domains of symptoms, activity limitations, emotional functions or overall quality of life. (Table 24).

4.3.5 Which variables (subscales on the EWash) are best associated with health related quality of life in the adult asthmatic patient in an urban community health care facility?

There are 11 subscales on the EWash. They are medical care needs, prescription drug needs, satisfaction with care, overall health insurance, health insurance coverage for medical needs, health insurance coverage for prescription drug needs, local availability of services, concerns related to health care, sources of health care, utilization of low cost health care, and sources of health care information. A higher mean score in each respective subscale implies that either study participants perceive needs are met or information easily obtainable. Consequently, a higher mean score on the MiniAQLQ indicates a perceived higher quality of life. Each subscale on the EWash was correlated to the four domains on the MiniAQLQ and overall quality of life. The two domains on the EWash that correlated significantly with all domains and overall quality of life were medical needs met and local availability of services (overall $p=0.00$ and $p=0.00$ respectively). Study participants who perceived their medical care needs were met and sufficient health care services in the local area reported a higher overall quality of life. (Table 25).

Stepwise multiple regression was also utilized to determine if any combination of two or more subscales on the EWash would predict health related quality of life better than a single subscale. Results showed that for each domain on the MiniAQLQ only one EWash subscale was a significant predictor of each individual domain and overall quality of life. The subscale with the best correlation is shown in Table 26.

4.3.6 What is the relationship between perceived barriers and compliance to follow-up care in adult asthmatic patients in an urban community health care facility?

Compliance questions related to following the plan of care, taking prescribed medications, and rescheduling appointments with the healthcare provider were included in the Healthstatus questionnaire. The first question asked study participants to state the level of difficulty experienced following the plan of care prescribed by their health care provider. The options were “very difficult,” “somewhat difficult” or “not at all difficult.” “Not at all difficult” was chosen by 18 (52.9%) of the study participants. Only 5 (14.7%) study participants believed following the prescribed plan of care was “very difficult.” One way ANOVA was the statistical approach used to measure the relationship between barriers to the perceived difficulty in following a plan of care. No significant relationship was found between the 10 barriers and difficulty following a prescribed plan of care. This finding applied to the overall barriers to health care variable (Table 27).

Table 24: Correlations between Perceived Barriers, Domains and Overall Quality of Life

Barrier	Domain								Overall	
	Symptom		Activity		Emotional		Environmental		r	Sig
	r	Sig	r	Sig	r	Sig	r	Sig		
Could not be seen by provider during an emergency	-0.19	0.28	0.04	0.82	-0.10	0.57	-0.33	0.06	-0.15	0.41
Cost of care too much	-0.25	0.18	0.02	0.89	-0.22	0.25	-0.55	0.00**	-0.25	0.18
Did not know where to go for services	-0.25	0.20	-0.03	0.87	-0.30	0.12	-0.46	0.02*	-0.29	0.15
Lack of transportation	-0.35	0.05	-0.18	0.32	-0.22	0.25	-0.10	0.57	-0.25	0.17
Long wait in provider's office	-0.16	0.37	-0.00	0.97	-0.11	0.55	0.02	0.91	-0.08	0.63
No one was available to watch children	-0.13	0.60	-0.25	0.33	-0.04	0.85	-0.10	0.68	-0.16	0.52
Office hours not convenient	-0.13	0.48	-0.03	0.84	-0.40	0.83	-0.30	0.09	-0.13	0.47
Poor quality of care by local providers	-0.31	0.08	-0.13	0.48	-0.33	0.96	-0.78	0.67	-0.25	0.16
Someone had to miss work	0.14	0.47	0.21	0.28	0.18	0.37	0.14	0.48	0.19	0.33
Too long to wait for appointment	-0.29	0.10	-0.10	0.58	-0.27	0.13	-0.31	0.08	-0.27	0.12
Overall barriers to health care	-0.26	0.12	-0.04	0.79	-0.18	0.29	-0.23	0.18	-0.20	0.23

*p<0.05

**p<0.01

Table 25: Correlation between Subscales on the EWash and Domains and Overall Quality of Life

Subscale	Domain								Overall	
	Symptom		Activity		Emotional		Environmental			
Medical care needs	0.64	0.00**	0.48	0.00**	0.54	0.00**	0.38	0.02*	0.59	0.00**
Prescription drug needs	0.08	0.63	0.03	0.85	-0.08	0.64	-0.11	0.52	-0.00	0.96
Satisfaction with care	0.29	0.09	0.08	0.62	0.25	0.14	0.06	0.71	0.20	0.24
Insurance for medical needs	-0.06	0.73	-0.08	0.65	-0.04	0.80	-0.11	0.51	-0.08	0.63
Insurance for prescription needs	0.09	0.60	0.12	0.47	0.05	0.75	0.21	0.22	0.13	0.44
Overall health insurance	0.11	0.51	0.11	0.50	0.09	0.59	0.14	0.40	0.13	0.44
Availability of local services	0.52	0.00**	0.49	0.00**	0.51	0.00**	0.52	0.00**	0.57	0.00**
Concerns related to health care	-0.16	0.36	-0.08	0.66	-0.20	0.26	-0.05	0.76	-0.14	0.42
Sources of health care	0.10	0.56	-0.02	0.89	0.12	0.49	0.16	0.35	0.09	0.59
Utilize low cost health services	0.03	0.86	-0.55	0.76	0.09	0.59	0.05	0.75	0.03	0.86
Sources of health information	-0.03	0.84	-0.18	0.31	0.12	0.47	0.12	0.47	-0.00	0.98

*p<0.05

**p<0.01

Table 26: Summary of Multiple Regression Results

MiniAQLQ subscale	Selected EWash Subscale
Symptoms	Medical Care Needs
Activity	Availability of Services
Emotional	Medical Care Needs
Environmental	Availability of Services
Overall	Medical Care Needs

Table 27: Relationship between Reported Difficulty to following Prescribed Plan of Care for Asthma and Perceived Barriers to Health Care

Barrier	F	Sig
Could not be seen by a provider during an emergency	1.83	0.17
Cost of care too much	0.16	0.84
Did not know where to go for services	0.49	0.61
Lack of transportation	0.57	0.57
Long wait in provider's office	0.05	0.94
No one available to watch children	0.73	0.49
Office hours not convenient	0.28	0.75
Poor quality of care by local providers	0.20	0.81
Someone had to miss work	0.30	0.74
Too long to wait for appointment	0.24	0.78
Overall barriers to health care	0.12	0.88

ANOVA was also used to determine whether or not a relationship existed between any of the ten perceived or overall barriers to the frequency that study participants reported missed taking any medication since their last health care provider's appointment. Once again, no significant relationship was found between any individual barrier or overall barriers and taking medications prescribed by their health care provider for asthma (Table 28). This is not surprising considering that 20 study participants (58.8%) reported missing a medication not more than once/month or never. Twelve study participants (35.2%) reported they missed taking any medication once a week or greater.

Table 28: Relationship between Frequency of Missed Medications and Perceived Barriers to Health

Care

Barrier	r	Sig
Could not be seen by a provider during an emergency	-0.22	0.24
Cost of care too much	-0.05	0.76
Did not know where to go for services	-0.23	0.24
Lack of transportation	0.04	0.84
Long wait in provider's office	-0.27	0.13
No one available to watch children	0.05	0.82
Office hours not convenient	-0.08	0.66
Poor quality of care by local providers	0.09	0.59
Someone had to miss work	0.01	0.92
Too long to wait for appointment	-0.18	0.32
Overall barriers	-0.04	0.80

The third question related to compliance asked study participants to rate how often they needed to cancel or reschedule an appointment with their health care provider. Answer options for this question were “frequent,” “occasionally,” or “never.” Within this sample, 20 study participants (58.8%) reported “never” rescheduling or cancelling an appointment. Only 2 study participants (5.9%) responded “frequently” to missed appointments. To condense response categories and compare missed or cancelled appointments to perceived barriers of care, the category “sometimes” was developed which included any study participant who reported either “frequently” or “occasionally” as a response.. A t-test was then employed to analyze the frequency of missed or cancelled appointments to individual or overall barriers of care. Study participants who “sometimes” had to miss or cancel an appointment with their health care provider perceived “lack of transportation” as a greater barrier than study participants who “never” had to reschedule an appointment ($p=0.00$). The relationship between overall barriers to care and rescheduled or cancelled appointments was not statistically significant (Table 29).

Table 29: Relationship between Frequency of Missed and/or Cancelled Appointments and Perceived Barriers to Health Care

Barrier	t	Sig
Could not be seen by a provider during an emergency	0.54	0.58
Cost of care too much	0.92	0.36
Did not know where to go for services	0.76	0.45
Lack of transportation	2.80	0.00**
Long wait in provider's office	-0.32	0.74
No one available to watch children	0.44	0.66
Office hours not convenient	0.40	0.69
Poor quality of care by local providers	1.04	0.30
Someone had to miss work	-0.74	0.46
Too long to wait for appointment	1.36	0.17
Overall barriers	1.69	0.10

**p<0.01

5.0 DISCUSSION

This descriptive cross sectional study examined the effect of barriers on health related quality of life (HRQL) and compliance in adult asthmatics who are followed in an urban community health care facility. Asthma continues to affect persons of all ages with the percentage of adults reported to be approximately 9% with rates for women exceeding those for men at 11% and 7% respectively (Allegheny County Health Department, 2002). Similar statistics for the United States reveal that asthma is more prevalent in women than men with the percentage of women averaging 11% of the population and men approximately 8% (Center for Disease Control, n.d. 2006). Ambulatory conditions, such as asthma, can be successfully managed by utilizing services at community health care facility thereby preventing unnecessary hospitalizations. While asthma prevalence has increased over time, hospitalizations for this condition decreased between 1994 and 2000 (Agency for Health Research and Quality). However, current admission rates for asthmatic episodes still fall short of the objectives set forth by *Healthy People 2010* (Agency for Health Research and Quality). Dependency on emergency rooms for episodic care has been viewed as an inadequate use of resources and poor self-management skills (Baren, et al, 2001, Goeman, Aroni, Sawyer et al, 2004; Murray, Strang, & Tierney, 1997). Studies have shown that reliance on emergency rooms for asthma management cannot be explained by simply financial barriers alone (Jerant, von Friederichs-Fitzwater, Moore 2004; Smith, Highsein, Jaffe, et al, 2006, Valerio, Cabana, White et al, 2006). Although there are numerous studies describing

parental and caregiver perceptions of barriers in the pediatric population, there is little research that identifies barriers in the adult population and these patient's perception of stated barriers on HRQL and compliance. Consequently, since asthma continues to increase in prevalence, it is important that health care professionals can identify barriers to outpatient care so that interventions can be developed and tested.

5.1 RESEARCH QUESTION

5.1.1 Identification of Perceived Barriers

There were 10 barriers identified on the EWASH instrument. Study participants rated their agreement as to whether or not they or any member of their household experienced any of the barriers during the past year. The perceived barrier with the highest percentage of agreement from study participants was "someone had to miss work" At least 46% of the sample strongly agreed or agreed with this factor being a barrier to asthma outpatient care within the prior year. Forty-one percent (41%) perceived "long waiting time in the provider's office" as a barrier and "cost of care too much" by 37.3% of the study sample. The other two barriers cited by at least 30% of the study participants were "too long to wait for an appointment" and "lack of transportation" by 35.5% and 31% of the respondents respectively.

"Someone had to miss work" has been reported as a barrier with both adult asthmatics and care givers of pediatric patients. One of the major perceived barriers to follow-up care after an asthmatic attack by parents was the necessity that parents take time off from work to access care for the child (Smith, Highstein, Jaffe, et al, 2006). The only barrier reported higher in the study of 147 participants was accessing transportation (Smith, Highstein, Jaffe, et al. 2006).

Another study examining utilization and accessibility of primary health care stated work commitments hinder not only access to primary care providers, but also specialty consults and home health care (Field & Briggs, 2001). The indirect costs of missing either full or partial work days for those employed have been reported to be on average \$1731 per person (Cisternas, Balnc, Yen, et al. 2003).

The organizational barriers identified, such as waiting time and scheduling, are similar to other reported studies. Niefeld and Kasper (2005) reported over one-third of elderly Medicare and Medicaid beneficiaries perceived that organizational barriers were greater than financial and geographic ones. Some of the organizational barriers included long waiting time and lack of knowledge regarding scheduling appointments and referrals (Neifeld & Kasper, 2005). Although difficulty communicating with nurses was not a problem, a focus group with chronically ill patients found difficulty scheduling appointments and communicating with a physician during an office visit as barriers to self-management of their disease (Jerant, von Friederichs-Fitzwater, Moore, 2004). Consequently, Baren et al (2006) found that scheduling an appointment at discharge increased 30-day follow-up with a primary care provider as compared to usual discharge care in adult asthmatics following an emergency room treatment for an exacerbation.

Finally, transportation barriers are common across the lifespan for asthmatic adults or caregivers of asthma patients. Studies with caregivers of pediatric asthma patients state a lack of transportation, either by personal vehicle or public venues as one of the primary impediments for any care (Davidson et al. 1994; Smith et al. 2006). Although parents were able to identify a usual place of care, a lack of transportation required some parents to utilize a hospital clinic or emergency room for after-hours treatment or exacerbations (Newacheck et al. 1996). Similarity, at least one-third of non-elderly urban Americans reported difficulty accessing transportation for

medical care (Ahmed, Lemkau, Nealeigh et al, 2001). Bender (2002) believes inadequate patient adherence to prescribed treatment regimes is multidimensional, including clinician-related barriers such as transportation.

5.1.2 Barriers and Selected Demographic Characteristics

Neither age, educational level, religion, importance of religion, nor difficulty paying for basic needs demonstrated a statistically significant association with any perceived barriers in this sample. Similar results by Diette, Krishnan Dominici et al (2003) and Eisner Katz Yelin et al (2001) reported that although older adults with asthma had greater respiratory symptoms and more co-morbidities than younger asthmatics, chronological age was not associated with barriers to health care utilization. Age, not religious heritage, marital status, or social support, may be a barrier in older women, as reported by Barr et al (2002). They found older women to be undertreated thus leading to nonadherence (Barr et al 2002). Although they did not measure the woman's educational level, a positive correlation was found between adherence and the husband's highest educational level (Barr et al. 2002). Although education was not associated with hospitalizations in older asthmatic patients; it has been cited as a barrier with disadvantaged minority patients (Diette et al, 2002; Rask et al, 1994). One possible explanation for the apparent lack of significant association between educational level and barriers to care in this sample may be that 19 (55.7%) of the study participants reported some college or beyond. Only 8.8% of the study participants reported less than a high school education.

The survey item, "poor quality of care by local providers," showed a statistically significant relationship among study participants that received their health care from LFHC. Although no definitive explanation can be offered, there were several occasions when turnover in

staff interfered with continuity of the study and identification of eligible subjects. In addition, community colleges in the area assign nursing students to this facility at various levels of education. It is likely that study participants who were assessed by newly oriented staff may not have had confidence in their clinical competence. LFHC is affiliated with the UPMC and some family practice residents complete a clinical rotation at this facility. There may be situations where the cultural and/or gender background of the family practice resident differs from the patient's background. Presently 81% of the current family practice residents at LFHC speak English as a second language (personal communication, J. South-Paul M.D., July 19, 2006). This may generate a language barrier between patient and family resident when either obtaining health information or conducting patient teaching. Women comprise approximately 72% of the family residents at LFHC (personal communication, J. South-Paul M.D., July 19, 2006). While female patients may not feel inhibited during a physical examination with a female resident, men may feel embarrassed. Consequently, communication of essential information required to prescribe a treatment regime for asthma maintenance may be hampered. Health care professionals can be an asset if they provide necessary information required for health maintenance. On the other hand, studies have cited office staff rudeness, insensitivity to patient needs, and a lack of confidence in the medical community as barriers to short-term asthma care (Crain, et al., 1998; Munro, et al. 1996). Further research related to barriers in care should examine cultural and gender difference of both the patient and health care provider and their interrelationships.

The EWash asked study participants to identify the health care facility in which they receive follow-up care for their asthma. It did not ask the sample to identify a specific health care provider in that facility. Both health care facilities employ family health residents through

UPMC. Study participants may have been seen and treated by one or more of the medical residents throughout the year. As a result, some study participants may not be able to identify and name their own health care provider. Furthermore, a lack of continuity of care hinders adherence to the treatment regimen and may interfere with open communication between patient and provider.

Employment status and income were significantly associated with some perceived barriers to care in the sample. Over half of the sample (53.9%) were either employed full time or retired. Study participants perceived a relationship between “someone had to miss work” with both demographic variables. This barrier is suggested by responses of the three study participants who took a day off from work in order to drive a family member to the health care facility for primary care. In addition, neither employment nor retirement guarantees adequate health care coverage. Medicare, as a source of health care insurance, was identified by 24% of the study participants. When the study was conducted, the Medicare Prescription Drug Plan of 2005 was not in effect. Consequently, this could be one explanation for the significance of the perceived barrier “cost of care too much” since about 70.0% of the study participants were prescribed two or more daily medications for their asthma.

“Office hours were not convenient” showed statistically significant relationship with racial/ethnic identification (Caucasian) study participant. Health service use by African Americans (AA) as compared to Caucasians with asthma have shown a higher rate of emergency room visits, rehospitalizations, and fewer visits to a specialist for the AA population (Blixen et al, 1999; Zoratti, et al, 1998). Another explanation for this finding may be the employment status of the white study participants. Job requirements may prohibit office visits during the normal business day. Furthermore, three of the 12 Caucasian study participants were responsible for

transportation of a family member to one of the health care facilities. The availability of office hours in the evening or on weekends may alleviate this barrier.

5.1.3 Barriers and Selected Health Status Characteristics

Study participants who identified their usual place of care for asthma in the emergency room perceived “lack of transportation” as a barrier. One of the health care facilities BG is located on a bus route while LFHC does not have direct access to public transportation. LFHC also accepts asthma patients from two subsidized housing facilities under the control of the McKeesport Housing Authority. The population of Harrison’s housing facility exceeds the poverty limit by 50% while Crawford’s site population is approximately 29% below the poverty limit. Study participants who reside in one of these housing facilities may not own a car, nor have available transportation via a family support system or public access. Although the EWash asked study participants to rate the availability of local services, public transportation was not included in the survey. Lack of transportation has often been cited as a barrier for low-income urban poor populations (Almed, et al., 2001; Boudreaux, Emond, Clark & Camargo, 2003; Eisner, et al., 2000; Munro. et al, 1996; Rask et al., 1994). In another study, 75% of respondents who did not own a car cited transportation as a barrier to access a primary health-care facility (Field & Briggs, 2001).

Four health status characteristics were significantly associated with the barrier “someone had to miss work.” The study participants who perceived missing work as a barrier were prescribed one or two medications, had no overnight admissions to the emergency room within the last year, required fewer visits to a health care facility for asthma and/or were not diagnosed with a psychological co-morbidity. One explanation for this finding could be the good health of

the study participants overall. It would appear that asthma in this sample is well controlled. Consequently, asthma may not be a hindrance with either activities of daily living or employment. Therefore, a visit to a health care facility may necessitate adjusting their work schedules or seeking assistance from grown children or friends who may be employed.

5.1.4 Barriers and HRQL

Study participants reported a “moderate” or better limitation with eight out of 11 activities restrictions on the MiniAQLQ. Work related and social activities restrictions apparently were not severely limited among these study participants. Their overall quality of life level mean score reported in the above categories were greater than “some of the time.” The only activity restriction the study participants stated as being a “moderate” limitation was strenuous activities which include hurrying, exercising, running up stairs, or sports (Juniper, 2000).

The only domain that showed a significant association with two of the barriers was irritants in the environment that may trigger asthma symptoms, including dust, cigarette smoke and weather/air pollution. Unfortunately, approximately one-fourth of the participants reported the presence of cigarette smoke in their residence. Another factor, household dust, is difficult to control especially in lower socioeconomic areas, such as the McKeesport area, where half of the study participants reside. This finding is consistent with the 35% of the sample reported difficulty avoiding triggers in their home environment. It is relevant that over half of the study participants were African American. HRQL studies with adult asthmatics demonstrate an association between HRQL among AA and socioeconomic factors, such as income, education, and employment (Apter, et al., 1999; Blanc, Yen, Chen, Earnest et al. 2006; Blixen, et al, 1997; Erickson, et al. 2002).

Another explanation for the findings with HRQL is the high proportion of women in the sample. Women have a higher reported incidence of asthma throughout the United States and similar findings have been reported in Allegheny County (Allegheny County Health Department, 2002). Furthermore, women tend to experience greater impairment of HRQL than men with similar clinical asthma severity (Juniper, 1999; Laforest, Bartsch, Vincken, et al. 2005; Wilson, Chittleborough, Kirke, et al. 2004). Two other significant findings reported in this sample are the high percentage of never married (41%) and single (29%) study participants. Marital status coupled with the characteristic of a low annual household income may give some credence to the barrier “cost of care too much” as perceived from the study participants and the significant relationship of a lower HRQL in the environmental domain. .

Due to the unavailability of an honest broker for this study at either site, no medical record data on severity of asthma of the study participants was obtained. As previously discussed, findings suggested that this sample of asthmatic adults are not critically hindered from their disease. The results obtained could be a product of the healthy status of study participants or small number in the study.

5.1.5 EWash Subscales and HRQL

The significant findings related to the degree that medical care needs for all members in the household are met and availability of local services with HRQL is not surprising in this sample. All but one study participant reported at least one form of health insurance. Over 70% of the sample reported only occasional or no difficulty avoiding triggers that precipitate exacerbations of the disease. Work is not hindered for at least 20 (62%) study participants. Compounded with the finding of few to no emergency room visits or over-night hospitalization for asthma within

the past 12 months, it would appear that study participants are compliant with the treatment regime for their disease. Although data was not collected about the duration of their disease, it is likely that some study participants may have been living with asthma for decades. Thus, the health education required for any disease state, such as medications, laboratory tests, local availability of services, an action plan for exacerbations, and rehabilitation may be understood in the sample.

It would be interesting to determine if any association exists between local availability of services, medical care needs and each subject's perception related to self-management of their disease. A positive relationship between HRQL and self-management has been reported in the literature with adult asthmatics (Eisner et al, 2002; Thoonen et al. 2003). The survey responses of this sample suggest that study participants are educated on services in the community that address their medical and psychological needs as well.

5.1.6 Compliance and Perceived Barriers

Over 50% of study participants report that they did not find it difficult to follow the plan of care discussed by the health care provider. Adherence to prescribed medications was also not perceived to be a problem in this sample. Twenty study participants (58.8%) reported the incidence of missed medications as less than once a month. The lack of significance between barriers to care and following a plan of care and taking prescribed medications may be explained by the controlled disease state with the sample. There were no emergency room visits within the last 12 months for 58.8% of the sample in this study. Furthermore, 64.7% of the study participants required two or fewer visits to their health care facility for asthma in the last 12 months.

“Lack of transportation” was perceived as a barrier for study participants who “sometimes” had to reschedule or cancel an appointment with a health care provider. The lack of available convenient transportation is often cited as a major barrier in community follow-up care (Field, et al., 2001; Jerant et al., 2004; Munro, et al., 1996; Rask et al., 1994; Smith et al., 2006). Data was not analyzed to determine whether any of the participants who recorded “sometimes” as an option for rescheduling appointments utilized LFHC for asthma follow-up care. However, this finding correlates with the significant relationship discussed in research question two between LFHC and BG in relation to perceived barriers to care.

5.2 LIMITATIONS

Several issues need to be noted related to limitations of the study.

1. The relatively low sample size in the study limited statistical power. A larger sample size is needed to verify these findings. Generalization of results should be taken cautiously.
2. Subjects were self-selected. The internal validity of the study may be hindered by self selection bias resulting in differences between those who participate and those who do not. Non-responders tend to be less agreeable and less open to experiences than responders (Marcus & Schutz, 2005).
3. The skewed distribution of race and gender. Less than 3% of the sample was male. No Asian or Hispanics were represented. Future studies should strive to include both ethnic groups since asthma is evident in all cultures. In addition, the population studied was a sample of convenience and is limited to patients with asthma who are followed in two

outpatient health care facilities. As such, findings from the analysis should be conservatively interpreted with caution and serve as a starting point for future studies.

4. The percentage of study participants that stated education levels above high school is greater than reported percentages from both health care facilities. Caution should be given to findings since they may represent a sample that may more be at a higher reading level than is typical for the clients of urban community health clinics. Additional data is needed for adult asthmatics with a broader range of educational and/or socioeconomic backgrounds.
5. All data was self reported. Furthermore, some of the data asked participants to remember events and perceived barriers within the past 12 months. Retrospective assessment strategies used in survey research are prone to recall bias and distortion. The bias may push the scores towards an extreme end, either positive or negative and exaggerate findings.
6. Although three out of four surveys were less than 25 questions in length, the EWash was over 60 questions with few open ended responses. Some potential study participants may have considered the survey too long or cumbersome to complete. Furthermore, the literacy level may be too high for some of the participants. The American Institute for Research's January 16, 2006 report on literacy levels of two- and four-year college students found that 75% of students at 2-year colleges did not score at the proficiency level of literacy (American Institute for Research, 2006). Consequently, future data collection related to barriers in outpatient care should elicit information from study participants gathered through oral questioning via members of the research team.

5.3 RECOMMENDATIONS

Several themes related to perceived barriers in this sample were constant. One prominent area of concern that limits access is the lack of transportation. Transportation has a direct link to positive patient outcomes. Health policies that include transportation initiatives can be regarded as a means of improving health. Although personal vehicles are most likely the major means to access follow-up care, alternative measures need to be explored. Transportation vouchers to and from a primary care visit has been shown to improve the initial follow-up appointment after treatment in an emergency room (Baren, et al., 2006). Contracts can be negotiated with taxi cab services to facilitate transportation for individuals who do not reside on a public bus route. Furthermore, all individuals reside within a public school district. Other than early morning or late afternoon when the buses are transporting children to and from school, the small vans can be utilized by adults and senior citizens to access community health care facilities. Patients would receive needed follow-up care and the school district benefits by increasing its revenue.

Another theme expressed repeatedly by the study participants centered on inconvenient office hours, extending time spent in the office and missing work. Fast track appointments managed by an advanced practice nurse or nurse practitioner should be created. The job requirements and responsibilities fall within the scope of practice established by State Boards of Nursing. The nurse practitioner would be available to assess the health issues of the patient and recommend treatment or consultation with a physician if the condition warrants. Evening and weekend appointments should be the norm especially for individuals who are employed. Naturally, exacerbations occur at all hours. For this reason, a 24/7 nurse answering line can be established that troubleshoots and recommends adjustments in medications versus emergency room treatment.

Patients who develop a healthy rapport with their primary care provider are more likely to adhere to the treatment regime. Asthma coordinators, employed by the health care facility, would serve to facilitate, manage, and provide consultation and education to this population. Patients would be more apt to call the coordinator for any concern since their health history is known. Alterations in health status may be alleviated early in the disease process as opposed to waiting until hospitalization is eminent

Study participants with children under the age of 18 years stated an inclination to using a school based clinic for medical or dental needs. Historically schools are a safe haven and provide support for children with a variety of health care needs. These health care needs can be extended to the parents as well. School based localities would serve as an excellent means for health education and follow-up care. In addition, health screening for parents of school aged children can be easily accomplished in an after-hours school clinic. Finally, for those individuals with internet access, computer generated reminders for follow-up appointments; health screening or education can be implemented.

5.4 FUTURE RESEARCH

The first key goal of this study was to make a contribution, however modest, to the growing body of research that expands health information professionals' understanding of barriers adult asthmatics encounter accessing services in community settings. The research presented here provides support that barriers related to demographic, health system organizational and economic factors impact the quantity and quality of follow-up care. The empirical explorations make a new

contribution by highlighting important barrier relationships between HRQL and compliance. Further research is needed to further explore and confirm both of these findings.

Ideally, future research in this domain would be conducted in several outpatient health care facilities across different socioeconomic levels. This would increase the researchers' ability to establish casual relationships. In pursuing this research, it would be preferable to collect description of barriers using refined diagnostic tools administered by clinicians along with self-reports and medical records measuring severity of illness. Given the preliminary work reported here, future work should be designed to explicitly test for differences in barriers related to the above factors. It may be that there are specific demographic, economic or health system organizational factors that affect different socioeconomic classes in their own way.

The second long-run objective of any applied research among chronically ill adults is to assist clinicians in developing effective strategies to improve the lives of patients and their families. The present study of the effect of barriers on HRQL and compliance in adult asthmatics raises the possibility that strategies designed to decrease the perceived barriers of lack of transportation, someone missing work, could not be seen in an emergency, and inconvenient office hours may improve follow-up care in this population. Such strategies would operate primarily (or even exclusively) through improving access and thus fostering asthma care in the community where it can be effectively managed. A program that limits barriers might improve compliance with the treatment regime, thus decreasing costs, absenteeism, and lack of continuity. Furthermore, HRQL may improve as a direct result of successfully treating asthma as a chronic disease and not sporadically when exacerbations occur.

Naturally, extensive clinical work guided by empirically informed theory, would be required to develop and test such programs. The present research is a small, but hopefully a

useful step forward in the important efforts to identify barriers that are central to HRQL and compliance among adult asthmatics followed in community health care facilities.

APPENDIX A

DEMOGRAGHC QUESTIONNAIRE

Directions: The information requested is important to understand more about you and your health. A person's characteristics have been shown to influence health, either through heredity or current and past lifestyle practices. The information that you provide will be used for research purposes only and will be held in **confidence**. For each question, please select the response that best describes you

1. What is your gender?
 - a. Male
 - b. Female

2. What is your age?
 - a. 18-24 years
 - b. 25-34 years
 - c. 35-44 years
 - d. 45-54 years
 - e. 55-64 years
 - f. 65-74 years
 - g. 75 years of older

3. What is the highest educational level you obtained?
 - a. 8th grade or less
 - b. Some high school
 - c. High school or GED
 - d. Vocational/technical school
 - e. Some college
 - f. College graduate
 - g. Graduate or professional degree

4. Which one of the following best describes your current marital status?
 - a. Never married
 - b. Currently married
 - c. Living with partner/significant other
 - d. Widowed
 - e. Separated
 - f. Divorced
 - g. Other (specify) _____

5. Is English your primary language (the one you speak most often)?
 - a. Yes
 - b. No (Please explain) _____

6. Where do you live?
 - a. Please enter the 5-digit ZIPCODE of your Primary Residence:
(Where you live most of the time)

7. Which urban health care facility do you see your primary care physician?
 - a. Bloomfield-Garfield
 - b. Latterman

8. In what type of area did you live most of your childhood?
 - a. Urban
 - b. Rural
 - c. Suburb
 - d. Other (please specify) _____

9. What is your current employment status?
- Full time (working at least 35 hours a week)
 - Part time (working less than 35 hours a week)
 - Laid off or unemployed
 - Retired
 - Disabled/unable to work
 - Full time homemaker
 - Student
 - I have never been employed
 - Other (please specify) _____
10. If you are currently employed, what is your primary occupation?
- Managerial (manager, purchasing agent, supervisor, etc)
 - Clerical (typist, cashier, clerk, etc)
 - Professional (lawyer, accountant, doctor, teacher, etc.)
 - Skilled occupations (mechanic, machine operator, plumber, carpenter, etc.)
 - Service occupations (cook, child care worker, maid, etc.)
 - Homemaker
 - Other
11. If you are not currently employed, what was your primary occupation?
- Managerial (manager, purchasing agent, supervisor, etc)
 - Clerical (typist, cashier, clerk, etc)
 - Professional (lawyer, accountant, doctor, teacher, etc.)
 - Skilled occupations (mechanic, machine operator, plumber, carpenter, etc.)
 - Service occupations (cook, child care worker, maid, etc.)
 - Homemaker
 - Other
12. Has your asthma interfered with your ability to work?
- Yes, because of the physical demands
 - Yes, because of the mental demands
 - Yes, due to other reasons (specify) _____
 - No, it has not interfered with my ability to work
13. Do you have a religious background or preference?
- Yes (please specify)
 - Catholic (ex Roman Catholic)
 - Jewish
 - Protestant (ex. Lutheran, Presbyterian, Episcopal, Methodist, Unitarian)
 - Other (specify) _____
 - No

14. How important is religion or spirituality in your life?
- Not at all important
 - Somewhat important
 - Extremely important
15. What is the total gross annual income for your household from all sources (before taxes and deductions):
- Under \$10,000
 - \$10,000 to \$12,999
 - \$13,000 to \$19,999
 - \$20,000 to \$29,999
 - \$30,000 to \$49,999
 - \$50,000 or greater
16. To what extent do you have difficulty paying for your basic needs (such as food, housing, utilities, and health care)?
- No difficulty
 - Some difficulty
 - A great deal of difficulty

APPENDIX B

HEALTH STATUS QUESTIONNAIRE

1. Has a medical doctor ever told you that you have asthma?
 - a. Yes
 - b. No: If no, stop here. Thank you for taking the time. Please return all completed surveys.

2. About how old were you when your asthma was first diagnosed by a medical doctor or nurse practitioner?
 - a. 0-17 years
 - b. 18-44 years
 - c. +45 years

3. How often do you come back to the health center for checkups for asthma?
 - a. Every _____ (circle one) week, month, year

4. Where do you usually go for your asthma care? Check only one
 - a. Private doctor office
 - b. Here at the clinic
 - c. Hospital outpatient
 - d. Emergency room
 - e. No regular care provider
 - f. Other (specify) _____

5. Are you currently taking medication prescribed by a medical doctor or nurse practitioner for your asthma?
 - a. Yes (total number of daily medications) _____
 - b. No

If you answered "Yes" to question 5, please complete question 6:

6. What types of medications are you currently using for your asthma? (Circle all that apply)

a. Steroids? (ex. Prednisone)



b. Metered dose inhalers (Puffers)



c. Long action beta₂ agonists; Salmeterol (Serevent); Advair discus



d. Mast cell stabilizers: Cromolyn sodium (Intal), Nedocromil sodium (Alocril, Mireze)



- e. Leukotriene antagonists: Zileuton (Zyflo); Zafirlukast (Accolate); Montelukast (Singular)



- f. Anticholinergics: Ipratropium bromide (Atrovent)



- g. Short acting Beta₂ agonists: Albuterol or terbutaline (Alupent), Proventil HC



- h. Methylxanthine: Theophylline



7. How many times within the last 12 months have you seen your primary care physician or nurse practitioner for asthma related health care?
_____ times

8. How many times within the last 12 months have you been seen in the emergency room for acute asthma attack?
_____ times
9. How many times have you been hospitalized overnight for your asthma in the past 12 months?
_____ times
10. Do you have any other medical condition that you are being treated for by a health care provider?
a. Yes (specify) _____
b. No
11. Do you have any psychological condition that you are being treated by a health care provider?
a. Yes (specify) _____
b. No
12. If you were seen in the emergency department within the last 12 months, was it because something prevented you from seeing your usual doctor/nurse practitioner?
a. Sometimes (specify) _____
b. No
13. Sometimes people have a hard time following their plan of care that was prescribed by a doctor or nurse practitioner. How difficult has it been for you? Would you say it has been:
a. Very difficult
b. Somewhat difficult
c. Not at all difficult
14. When was your last appointment to see a doctor or nurse practitioner for your asthma?
_____ (month, year)

15. How often have you missed taking any of your asthma medications since your last doctor's appointment? Would you say it has been:

- a. Every day
- b. Several times a week
- c. About once a week
- d. Several times a month
- e. About once a month
- f. Less often than once a month
- g. Never

16. If you sometimes miss taking your asthma medications, what are the usual reasons?

Check all that apply

- a. I forget to take them
- b. They do not help me
- c. They makes me feel bad
- d. I wasn't having any symptoms
- e. I've had a major change in my life
- f. Traveling/vacation
- g. My prescription ran out
- h. Other reasons _____

17. Have you had to cancel or reschedule appointments related to your asthma with your doctor/nurse practitioner? Would you say that has happened:

- a. Frequently
- b. Occasionally
- c. Never

If so, for what was the reason (s) have you canceled or changed appointments?

(Check all that apply)

- a. forgot appointment
- b. appointment time conflicted with something else
- c. financial concerns
- d. Not having any symptoms and did not think I needed to be seen
- e. other _____

18. How often do you find it difficult to avoid things those things that cause your asthma to flare up? Would you say this has happened:

- a. Frequently
- b. Occasionally
- c. Never

19. Are the factors that make your asthma worse associated with: (check all that apply)

- a. Home environment
- b. Work environment
- c. Outdoors
- d. Exercise
- e. Social situations

20. Do you smoke cigarettes/cigars/pipe?

- a. No
- b. Light smoker
- c. Heavy smoker

21. Do other members in your house smoke cigarettes/cigars/pipe?

- a. Yes
- b. No

APPENDIX C

MINI ASTHMA QUALITY OF LIFE QUESTIONNAIRE

MINI ASTHMA QUALITY OF LIFE QUESTIONNAIRE (MiniAQLQ)

SELF-ADMINISTERED

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For further information:

Professor Elizabeth Juniper, MCSP, MSc
20 Marcuse Fields,
Bosham, West Sussex,
PO18 8NA, UK
Tel: +44(0)1243 572124
Fax: +44(0)1243 573680
E-mail: juniper@qoltech.co.uk
Web: www.qoltech.co.uk

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OCTOBER 2000

MINI ASTHMA QUALITY OF LIFE QUESTIONNAIRE

PATIENT ID _____

SELF-ADMINISTERED

DATE _____

Page 1 of 2

Please complete **all** questions by circling the number that best describes how you have been during the **last 2 weeks as a result of your asthma.**

IN GENERAL, HOW MUCH OF THE TIME DURING THE LAST 2 WEEKS DID YOU:

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	Hardly Any of the Time	None of the Time
1. Feel SHORT OF BREATH as a result of your asthma?	1	2	3	4	5	6	7
2. Feel bothered by or have to avoid DUST in the environment?	1	2	3	4	5	6	7
3. Feel FRUSTRATED as a result of your asthma?	1	2	3	4	5	6	7
4. Feel bothered by COUGHING?	1	2	3	4	5	6	7
5. Feel AFRAID OF NOT HAVING YOUR ASTHMA MEDICATION AVAILABLE?	1	2	3	4	5	6	7
6. Experience a feeling of CHEST TIGHTNESS or CHEST HEAVINESS?	1	2	3	4	5	6	7
7. Feel bothered by or have to avoid CIGARETTE SMOKE in the environment?	1	2	3	4	5	6	7
8. Have DIFFICULTY GETTING A GOOD NIGHT'S SLEEP as a result of your asthma?	1	2	3	4	5	6	7
9. Feel CONCERNED ABOUT HAVING ASTHMA?	1	2	3	4	5	6	7
10. Experience a WHEEZE in your chest?	1	2	3	4	5	6	7

MINI ASTHMA QUALITY OF LIFE QUESTIONNAIRE

PATIENT ID _____

SELF-ADMINISTERED

DATE _____

Page 2 of 2

IN GENERAL, HOW MUCH OF THE TIME DURING THE LAST 2 WEEKS DID YOU:

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	Hardly Any of the Time	None of the Time
11. Feel bothered by or have to avoid going outside because of WEATHER OR AIR POLLUTION?	1	2	3	4	5	6	7

HOW LIMITED HAVE YOU BEEN DURING THE LAST 2 WEEKS DOING THESE ACTIVITIES AS A RESULT OF YOUR ASTHMA?

	Totally Limited	Extremely Limited	Very Limited	Moderate Limitation	Some Limitation	A Little Limitation	Not at all Limited
12. STRENUOUS ACTIVITIES (such as hurrying, exercising, running up stairs, sports)	1	2	3	4	5	6	7
13. MODERATE ACTIVITIES (such as walking, housework, gardening, shopping, climbing stairs)	1	2	3	4	5	6	7
14. SOCIAL ACTIVITIES (such as talking, playing with pets/children, visiting friends/relatives)	1	2	3	4	5	6	7
15. WORK-RELATED ACTIVITIES* (tasks you have to do at work)	1	2	3	4	5	6	7

*If you are not employed or self-employed, these should be tasks you have to do most days.

DOMAIN CODE:

Symptoms: 1, 4, 6, 8, 10
 Activity Limitation: 12, 13, 14, 15
 Emotional Function: 3, 5, 9
 Environmental Stimuli: 2, 7, 11

APPENDIX D

EWASH

Eastern Washington Access to Health Care Consumer Survey

*Intercollegiate College of Nursing
Washington State University College of Nursing
Health Improvement Partnership
August 2001*

Bayne, Higgs, & Gruber Copyright 2001

Directions: This survey asks questions about your access to health care; including the health care available to all members of your household. A household defined as everyone living at the address. Your answers are important! They will help us to plan health care services.

Please read the following statements and mark the answer that best fits your household's situation **during the last year**.

Answer questions by marking the space under the answer or by writing in the answer as requested. Mark the N/A (Not Applicable) box for any question that does not apply to your household.

(1) Mark boxes like this: OK

A To what degree are the overall medical care needs of the following members of your household being met?

1. Children up to 18 years of age	N/A	Never	Seldom	Sometimes	Nearly Always	Always
2. Adults 19-64 years	N/A	Never	Seldom	Sometimes	Nearly Always	Always
3. Adults 65 and over	N/A	Never	Seldom	Sometimes	Nearly Always	Always

B. Prescription Drug Needs

To what degree does the inability to obtain prescription drugs impact the **overall** health or daily activities of any member or members of your household?

N/A Never Seldom Sometimes Nearly Always Always

To what degree are the prescription drug needs of the following members of your household being met?

- 4. Children up to 18 years of age N/A Never Seldom Sometimes Nearly Always Always
- 5. Adults 19-64 years N/A Never Seldom Sometimes Nearly Always Always
- 6. Adults 65 and over N/A Never Seldom Sometimes Nearly Always Always

C. Satisfaction with Care

Overall to what degree are members of your household satisfied with the following types of health care they received last year?

- 7. Medical N/A Unacceptable Poor Fair Good Very Good Excellent
- 8. Dental N/A Unacceptable Poor Fair Good Very Good Excellent

D. Health insurance

Insurance coverage includes privately paid, employer sponsored, and state or federal sponsored, such as Medicaid, Medicare, UPMC, Highmark

9. What type(s) of insurance do you have? (Choose all that apply)

- Medicare
- Medicaid
- SSI
- Veterans Administration
- Workers Compensation
- Private health insurance
- Other (specify) _____

NO Insurance

E. Health Insurance Coverage

Overall, to what degree does insurance cover most of the **medical** care needs of the following members of your household?

10. Children up to 18 years of age	N/A	Never	Seldom	Sometimes	N early	Always	Always
11. Adults 19-64 years of age	N/A	Never	Seldom	Sometimes	Nearly	Always	Always
12. Adults 65 and over	N/A	Never	Seldom	Sometimes	Nearly	Always	Always

Overall to what degree does insurance cover most of the **prescription drug** needs of the following members of your household?

13. Children up to 18 years of age	N/A	Never	Seldom	Sometimes	Nearly	Always	Always
14. Adults 19-64 years of age	N/A	Never	Seldom	Sometimes	Nearly	Always	Always
15. Adults 65 and over	N/A	Never	Seldom	Sometimes	Nearly	Always	Always

F. Local Availability of Services

There are enough of the following health care services in my local area?

16. Ambulance/emergency transportation	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
17. Dentists	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
18. Emergency/urgent care services	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
19. Health and safety education programs	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
20. Home health care (such as visiting nurses, home health aids)	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
21. Pharmacies/drug stores	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
22. Primary care providers (such as doctors, nurse practitioners, physician assistant)	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
23. Rehabilitation services (such as physical or occupational therapy)	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
24. Specialty physicians available for a referral or second opinion	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

What are the **two (2) most important health care services** needed in our local area that are currently not available or in short supply?

G. Barriers to Obtaining Health Care

During the last year, the following health care barriers were experienced by a member of my household:

25. Could not be seen by a health care provider during an emergency	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
26. Cost of care was too much	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
27. Did not know where to go for services	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
28. Lack of transportation	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
99. Long waiting time in the provider's office	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
30. No one was available to watch the children	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
31. Office hours are not convenient	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
32. Poor quality of care by local providers	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
33. Someone had to miss work	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
34. Too long to wait for an appointment	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

H. Concerns relate to health Care

During the last year, the following health care concern were experienced by a member of my household:

35. A provider did not notify us of test results	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
36. Could not get health care advice by phone	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
37. Felt a health care provider did not care enough	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
38. Felt a provider did not take enough time to understand our race/ethnic background	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
39. Felt a provider did not take enough time to understand our family situation	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
40. Felt a provider gave unclear or no health-related instructions	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
41. Felt uncomfortable with a health care provider	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
42. Office staff was not respectful	N/A	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree

I. How many people live in your household in each of the following age groups?

43. How many people live in your household? _____

44. What are their ages? _____

J. Sources of Health Care and Health Information

Please estimate how many times in the last year members of your household have used the following sources of health care.

45. Alternative medicine (homeopathic, naturopathic, acupuncturist)	N/A	1-2	3-5	6-8	9 or greater
46. Chiropractor	N/A	1-2	3-5	6-8	9 or greater
47. Community/neighborhood medical clinic	N/A	1-2	3-5	6-8	9 or greater
48. Health department clinic	N/A	1-2	3-5	6-8	9 or greater
49. Hospital emergency room	N/A	1-2	3-5	6-8	9 or greater
50. Mental health counselor	N/A	1-2	3-5	6-8	9 or greater
51. Private physician office	N/A	1-2	3-5	6-8	9 or greater
52. Urgent care/minor emergency center	N/A	1-2	3-5	6-8	9 or greater

To what degree would you and the members of your household use low cost health care services (medical, dental, mental health) if available in the following sites?

53. Community/neighborhood health clinic	N/A	Never	Seldom	Sometimes	Nearly Always	Always
54. Hospital outpatient clinic for non-emergency care	N/A	Never	Seldom	Sometimes	Nearly Always	Always
55. Mobile health van	N/A	Never	Seldom	Sometimes	Nearly Always	Always
56. Public health department	N/A	Never	Seldom	Sometimes	Nearly Always	Always
57. School based clinic	N/A	Never	Seldom	Sometimes	Nearly Always	Always

To what degree do you and the members of your household use the following sources to obtain health information and advice?

58. Child's school	N/A	Never	Seldom	Sometimes	Nearly Always	Always
59. Health care provider	N/A	Never	Seldom	Sometimes	Nearly Always	Always
60. Health-related books	N/A	Never	Seldom	Sometimes	Nearly Always	Always
61. Neighbors/friends	N/A	Never	Seldom	Sometimes	Nearly Always	Always
62. Newspaper/magazine	N/A	Never	Seldom	Sometimes	Nearly Always	Always
63. Public health department	N/A	Never	Seldom	Sometimes	Nearly Always	Always
64. Radio	N/A	Never	Seldom	Sometimes	Nearly Always	Always
65. Television	N/A	Never	Seldom	Sometimes	Nearly Always	Always
66. World wide web-the Internet	N/A	Never	Seldom	Sometimes	Nearly Always	Always

K. Health Improvement

Please describe what you think could be done to improve your household's access to health care?

Please describe what you think could be done to assist members of your household to be healthier.

Thank you for taking the time to complete the survey and return it in the enclosed postage paid envelope.

APPENDIX E

POSTER

Are You An Adult With Asthma?

Would you like to earn \$25.00?

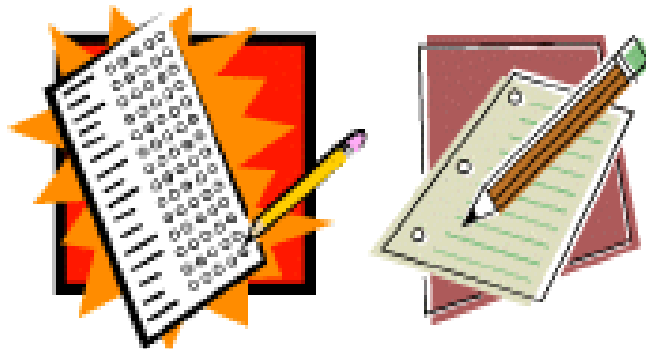


The University of Pittsburgh

School of Health and Rehabilitation Sciences

Wants your opinion on Outpatient Asthma Care

By completing four easy questionnaires



For Information Contact

The Administrator of this healthcare facility

Or

Call 412-765-4132

APPENDIX F

BROCHURE

Do You Have Asthma?
Are you over 18 years of age
Would you like to make \$25.00

The University of Pittsburgh
School of Health & Rehabilitation Sciences
Wants you opinion on outpatient asthma care
by completing four easy questionnaires

For Additional Information
Contact the administrator of this health care facility

Or call
412-765-4132



APPENDIX G

SCREENING TOOL

Thank you for inquiring more about our research study. My name is _____ and I am a researcher at the University of Pittsburgh School of Health and Rehabilitation Science. The purpose of this research study is to identify barriers to outpatient asthma care for the adult in the community. A secondary purpose is to determine if any association exists between the identified barriers and quality of life.

As part of our formal study, we will be asking people to complete four questionnaires. The four questionnaires asks questions related to your general health status, barriers to obtaining outpatient health care, and your health related quality of life. The final questionnaire asks questions about your characteristics. Do you think you might be interested in participating in this study?

(If no) Thank you very much for inquiring.

(If yes) Before enrolling people in this study, we need to determine if you they are eligible. You do not have to answer these questions if you do not want to. And so what I would now like to do is to ask you a series of questions about your age and health status. There is a possibility that some of these questions may make you uncomfortable or distressed, if so, please let me know. You don't have to answer those questions if you don't want to. You also need to understand that all information that I receive from you by phone, including your name and any other identifying information, will be strictly confidential and will be kept under lock and key.

The purpose of these questions is only to determine whether or not you are eligible for our larger study. Remember, your participation is voluntary.

Do I have your permission to ask you these questions? Yes _____ No _____

Are you 18 years of age or older? Yes _____ No _____

Have you ever been told by a physician that you have asthma?
Yes _____ No _____

Do you receive your routine health care from either at the Bloomfield Garfield, Latterman, Harrison or Crawford Health Care facilities? Yes _____ No _____

Thank you for answering these questions. Based on your answers you do/do not qualify to be in the study. I will be contacting you in the near future to explain the study in more detail and obtain your written consent to be in the study if you wish to participate at that time.

APPENDIX H

COVER LETTER

November 18, 2004

Dear Adult Asthmatic,

The purpose of this research study, *The Effects of Barriers on Health Related Quality of Life (HRQL) and Compliance in Adult Asthmatics who are followed in an Urban Community Health Care Facility* is to identify your self-reported barriers that prevent you from receiving quality outpatient care for your asthma. It also seeks to determine whether or not there is a relationship between these barriers and your health related quality and life and compliance with your treatment plan prescribed by your primary care provider. You have received this letter and packet because you requested additional information related to study participation.

If you agree to participate in this study, you will find four short questionnaires in this packet and a consent form to sign for participation. If you agree to participation, please initial the bottom of every page of the consent form and sign and date the last page. The four questionnaires should take less than one hour to complete. One questionnaire will ask you questions related to your health status, while another questionnaire will ask you basic information about yourself and your family. The third questionnaire will ask you questions about your quality of life with asthma and the final questionnaire will ask you to identify barriers to care. Information obtained from this study will help health team members plan directives that facilitate follow-up care in a community setting for your asthma.

There are no foreseeable risks associated with participation in this study. Each participant will receive \$25.00 reimbursement for completion and return of all forms. Once the questionnaires are completed, please return them in the self addressed envelope. Place your name and address on the envelope so your stipend can be mailed to you. All responses will be confidential and study results will be kept under lock and key. Your participation is voluntary. Future health care services at this facility will not be affected if you choose whether or not to participate. If you have any questions, please contact Rose L. Hoffmann at 412-765-4132

Sincerely,

Rose L. Hoffmann, RN, MSN

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