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**FACTORS THAT INFLUENCE NONADHERENCE OUTPATIENT MEDICAL
FOLLOW-UP BY AFRICAN AMERICANS WITH HIV/AIDS AT AN
OUTPATIENT INFECTIOUS DISEASE CLINIC**

by

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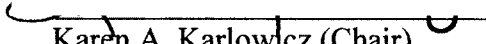
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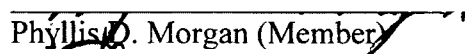
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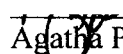
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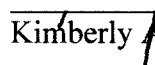
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ABSTRACT

FACTORS THAT INFLUENCE NONADHERENCE OUTPATIENT MEDICAL FOLLOW-UP BY AFRICAN AMERICANS WITH HIV/AIDS AT AN OUTPATIENT INFECTIOUS DISEASE CLINIC

Cynthia Burrell Banks
Old Dominion University, 2012
Chair: Dr. Karen A. Karlowicz

Human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) does not discriminate among different races, ethnicities or genders; however, African Americans carry a larger burden related to the HIV epidemic than others (CDC, 2010c; Cunningham, Sanchez, Heller & Sohler, 2007; Mugavero, et al., 2009). Persons living with HIV/AIDS (PLWHA) who do not adhere to their medical regimen, including failure to maintain contact with their health care provider for health care monitoring, tend to have poorer health outcomes from the disease as compared to HIV/AIDS patients who adhere to their medical regimen (Cunningham et al., 2006; Lima et al., 2009). African Americans represent 14% of the population in the United States, but they account for almost half (44%) of people living with HIV and nearly half (45%) of persons newly infected each year (CDC, 2010d; 2011b).

The purpose of this study was to examine non-adherence to medical follow-up among African American subjects with HIV/AIDS using an adapted version of the Andersen Behavioral Model of Health Services Utilization by Ulett et al. (2009). This study explored perceived barriers to adherence to the medical regimen and appropriate follow-up care and determined the predisposing, enabling, and environmental factors that influenced adherence to outpatient medical follow-up care.

This study used a descriptive correlational research design with a mixed methods approach. A retrospective electronic medical records review was completed in 2010 (N = 125). Subjects (N = 20) who attended a “walk-in” clinic for HIV/AIDS completed a survey and the Engagement with Health Care Provider Tool.

After reviewing the electronic medical record (EMR), the researcher concluded there were statistically significant findings for predisposing factors. Predisposing factors were related to the number of scheduled visits and Highly Active Antiretroviral Therapy (HAART) medications initiated. On the open-ended questionnaire, subjects identified barriers to care/obstacles/difficulties to keeping scheduled appointments. Psychosocial, personal, and scheduling conflicts were identified, along with experienced stigma. The Behavioral Model of Health Services Utilization did explain non-adherence to outpatient medical follow-up for PLWHA.

This dissertation is dedicated to my husband, Vernal Banks; my children, Carita Victoria Banks, Vernal Alphonsia Banks (Buddy), and Keith Butler; my mother, Mary Melton, and my father-in-law, David Banks.

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The completion of this degree is truly an act of the Holy Spirit working in my life. I acknowledge God for His divine will in all aspects of my life.

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TABLE OF CONTENTS

	Page
LIST OF TABLES.....	ix
LIST OF FIGURES.....	x
 Chapter	
I. INTRODUCTION.....	1
STATEMENT OF THE PROBLEM	3
BACKGROUND	8
RYAN WHITE HIV/AIDS PROGRAM	9
PURPOSE OF THE STUDY	10
BRIEF DESCRIPTION OF THE THEORETICAL FRAMEWORK.....	11
RESEARCH QUESTIONS	13
OPERATIONAL DEFINITIONS.....	14
SIGNIFICANCE TO HEALTH SERVICES RESEARCH.....	16
SUMMARY	18
II. REVIEW OF LITERATURE.....	19
OVERVIEW OF THE BEHAVIORAL MODEL OF HEALTH SERVICES UTILIZATION	19
COMPONENTS OF THE BEHAVIORAL MODEL OF HEALTH SERVICES UTILIZATION: FOCUS ON PERSONS WITH HIV/AIDS	35
SUMMARY OF LITERATURE REVIEW.....	63
III. METHODOLOGY	68
RESEARCH DESIGN	68
DATA COLLECTION	73
SUMMARY	90
IV. RESULTS.....	91
RESULTS OF SURVEYS	100
SUMMARY OF RESEARCH QUESTION ANALYSES	107
V. DISCUSSION, CONCLUSION, IMPLICATIONS, RECOMMENDATIONS, SUMMARY.....	111
DISCUSSION.....	111
CONCLUSION.....	120
IMPLICATIONS.....	123
RECOMMENDATIONS.....	129
SUMMARY.....	133

TABLE OF CONTENTS (CONTINUED)

	Page
REFERENCES.....	135
APPENDICES.....	148
A. PERMISSION GRANTED TO USE ANDERSON MODEL.....	148
B. PERMISSION GRANTED: RONALD ANDERSON AND WILEY BLACKWELL.....	150
C. PERMISSION GRANTED: K. PHILLIPS AND WILEY BLACKWEL.....	153
D. PERMISSION GRANTED: J. MUGAVERO AND LIBERT PUBLISHING.....	157
E. ELECTRONIC MEDICAL RECORD (EMR) DATA COLLECTION TOOL.....	159
F. SURVEY TOOL (FACE-TO-FACE).....	163
G. ENGAGEMENT WITH HEALTH CARE PROVIDER TOOL.....	167
H. PERMISSION TO USE ENGAGEMENT WITH HEALTH CARE PROVIDER TOOL.....	169
I. RECRUITMENT LETTER.....	172
J. INFORMED CONSENT DOCUMENT – OLD DOMINION UNIVERSITY.....	175
K. INFORMED CONSENT – EASTERN VIRGINIA MEDICAL SCHOOL.....	179
L. PERMISSION TO MODIFY ULETT’S MODEL.....	182
VITA.....	185

LIST OF TABLES

Table	Page
1. Dimensions of Access to Medical Care and Their Indicators.....	28
2. Predisposing Variables Category and Level of Measurement.....	86
3. Enabling Variables Category and Level of Measurement.....	87
4. Environmental Variables Category and Level of Measurement.....	88
5. African Americans' Demographics.....	91
6. Demographics of Survey Subjects.....	93
7. Predisposing Factors (Continuous Variables) —Adherence Versus Nonadherence with Attendance.....	94
8. Predisposing Factors (Categorical Variables)—Adherence Versus Nonadherence with Attendance.....	95
9. Enabling Factors—Adherence Versus Nonadherence with Attendance.....	96
10. Health Care Environmental Factors (Provider) Adherence Versus Nonadherence with Attendance.....	98
11. Health care Environmental Factors (System-Referral Services) — Adherence Versus Nonadherence with Attendance	98
12. Logistic Regression of Significant Factors to Nonadherence (Univariate Analysis).....	99
13. Descriptive Statistics Engagement with Health Care Provider.....	101

LIST OF FIGURES

Figure	Page
1. A Behavioral Model of Health Services Utilization.....	20
2. Utilization Model.....	31
3. Blueprint for HIV Treatment Success.....	36

CHAPTER 1

INTRODUCTION

The human immunodeficiency virus (HIV) remains a global health problem of unparalleled dimensions. This virus has currently caused an estimated 25 million deaths worldwide and has changed the demographics of many countries (UNAIDS, 2009). In 2010, it was estimated that approximately 34 million persons globally were living with HIV (UNAIDS, 2010). Each year, the number of people living with HIV has steadily increased as new infections occur because HIV treatments have extended life expectancy (UNAIDS, 2009). The population of individuals newly infected with HIV is 2.7 million, which is a decline from a reported 3.0 million in 2001, but this population is still higher than the number of individuals (2.0 million) who die of acquired immune deficiency syndrome (AIDS) worldwide (UNAIDS, 2011). Women account for 60% of all HIV infections (UNAIDS, 2011). Sub-Saharan Africa is the region most heavily infected by HIV; it accounts for 68% of all the people living with HIV (UNAIDS, 2011) and nearly 75% of AIDS deaths in 2008 (UNAIDS, 2009).

HIV is linked with significant public health problems in the United States, especially in ethnic minority groups who are disproportionately affected by the epidemic (Bonney & Del Rio, 2009; Centers for Disease Control and Prevention [CDC], 2011c; Radcliffe et al., 2010). The CDC estimates that more than one million people are living with HIV in the United States, with an estimated 50,000 people infected with HIV each year (CDC, 2011c). African Americans face the most severe burden of all ethnic/racial groups. HIV/AIDS incidence and prevalence rates are greater among those of Black African descent than of any other ethnic and racial group in the world (CDC, 2008;

2010c; 2011b; 2011c; Laurencin, Christensen, & Taylor, 2008). African Americans represent about 14% of the population of the United States, but they account for almost half (44%) of those living with HIV and nearly half (45%) of those who are newly infected each year (CDC, 2010d; CDC, 2011b). The CDC (2010c) has estimated African Americans have an HIV-incidence rate 7 times higher than that of Whites. Incidence of HIV infection among African American men is 6 times that of White men, nearly 3 times that of Hispanic/Latino men, and more than twice that of African American women. For African American women, the HIV incidence rate is nearly 15 times higher than of White women and nearly 4 times that of Hispanic/Latina women (CDC, 2010c).

The estimated number of persons diagnosed with AIDS through 2009 in the U.S. was 1,142,714 (CDC, 2009). That year, 2009, the estimated number of persons diagnosed with AIDS in the United States was 34,993 (CDC, 2009). Of this number, approximately 16,741 were African American (CDC, 2011b). The states with the most AIDS diagnoses were found in the South (CDC, 2009; 2011b). AIDS is the leading cause of death for African American women between the ages of 25 and 44 years old and African American men between 35 and 64 years old. African Americans account for the highest proportion of AIDS diagnoses throughout the country, except in the Western part of the U.S., where the highest number of diagnosed cases is among Whites (CDC, 2009; 2011b).

As of 2009, an estimated 21,000 of people were living with HIV/AIDS in Virginia (Virginia Department of Health [VDH], 2010). Individuals diagnosed with HIV/AIDS are living longer because of advanced drug therapy used in treatment of the disease, but African Americans are still disproportionately impacted by HIV/AIDS in

Virginia. African Americans comprise 23% of the state's population, but comprise approximately 60% of those living with HIV/AIDS (VDH, 2011). Statistics show that African Americans are 9 times more likely to be living with AIDS than Whites, and African American women account for 77% of all women living with HIV/AIDS in Virginia (VDH, 2010). African American males are 9 times more likely to be diagnosed with HIV/AIDS as White males, and African American women are 16 times more likely to be living with HIV/AIDS than White women (VDH, 2009a). For every five Virginians living with HIV/AIDS, approximately four are men and three are African American (VDH, 2010). The HIV/AIDS rates in Virginia in 2008 were 47.9 per 100,000 for African Americans, 5.2 per 100,000 for Caucasians, and 18.4 per 100,000 for Hispanics (VDH, 2010). In the eastern region of the state, the distribution of HIV/AIDS cases by race/ethnicity was reported as 23% Caucasian, 71% African American, and 3% Hispanic (VDH, 2009b).

Statement of the Problem

HIV is a ribonucleic acid virus discovered in 1983 (Lewis, Heitkemper, Dirksen, O'Brien, & Bucher, 2007). HIV is a delicate virus that replicates inside a living cell, and this process destroys the CD4 cells that help fight infections; as a result, the immune system becomes weak (NIH, 2009a). The HIV virus is transmitted under precise conditions where there is contact with infected body fluids, such as blood, semen, vaginal secretions, and breast milk (CDC, 2010a; Lewis et al., 2007). HIV spreads primarily by infected individuals having unprotected sex; sharing needles, syringes, and other equipment used to prepare illicit drugs for injections; and being born to an HIV-infected mother because HIV can be passed from mother to child during pregnancy, birth, or

breast feeding (CDC, 2010a). HIV-infected persons can transmit the virus to others within a few days after becoming infected and become lifelong carriers of the disease (CDC, 2010a; Lewis et al., 2007). Within a few weeks of being infected, some individuals develop flu-like symptoms but others do not (CDC, 2010a). Individuals living with HIV may look and feel healthy; however, HIV is still affecting their immune system (CDC, 2010a).

HIV was unknown 30 years ago, but the virus has already has infected millions of people worldwide (UNAIDS, 2009). The virus does not discriminate among different races, ethnicities or genders; however, African Americans carry a larger burden related to the HIV epidemic than others (CDC, 2010c; Cunningham, Sanchez, Heller, & Sohler, 2007; Mugavero et al., 2009). When an individual is not actively being treated for the disease, he/she increases the risk of developing AIDS.

AIDS is the advanced stage of chronic HIV infection and the most serious stage of HIV (NIH, 2009a; CDC, 2010a, 2010c; Lewis et al., 2007). HIV progresses to AIDS when an individual's immune system is severely damaged and has trouble fighting diseases (NIH, 2009a; CDC, 2010a). AIDS is diagnosed when a person with HIV has a CD4 count that falls below 200 cells/mm³ or the person develops an AIDS-defining condition (NIH, 2009a). An AIDS-defining condition is defined as an illness that is not typical in someone who is not infected with HIV (NIH, 2009a), such as *pneumocystis jirovecii* pneumonia. The most current list of AIDS defining conditions was published in 1992 by the CDC (NIH, 2009a).

Before the development of HIV/AIDS medications, individuals with HIV could develop AIDS within a few years (CDC, 2010a). The development of highly active

antiretroviral therapy (HAART) in the 1990s has allowed HIV-infected individuals to live longer, but requires adherence to a medical regimen and attendance at scheduled medical appointments. Treatment regimens with HIV medications can be complicated due to the need of the individual to comply with daily medication administration for the rest of his/her life and the need to be constantly monitored due to the side effects of the medications (CDC, 2010a; NIH, 2009b). Individuals living with HIV/AIDS who do not adhere to their medical regimen, including failing to maintain contact with their health care provider for health care monitoring, tend to have poorer health outcomes compared to patients who adhere to their medical regimen (Cunningham et al., 2006; Lima et al., 2009). HIV/AIDS is a chronic debilitating disease, and death can result if patients are not regularly monitored by a health care provider or do not adhere to a medical regimen.

Bradford (2007) reported on a study that was completed through the Health Resources and Services Administration (HRSA) Special Projects of National Significance Outreach Initiative. The study involved 10 sites across the United States and the researchers located out-of-care individuals to learn how to engage and retain them in HIV treatment. Of the 763 participants who responded, 25% were uninsured; 43% faced practical barriers to care; 38% faced HIV stigma barriers; 53% faced health beliefs barriers; and 63% had unmet needs for support services (Bradford, 2007). Additionally, the study revealed that as many as 33% of HIV/AIDS patients fail to comply with recommended clinical visits and treatments while 29% are completely lost to follow-up (Bradford, 2007). The need for improved retention and positive outcomes in clinical care for PLWHA must be achieved both from the perspective of the individual and the public (Bakken et al., 2000; Giordano et al., 2005; Knowlton et al., 2010). A study conducted

by Knowlton et al. (2010) investigated adherence to HAART by HIV-seropositive active injection drug users. The researchers noted that approximately 13% of the sample was not included in data collection because of missing information due to a lack of follow-up with the primary care physician. Missing data resulted in the inability of some participants to complete an adherence self-report, and this is necessary to determine if the participant complied with the medication regimen.

Missed appointments with one's health care provider can lead to adverse economic and clinical consequences, regardless of the type of medical care warranted (Clarke et al., 2004; Whittle, Schectman, Lu, Barr, & Mayo-Smith, 2008). A failure to keep appointments has been associated with an increase in adverse effects in chronic diseases, such as acute asthma, hypertension, diabetes, increased cholesterol; increased risk of developing cancer; and unfavorable mental health outcomes (Fattal, Lampe, Barcelona, & Muzina, 2005; Schectman, Schorling, & Voss, 2008; Whittle et al., 2008). Baren et al. (2006) stated that poor management and compliance with recommended outpatient care can lead to increased morbidity in patients with chronic diseases. Therefore, when individuals adhere to their medical appointments they may be establishing a strong propensity toward decreasing negative outcomes of disease progression. When appointments are rescheduled, it is at considerable cost of staff and clerical time. In addition to cost factors, unused clinic appointment times can negatively impact productivity of the service provider (Whittle et al., 2008).

Proper treatment of persons diagnosed with HIV/AIDS is associated with wide variations in health status and complex treatment regimens (U.S. Department of Health and Human Services [USDHHS], 2005). Due to the chronic nature of HIV/AIDS,

providing comprehensive services such as case management, transportation, substance abuse, and mental health services to people living with HIV/AIDS in the community is necessary to enhance compliance with the recommended treatment regimen that is monitored through outpatient appointments (Pillai, Kupprat, & Halkitis, 2009).

Cunningham et al. (2007) found that patients with chronic illnesses may require extra support that often places a burden on the health care system, family, and friends. Federal clinical guidelines recommend that people living with HIV/AIDS receive their medical care from practitioners specializing in HIV/AIDS care at least every three to six months (Rajabiun et al., 2007; USDHHS 2005). Some HIV/AIDS patients may require more frequent care if their medical condition warrants more intensive treatment (Rajabiun et al., 2007).

The introduction of antiretroviral therapy (ART) medications has proven to be highly effective in treating HIV/AIDS and has significantly improved morbidity and mortality rates (CDC, 2008; Fleishman et al., 2005; Lemly et al., 2007; Ulett et al., 2009). Over the past decade, changes in the types of medications used to treat HIV/AIDS along with modifications in drug dosages have also had an impact on survival (DHHS, 2009). Despite the advances in the treatment of HIV/AIDS, research has shown that an individual must be in care to receive treatment, and retention in HIV/AIDS medical care improves adherence to HAART, increases survival, and slows the progression of AIDS (Giordano et al., 2005; Rajabiun et al., 2007; Mugavero et al., 2009; Ulett et al., 2009). The problem is that up to 50% of PLWHA fail to adhere to scheduled appointments with care providers for an ongoing monitoring of their health status, or they do not attend

follow-up appointments after the intake visit (Beer, Fagan, Valverde, & Bertolli, 2009; Bradford, Coleman, & Cunningham, 2007; Giordano et al., 2005; Ulett et al., 2009).

Background

Several studies reported that non-adherence to a HIV/AIDS medical regimen was more common with African American patients than with any other ethnic group (Lemly et al., 2007; Mugavero et al., 2009). Adherence to a medical regimen is defined as patients keeping their scheduled appointments, taking their prescribed medications, and attending to other consultative services prescribed by the health care provider. Scheduling and adhering to medical appointments would seem to be an obvious requirement in order to receive necessary medical care and to remain in an optimal state of health. However, many African Americans do not attend follow-up appointments and/or adhere to follow-up instructions, whether for treatment of HIV/AIDS or other medical care needs (Bakken et al., 2000; Compton, Rudisch, Craw, Thompson, & Owens, 2006; Grindley, Zizzi, & Nasypany, 2008; Mugavero et al., 2009). Connecting the patient to outpatient treatment, antiretroviral initiation, and long-term retention in care is a strong foundation for successful treatment of HIV/AIDS (Lemly et al., 2007, Rajabiun et al., 2007; Ulett et al., 2009). In a retrospective medical record analysis of a freestanding clinic for indigent HIV-infected persons, Giordano et al. (2005) found that 48% of patients failed to establish regular care, which included 11% who never returned after their intake appointment and 37% who experienced long gaps in receiving care.

There are various reasons why patients with HIV/AIDS miss medical appointments (Grindley et al., 2008; Lemly et al., 2007). Factors contributing to non-adherence to regularly scheduled follow-up appointments include sociodemographic,

sociopsychological, socioeconomic, and environmental causes; clinical outcomes; drug and alcohol dependency; antiretroviral prescriptions; employment status; organizational factors; and health care utilization characteristics of those with HIV/AIDS (Cunningham et al., 2006; Fleishman et al., 2005; Grindley et al., 2008; Lemly et al., 2007). However, stigma is another barrier that prevents African Americans from keeping medical appointments (CDC, 2010 a). Stigma is related to perceived negative attitudes, beliefs, and actions directed toward people living with HIV/AIDS (Rajabiun et al., 2007). According to Bradford (2007), 38% of out-of-care persons surveyed (n = 1076) reported HIV stigma was a significant barrier to engaging in HIV medical care, and this finding also reflected the opinions of the sample (n = 763) retained and not lost to follow-up.

Ryan White HIV/AIDS Program

On August 18, 1990, the U.S. Congress passed Public Law 101-381, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act (DHHS, 1998). Enactment of this law was in response to the increasing cost of caring for Americans living with AIDS who had little to no insurance, which created a burden for U.S. metropolitan areas (DHHS, 1998). During this period, the AIDS epidemic surpassed the capacity of local health departments, hospital emergency rooms, and other health care institutions. The CARE Act was created to help states, communities, and families cope with the AIDS epidemic and was named in honor of Ryan White, an Indiana teenager with hemophilia who contracted AIDS through a blood transfusion (DHHS, 1998). Ryan's mother struggled with AIDS discrimination against her son within the public school system and identified the need to educate the nation about the needs of people with AIDS (USDHHS, 1998; 2005).

The CARE Act, now titled the Ryan White HIV/AIDS Program, has been reauthorized several times since its' original enactment and is the single largest federal program designed specifically for people with HIV/AIDS (USDHHS, 2005). This federal program provides care and support for individuals and families affected by HIV by functioning as the "payer of last resort" (USDHHS, n.d., "Who was Ryan White?"). These funds allow grantees discretion in designing local programs, including setting clients' eligibility requirements and service priorities (USDHHS, n.d., "Who was Ryan White?").

The Ryan White HIV/AIDS Program has an ongoing critical role in providing care for low-income people with HIV/AIDS who have no other sources of care. This program bridges gaps in care not covered by other sources. According to the Health Resources and Services Administration (USDHHS, n.d., "Ryan White Parts A-F"), the services offered for persons are as follows: (a) medical care by providers who specialize in HIV care; (b) specialty care referrals; (c) social and medical case management; (d) medical counseling and medication education; (e) access to HIV and non HIV medications; (f) early access to new HIV medications at no charge through clinical research trials; and (g) linkages to various providers, such as nutritionists, dentists, and substance abuse counselors.

Purpose of the Study

The purpose of this study is to examine non-adherence to medical follow-up among African American subjects with HIV/AIDS by (a) exploring perceived barriers to adherence to a medical regimen and appropriate follow-up care; (b) determining which predisposing, enabling, and environmental factors that influence adherence to outpatient

medical follow-up care; and (c) examining the strongest indicators of non-adherence to outpatient medical follow-up care.

Brief Description of the Theoretical Framework

An adapted version of the Behavioral Model of Health Services Utilization by Ulett et al. (2009) was used to frame this study. Andersen (1968) developed the Behavioral Model of Health Services Utilization and published a major revision of the model in 1995 (Phillip, Morrison, Andersen, & Aday, 1998). Since then, others have revised and tested the model (Phillip et al., 1998; Ulett et al., 2009). In general, the model delineates the characteristics of the delivery system and characteristics of individuals, such as age, insurance coverage, and health status, and the impact of these factors on health care utilization.

According to the theoretical model, individual factors may predict the use of health care services. Attributes of individuals who ultimately influence their health care-seeking behaviors are characterized as predisposing, enabling, and perceived need factors (Andersen, McCutcheon, Aday, Chiu, & Bell, 1983). Predisposing factors are those that exist prior to the onset of illness and describe the likelihood of individuals to use services. Enabling factors describe the means that persons have available to them to use services. Perceived need factors for care refer to the level of experienced illness, which may be seen as perceived health, level of symptoms, or activity-limiting morbidity (Andersen et al., 1983).

Environmental factors also have an impact on the use of health care services. Characteristics of the environment that may contribute to issues associated with health-seeking behavior include the health care delivery system, external environment, and

community (Andersen et al., 1983; Phillips et al., 1998). In the adapted version of the model reported by Ulett et al. (2009), the environment consists of provider-related factors and system-related factors. Provider-related factors include the perceived level of trust of providers as experienced by the person seeking and utilizing services, experience in receiving specialized services from providers, and demonstration of engaging behaviors by providers toward individuals seeking care (Ulett et al., 2009). System-related factors incorporate the use of mental health services, substance abuse services, and/or case management services (Ulett et al., 2009). Patient characteristics may have an impact on the health care environment, and the health care environment can have an impact on patient characteristics (Ulett et al., 2009).

The Behavioral Model of Health Services Utilization was selected for use in this study for several reasons. First, it is one of the most frequently used frameworks for analyzing the factors associated with patient utilization of health services (Phillips et al., 1998). Second, it was selected because of its ability to predict and explain health services use (Andersen, 1995). Third, this model utilizes a systems perspective to integrate individual, environmental, and provider-related variables associated with decisions to seek care (Phillips et al., 1998). From a programmatic and policy perspective, this model can be used to understand the relationships and contributions of patient, provider, and environmental factors as well as how the individual's perceived need influences utilization (Phillips et al., 1998). This type of analysis facilitates the formulation of policies and programs that encourage appropriate utilization, discourage inappropriate utilization, and promote cost-effective care (Phillips et al., 1998). Lastly, the behavioral model is a framework for analysis, not a mathematical model. The behavioral model

does not dictate the precise variables and methods that must be used, which allows for greater flexibility in identifying the relationships among a variety of factors (Phillips et al., 1998).

Andersen et al. (1983) stated that utilization rates are objective measures that can be calculated in many ways. Utilization rates could be (a) a simple proportion of those who did or did not have contact with a provider within a given period of time or (b) an overall volume of services consumed once contact is made. Thus, the predisposing factors (sociodemographic, medical, and laboratory variables), enabling factor (social support), and environmental factors (systems and providers) that influence health services utilization behaviors for African American with HIV/AIDS were studied.

Research Questions

The research questions for this study are as follows:

1. Which predisposing factors (age, race, gender, education, medical history [initial treatment date, substance use, alcohol use, antiretroviral medication initiation, and mental disorders] and laboratory data [baseline CD4 and plasma HIV viral load]) among African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia will best explain nonadherence to outpatient medical follow-up appointments?
2. Which enabling factors (support by family/significant others and insurance) among African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia will best explain nonadherence to outpatient medical follow-up appointments?

3. Which environmental factors (provider: race/ethnicity, gender, and specialty; system: referral or use of mental health services, substance abuse services, and case management services) among African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia will best explain nonadherence to outpatient medical follow-up appointments?
4. For African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia, is there a difference in predisposing, enabling, and environmental factors for those who adhere to their outpatient medical follow-up appointments and those who do not adhere to their outpatient medical follow-up appointments?
5. For African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia, what are relevant factors related to engagement with the provider for understanding nonadherence to outpatient medical follow-up appointments?
6. What health care environmental and personal factors are barriers to medical appointments for African Americans with HIV/AIDS?

Operational Definitions

1. Acquired Immune Deficiency Syndrome (AIDS) – defined by the CDC on the basis of a CD4 positive T cell count of less than 200 per mm³ of blood.
2. Adherence – an appointment that was kept as scheduled or the person attended at least one appointment during the six-month time frame.
3. African-American – term used to include Black or African Americans.
4. Cancelled appointment – the appointment did not occur on the date scheduled.

5. Case management services – resources used to help clients in negotiating, gaining, and maintaining access to health care and social service system (Magnus et al., 2001).
6. Case manager – a social worker, a nurse, an AIDS service organization staff member, staff in other service organizations, or anyone else who is assigned to help clients with receiving and coordinating care (Katz et al., 2001).
7. Caucasian – White ethnicity
8. CD4 cells – types of white blood cells that fight infections. When HIV enters a person's CD4 cells, it uses the cells to make copies of itself. As the patient loses CD4 cells, their immune system become weak. A weak immune system makes it harder for the patient to fight infections.
9. CD4 count – the number of CD4 cells in a sample of blood.
10. Highly active antiretroviral therapy (HAART) – 1998 US National Institutes of Health (NIH) guidelines defined HAART as two or more nucleoside reverse transcriptase inhibitors (NRTIs) with a protease inhibitor (PI) or in combination with nonnucleoside reverse transcriptase inhibitors (NNRTI). This class of drugs is designed to target group pathogens known as retroviruses, HIV is the most well-known of these pathogens. It is a combination of at least three retroviral drugs.
11. Human immunodeficiency virus (HIV) – the virus that damages a person's body by destroying specific blood cells, called CD4 +T cells, which are crucial in helping the body fight diseases (CDC, 2010a).

12. Medical services – aid provided by physicians, physician assistants, nurse practitioners, and registered nurses.
13. Medical regimen – the prescribed recommended care of the person with HIV/AIDS. This means that the individual keeps their scheduled appointments, takes their medication, and receives other consultative services (Mugavero et al., 2009).
14. Mental health services – aid provided by psychiatrists, psychologists, substance abuse counselors, and licensed mental health counselors.
15. Non adherence – an appointment that was not kept at the scheduled time or the patient did not come to a scheduled appointment within the six-month time frame.
16. No show – an appointment that occurs when the patient does not come for the scheduled appointment and the patient did not reschedule the appointment.
17. Plasma HIV viral load – the amount of HIV that is in the blood. The lower the viral load, the less the amount of the HIV virus (Mugavero et al., 2009).
18. Specialty of provider – level of professional practice (physician, nurse practitioner, physician assistant, registered nurse).
19. Time frame – six-month intervals beginning from the initial date of service or the last scheduled appointment.
20. Walk-in clinic services – services that are provided on the same day that the patient arrives to the clinic. The patient did not have a scheduled appointment.

Significance to Health Services Research

HIV/AIDS remain a persistent threat to the health, well-being, and productivity of many African American communities (CDC, 2010c; VDH, 2009a, 2010). A study by

Ulett et al. (2009) focused on patient factors related to HIV/AIDS care, but did not evaluate the impact of environmental factors on timely linkages and early retention in HIV care. The authors recommended other researchers “engage in such research to advance the field” (Ulett et al., 2009, p. 47). This research study builds on one of the study recommendations to evaluate how environmental factors influence utilization. Ulett et al. (2009) found that examining data about the environmental impact of the health system on clinical outcomes, as well as the influence of health care provider variables on clinical outcomes, is important.

According to the CDC (2010c), African Americans with HIV/AIDS have more illnesses, shorter survival times, and more deaths. African Americans account for about 13% of the U.S. population; however, they account for almost half (49%) of the people who get HIV and AIDS (CDC, 2010c). HIV/AIDS is the leading cause of death for African Americans (CDC, 2010c). African Americans with HIV/AIDS who adhere to outpatient medical follow-up are (a) less likely to suffer HIV-related opportunistic infections and thus have better restoration and preservation of immune functions; (b) more likely to experience reduced morbidity and mortality; and (c) more likely to experience a better quality of life (Fleishman et al., 2005).

The findings of this study aid in the identification of factors that best predict which African American PLWHA are receiving care are likely to be retained in medical outpatient follow-up care. This study also can provide information that can be used to tailor interventions to increase patients’ adherence with all aspects of outpatient follow-up. Lastly, findings from this research study add to the body of health services research related to behaviors and health services utilization of African American PLWHA.

Summary

HIV/AIDS is a worldwide health problem. People living with HIV/AIDS must perceive the importance and adhere to their prescribed medical regimen to achieve optimal outcomes. The identification of factors that will keep PLWHA in medical outpatient follow-up care is critical. Adherence to medical care for PLWHA is both the challenge of a lifetime and a challenge for a lifetime (USDHHS, 2005).

African Americans are disproportionately affected by HIV/AIDS, have greater health disparities related to chronic illnesses, and poorer health outcomes (Cunningham, et al., 2007). These factors are related not only to race/ethnicity, but also to barriers that are faced by many African Americans (CDC, 2010c). Some of these barriers are poverty, lack of health care insurance, poor access to HIV primary care services, stigma, and poorer health care outcomes (Beer et al., 2009; CDC, 2010c; Cunningham et al., 2007).

In order to have more positive health care outcomes, PLWHA need to be engaged in care and follow a prescribed regimen of care, including HAART. African Americans with HIV/AIDS who are not receiving care are likely to jeopardize their overall health and quality of life. It is important to understand factors that prevent African Americans with HIV/AIDS from adhering to their scheduled outpatient medical appointments. While the rate of HIV transmission has declined by 89% in the U.S. since the peak of the epidemic (VDH, 2010), African Americans remain the ethnic group that continues to have a greater incidence of the disease. Therefore, interventions designed to help African Americans stay in treatment must be based on a greater understanding of factors that influence utilization and adherence (Mugavero et al., 2009; Phillips et al., 1998; Rajabiun et al., 2007).

CHAPTER 2

REVIEW OF LITERATURE

A search of the literature was performed using the following online databases: CINAHL Plus, ERIC, ProQuest, and Ovid. Keywords used in the search for relevant literature included *adherence to medical appointments*, *HIV/AIDS*, *African Americans/Blacks and HIV/AIDS*, *Behavioral Model of Health Services Utilization*, *utilization behavior*, and *patient engagement with providers*. The literature review included both quantitative and qualitative research studies.

Overview of the Behavioral Model of Health Services Utilization

Initial Development

The Behavioral Model of Health Services Utilization was first described by Anderson (1968), who presented this model using the family as the unit of study in his dissertation entitled, "Families' Use of Health Services: A Behavioral Model of Predisposing, Enabling, and Need Components." The use of health services was perceived to be a result of a complex interrelated set of factors. Differences in family health services utilization were explained by the three-stage model. The author made various assumptions in the original model: the family must be predisposed to receiving medical care; there are enabling conditions that allow families to attain health services; the family must perceive a need for those services; and when family discretion was involved in determining the type and amount of services used, the predisposing and enabling components of the model will be most important (Andersen, 1968).

To test the model and its various components, Andersen conducted a nationwide survey of 2,367 families in early 1964 (Andersen, 1968). Predisposing components

consisted of family composition, social structure, and health beliefs. Enabling components consisted of family and community resources, and the need component was composed of illness and response (see Figure 1).

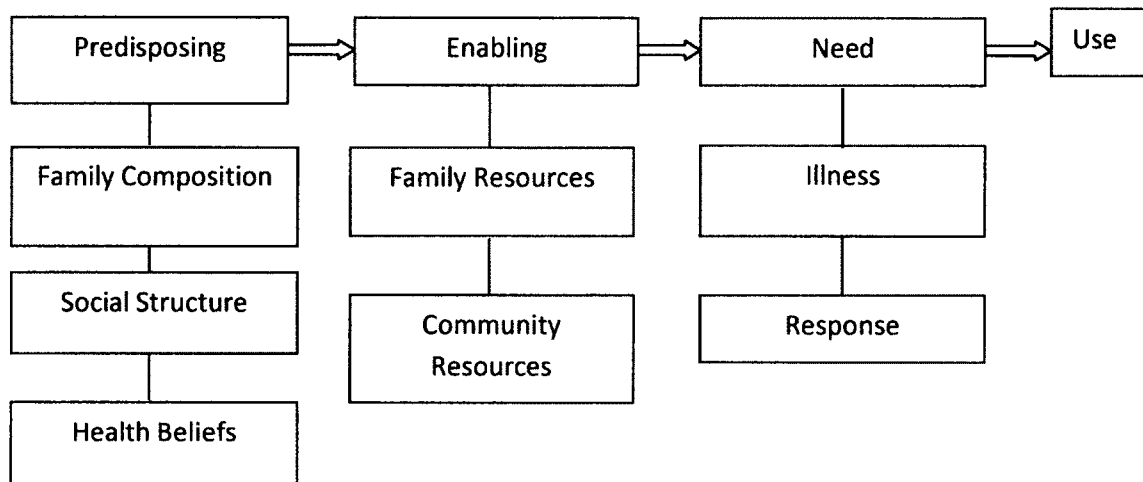


Figure 1. A Behavioral Model of Health Services Utilization (Andersen, 1968). From "Families' Use of Health Services: A Behavioral Model of Predisposing, Enabling and Need Components" by R. Andersen, 1968, p.24. Copyright [1968]. Reprinted with permission from R. Andersen.

When considering the predisposing components of the model, Andersen (1968) found that some families have a greater propensity to use more health services than others. Factors such as age, sex, family size, marital status, and head of the family contributed to the use of health services. The social structure of the family, including the physical and social environment, also influenced the used of health services with factors such as employment, social class, occupation, education, race, and ethnicity playing a significant role. Health beliefs related to families' views concerning medical care were

also considered important. Andersen (1968) believed that what the family thought about health may influence health and illness behaviors.

Andersen (1968) discussed the use of health services and how to make those resources available to the family. Family resources were assessed in relationship to economic resources and the family's source of medical care. Economic resources, according to Andersen, consisted of income, health insurance, personal savings, and whether the family received welfare. Areas with persons who have high health education levels and who focus on scientific medicine (versus folk medicine) use community resources more frequently. Community resources included factors such as the physician-to-population ratio, hospital bed-to-patient ratio, and location of the primary residence (Anderson, 1968).

Need in the original model was defined as the most immediate cause of health services use and was measured by the degree of illness perceived by the family and the family's response to the illness (Andersen, 1968). Illness was self-identified and self-reported, and responses were based on a perceived illness and the family's reaction to it. The perceived illness was a belief that the person had a disease based on a physician's visit due to experiencing specific symptoms or after a regular physical exam and was considered indicative of the need for health services. The presence of all three factors (predisposing, enabling, and need) would be seen in the use of health services by the family (see Figure 1).

Andersen's findings revealed that the most important component of the model was measured by the families' perceptions of illness and by their responses to those perceptions in explaining differences in the use of health services. Family interaction

regarding compliance with a medical regimen appeared to be less important if the physician consultation and treatment was for a short term, whereas interaction was more important if patient compliance was needed for long-term adherence to a regimen. Additionally, the ability of the family to obtain and sustain professional care for individual family members varied with such factors as family income and health insurance coverage (Andersen, 1968).

Framework for the Study of Access to Care

Building on the initial work of the Behavioral Model Health Services Utilization, researchers developed a framework about access (Aday & Andersen, 1974; Andersen & Aday, 1978; Andersen et al., 1983) in order to study access to medical care as it related to the interrelationship of health policy, characteristics of the population at risk, characteristics of health delivery system, consumer satisfaction, and utilization of health services. According to Aday and Andersen (1974), the term, access, had been used from a political perspective and was not an operational idea in which policy makers and others could monitor the effectiveness of various programs in meeting the goal of accessing care.

Aday and Andersen (1974) found many concepts about access in the literature that tied “access with characteristics of the population (such as family income, insurance coverage, attitudes toward medical care) or of the delivery system (the distribution and organization of manpower and facilities” (p. 209). Access also was viewed from the perspective of outcome indicators, such as utilization rates or satisfaction scores, as the individual moved through the health care system. Utilization of services is influenced by

the participant's willingness to seek care based on attitudes and knowledge about health care as well as learned social and cultural definitions (Aday & Andersen, 1974).

The framework for the study of access included health policy, characteristics of the health care delivery system, characteristics of the population at risk, utilization of health services, and consumer satisfaction (Aday & Andersen, 1974). Characteristics of the population at risk in the framework proposed by Aday and Anderson (1974) were the predisposing, enabling, and need components that were described as individual determinants of utilization. The predisposing component included variables that described the "propensity" of persons to use services (p. 213). Included are variables such as age, sex, race, religion, and values concerning health and illness (Aday & Andersen, 1974). The enabling component described the "means" that individuals have available to use services (p. 213). These are resources specific to the individual and his family and attributes of the community in which the individual lives (Aday & Andersen, 1974). Illness level was reflected in the need component "which is the most immediate cause of health services use" (Aday & Andersen, 1974, p. 213).

The individual was the unit of analysis used when considering the population at risk. In considering the utilization of health care services in terms of access, the interrelationship of all five aspects of the framework was important to policy makers. At the time of the development of this framework, Medicare and Medicaid were the federal programs designed to equalize access to care in the United States using an economic approach. Aday and Andersen (1974) believed it was important to consider both economic and organizational aspects when evaluating the success of existing health policy or predicting the potential effectiveness of proposed changes related to improving

access. In summary, the expected outcome was that health services utilization research would provide a framework to describe factors that promote or inhibit entrance into the health care delivery system. Measurements related to where, how often, and for what purposes individual gained access to health care services as well as how inhibiting or facilitating factors operated to influence admittance were also integral to the framework (Aday & Andersen, 1974). The researchers stated that the “level and pattern of the population’s actual utilization of the system is one measure that may be used to test the predictive validity of these system and individual-based indicators” (Aday & Andersen, 1974, p. 214).

Study of Access to Care Framework

Andersen and Aday (1978) continued their pursuit to define how access to medical care could be operationalized using social survey techniques, documenting current levels of access to medical care, providing a theoretical framework for understanding differential levels of access among subgroups, and achieving equity among these groups. At the time this study was conducted, policy makers and consumers were still trying to measure access, and several definitions of access had evolved. These definitions were (a) physician-to-patient ratio, (b) various costs of using the facilities and personnel, (c) actual use of health services, and (d) use of health services in terms of perceived need. Andersen and Aday (1978) concluded that access is best measured “through observations of people’s behavior,” meaning their actual patient use of health services (p. 544). Equity would be based on actual health service utilization in relationship to some measure of illness experienced.

The use of the Behavior Model of Health Services Utilization would help to expand the understanding of the differential levels of access among subgroups and the equity in service utilization (Andersen & Aday, 1978). In using this model, equity and mutability become factors. Equity or inequity in access can be any sources of variation in health services utilization depending on the values applied to the classification process (Andersen & Aday, 1978). According to Anderson and Aday (1978), mutability referred “to the extent to which a given component can actually be altered to influence the distribution of health services” (p. 535). A path analysis approach was used to examine possible cause and effect relationships of variables within the model. Using this method, the researchers recognized that predisposing variables can influence utilization through their effect on enabling variables and level of illness. The enabling variables influence utilization directly, as well as through the illness variables, and those illness variables have direct effects on utilization (Andersen & Aday, 1978).

Data used to test this framework were gathered from a national survey of the non-institutionalized population of the United States conducted by the Center for Health Administration Studies and the National Opinion Research Center of the University of Chicago. There was an oversampling of individuals experiencing episodes of illness, rural Southern Blacks, and individuals of Spanish heritage persons living in the Southwest. The sample size consisted of 7,787 individuals who accessed medical care in 1975 and 1976, and the predisposing variables were age, race, and education.

Enabling variables were insurance coverage, physician population ratio, and existence of a primary care provider. Need variables were the number of symptoms reported in a year and perceived health. The dependent variable consisted of the total

number of face-to-face (home and office) physician visits the participant reported during the 12 months preceding the interview.

The findings indicated that the strongest correlations were age with the illness variables, education with family income, income and education with perceived health showing a negative correlation, symptoms with perceived health, and both illness variables with number of visits. When looking at equity and mutability, age and race had no direct effect on the number of visits. Inequitable direct effect was seen in that highly educated persons attended more visits. Results also showed an indirect effect in that a higher education level lead to less illness and fewer physician visits. Therefore, education was considered immutable because levels can be altered over time. Income on utilization was not statistically significant. Health insurance had a direct effect on the number of visits, which was seen as mutable and inequitable. The enabling variable that was most significant was physician utilization, referring to whether the person saw the same provider with each visit. This was judged as mutable and inequitable. Path analysis use in health services research is an effort to better explain the many factors that may influences health behavior and outcomes as well as predicting variables with the strongest effect (Andersen & Aday, 1978).

Dimensions of Access to Medical Care

Defining access to medical care in terms of cost efficiency was incorporated into the emerging framework in response to concerns raised by policy makers and federal resource administrators regarding the economical use of health care services (Andersen, McCutcheon, Aday, Chiu, & Bell, 1983). Anderson et al. (1983) used a combination of

cost efficiency and components of the Behavioral Model of Health Services Utilization tool to examine the extent more prudent indicators of access could be developed.

The framework's organizational features were based primarily on individual respondents' self-reports of the structure and convenience of the places they usually used for medical care (Andersen et al., 1983). In addition, predisposing, enabling and need factors descriptive of the population and available as aggregates of the geographical and political units of the individual's county of residence were used (Andersen et al., 1983). Predisposing, enabling, and need factors referred to attributes of individuals that eventually influenced their health-seeking behaviors.

The goal of this model was to assist in defining and measuring multiple dimensions of access to care. Variables were deleted through a three-stage process of data reduction resulting in a set of key indicators of the concept access (see Table 1). According to Andersen et al. (1983), "The interrelationships of variables *within* the major dimensions of access suggest that some components might be represented by fewer variables than the number in our original set" (p. 72).

Revisiting the Behavioral Model and Access to Medical Care

Subsequent work by Andersen shifted its focus to the individual as the unit of analysis rather than the family because of the difficulty in developing measures at the familial level that could encompass the array of differences inherent among family members (Andersen, 1995; Mkanta & Uphold, 2006). Furthermore, when the model was originally developed, increased utilization was a major policy goal. Andersen (1995)

Table 1

Dimensions of Access to Medical Care and Their Indicators.

<u>Potential Access</u>		<u>Realized Access</u>	
<i>System (County)</i>	<i>Individual</i>	<i>Objective</i>	<i>Subjective Satisfaction</i>
<i>Availability</i>	<i>Predisposing</i>	<i>Use</i>	<i>Convenience</i>
MD/Population	Age 6 or Less	Time Since Exam*	Travel Time
Bed/Population	Age 65 or Over	Preventive Exam	Travel Cost*
Dentist/Population	Sex	MD Visits	Appointment Time
	Race	Hospital Visits	Waiting Time
<i>Community (County) Characteristics</i>	Education	Dental Visits	Visit Cost
Predisposing			
% 65 or Over	<i>Enabling</i>	<i>Use Relative to Need</i>	<i>Provider Behavior</i>
Enabling	Financing		
% below Poverty	Income	Symptoms Response	Time with MD*
Region	Group Insurance*	Use Disability	Information*
Rural Residence	Major Medical*	Dental Want	MD Courtesy*
Central City	Hospital Insurance		RN Courtesy
Residence	Dental Insurance		Receptionist Courtesy*
Need	MD Office Insurance*		MD Concern*
Infant Mortality	Visit Cost		Quality
	Organization		Overall*
	Regular Care Source*		
	Particular Provider		
	Specialty of Provider		
	Travel Time		
	Prior Appointment		
	Appointment Time		
	Waiting Time		
	Time with MD		
	<i>Need</i>		
	Perceived Health		
	Worry about Health*		
	Symptoms*		
	Dental Symptoms		
	Disability Days		
	Illness Episode*		

* Signifies a deleted variable

From "Exploring dimensions of access to medical care", *Health Services Research*, 18, 1983, p. 51. Reprinted with permission from R. Andersen and Wiley Blackwell publisher.

designed the model to explain the use of formal personal health services and did not focus on the important interactions that occur as individuals receive health care or on outcomes (Andersen, 1995). Growing concern over the cost of health care services in the 1990s prompted further study to determine whether the model could be used to discover conditions, such as the economic factors, which either facilitate or hinder the utilization of health care services (Andersen, 1995).

In the 1970s, the model had evolved to include the following components: population characteristics (predisposing, enabling, and need), health care system (policy, resources, and organization), use of health services (type, site, purpose, and time interval) and consumer satisfaction (convenience, availability, financing, provider characteristics, and quality). According to Andersen (1995), the variables under population characteristics and health care systems impacted the individual's use of health services. The health care system was included in this phase, showing the importance of national health policy, resources, and organizations as important determinants of the population's use of services (Andersen, 1995). Evolution of the model through the 1980s and 1990s resulted in the inclusion of health status outcomes, which allowed the researchers to study health policy and reform in terms of health utilization and access (Andersen, 1995). The purpose of using the model is to discover conditions that facilitate and/or impede utilization (Andersen, 1995).

Incorporation of Environmental and Provider-Related Variables into the Model

The Behavioral Model of Health Services Utilization is the most frequently used framework for analyzing factors associated with health care services and individual utilization (Phillips et al., 1998). The conceptual framework uses a systems perspective to

integrate individual, environmental, and provider-related variables. However, Phillips et al. (1998) stated that the assessment of environmental and provider-related factors has been largely neglected. The researchers conducted a systematic literature review and analysis to determine if studies of medical care utilization during the past 20 years (1975–1995) had included environmental and provider-related variables; the methods used to analyze these variables were also examined (Phillips et al., 1998). A total of 139 articles were identified that cited use of the behavioral model, including empirical analyses and studies of formal medical care utilization. Figure 2 depicts the model that was used in the analysis, and it was adapted from Andersen (1995).

Forty-five percent of the studies included environmental variables, such as location (urban versus rural), and the variables were measured at the individual level. Fifty-one percent of the studies included provider-related variables. Only two studies looked at providers' characteristics using data obtained from providers. Characteristics in those studies related to the physician specialty, type of practice, and quality of patient-physician interaction.

The most frequently used provider variable was whether or not the individual had a regular source of care and if the individual had previously utilized services. Phillips et al. (1998) stated, "It was unclear whether high prior use reflects greater illness levels, a greater predisposition to seek care, provider factors or other factors" (p. 588). Future research was suggested. Only a few studies examined specific measures of the health care system and provider characteristics or used methods other than simple regression.

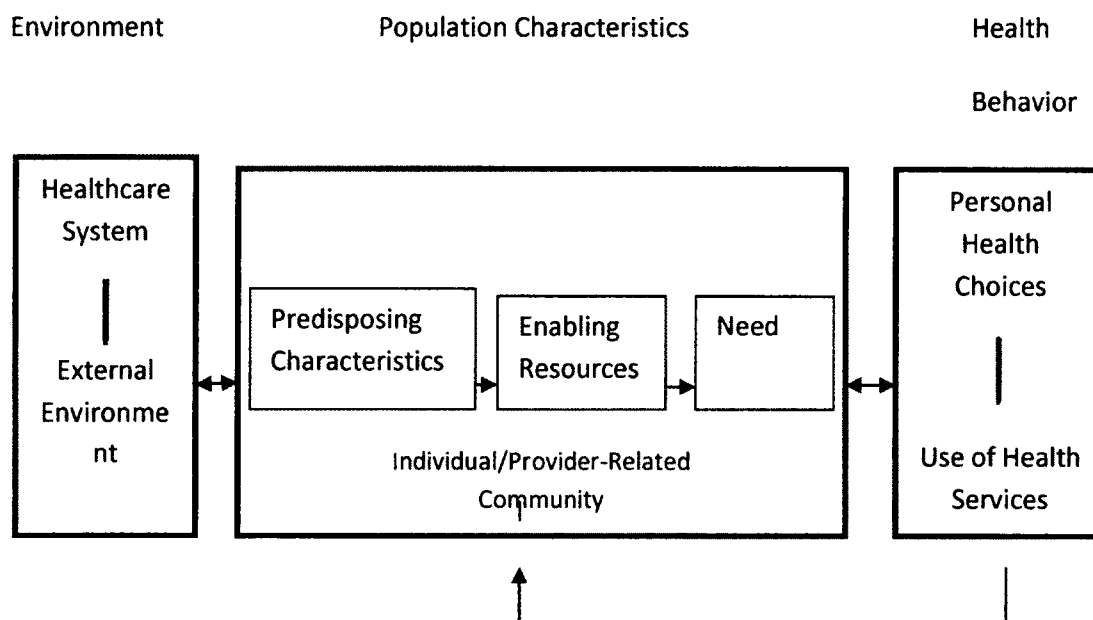


Figure 2. Utilization Model. From "Understanding the context of health Care utilization: Assessing environmental and provider-related variables in the behavioral model of utilization" by Phillips, Morrison, Andersen and Aday, (1998), *Health Services Research*, 33, p.575. Reprinted with permission from K. Phillips and Wiley-Blackwell publisher.

According to Phillips et al. (1998), only 14% of studies examined the context of health care by including both environmental and provider-related variables. The results from the systematic literature review showed that contextual variables using explanatory methods are less frequently examined when using the behavioral model (Phillips et al., 1998). Furthermore, the authors believed that this inadequacy could lead to biased and misleading results as well as variances that hinder the understanding of utilization behavior. To overcome the barriers of lack of data, analytical difficulties, and model conceptualization, the researchers provided solutions. There was a lack of data on contextual variables and individual-level utilization data associated with the predominant use of secondary data, most frequently on surveys conducted by the federal government.

The solution proposed to remove this barrier was to merge databases that included detailed patient-level utilization data with databases that included environmental or provider characteristics (Phillips et al., 1998).

Environmental variables were measured most often at the aggregate level while utilization was measured on an individual level. This barrier was attributed to problems of interpretation. The solution offered was to use multilevel models that allow for a simultaneous examination of variables measured at different levels. Another analytical barrier discussed is the use of feedback loops because results can be interpreted one-directionally; however, the relationship may be two-directional. The barrier with the model conceptualization was stated that the lack of environmental variables may reflect confusion over the model's conceptualization since overlap existed between environmental and enabling variables. This may be accounted for due to the model has become well known for the predisposing, enabling, and need variables, and environmental components may be overlooked by the researchers (Phillips et al., 1998). The suggested solution was that future research should focus on the conceptual framework used to examine the role of provider characteristics as well as provider-patient interactions.

In 2009, Ulett et al. (2009) published the results of testing on a new model that was an adaptation of Andersen's Behavioral Model of Health Services Utilization, as well as an adaptation of the blueprint for HIV treatment success based on the work by Giordano et al. (2005), Samet, Freedberg, Savetsky, Sullivan, and Stein (2001), and Ulett et al. (2009). This new iteration of the Behavioral Model of Health Services Utilization provided a conceptual framework to evaluate the relationship between patient

characteristics (predisposing, enabling, need factors), environment (contextual and health care environmental factors), health behavior (linkage to care, retention in care, and ARV receipts and adherence), and clinical outcomes.

Ulett et al. (2009) completed a retrospective of medical records of patients starting primary HIV care. The patients had initiated care at the University of Alabama at Birmingham in 1,917 HIV/AIDS clinics between January 1, 2000 and December 31, 2005. Initial outpatient appointments were used for analysis, and patients were excluded if they had received outpatient care prior to the initial outpatient visit. The independent variables were selected *a priori* based upon the review of the literature and the Behavioral Model of Health Services Utilization and included sociodemographic variables, medical history, history of affective mental health disorder, substance abuse, alcohol abuse, antiretroviral medication initiation, and laboratory and clinical utilization measures. The dependent variables were late presentation for HIV care based on a CD4 count < 350 cells/mm³, the time that ART was initiated, and early retention of outpatient HIV care. Ulett et al. (2009) defined retention: “Retention in care was measured as the number of 6-month blocks during which at least one clinic visit was attended over the 2-year period following the initial attended visit (range, 1-4)” (p. 43).

The results revealed that 567 patients established initial care from January 1, 2000 to December 31, 2005, and 197 patients entered care in 2000–2001, 197 in 2002–2004, and 196 in 2004–2005. The majority of the patients were African American (55%), and nearly half of the entire sample (49%) had private medical insurance. Alcohol and illicit drug use were present at a rate of 19% and 26% respectively. The baseline CD4 count

was < 350 cells/mm³ in 63 % of the patients. Seventy percent of the patients had a baseline plasma HIV viral load (VL) of less than 100,000 copies/mL.

Late presentation for care was associated with older age (OR = 1.31 per 10 years; 95% CI= 1.06–1.62), African American ethnicity (OR = 2.45; 95% CI = 1.60–3.74), and baseline viral load $> 100,000$ (OR = 5.81; 95% CI=3.54–9.56). African Americans were more likely to establish care when the clinical manifestations of HIV/AIDS were more advanced. In the original sample, 95% of the patients had not started ART therapy prior to their first outpatient clinic visit. Within a year, 66% had started ART. Faster initiation of ART was based on lower baseline CD4 counts and attendance at all scheduled primary HIV care clinic visits and not sociodemographic factors (Ulett et al., 2009). There were four frames analyzed within the two-year time frame; 16% of the patients attended the first six months, 12% in the second frame, 13% in the third frame, and 59% in all four 6-month intervals. Multivariate logistic regression analysis demonstrated that early retention in care was least likely with persons with a higher baseline CD4 (patients are usually asymptomatic) and those with a history of substance abuse. Older patients and those with a history of mental health disorders had better retention in care.

Ulett et al. (2009) found that benefits of treatment were not realized fully unless patients remained engaged in uninterrupted HIV clinical care throughout all phases of the treatment process. Diagnosis represented only the first step and should be followed by timely linkage in care (Ulett et al., 2009). The conceptual framework illustrates that retention in care and treatment success proceeded from initial diagnosis to long-term clinical outcomes (see Figure 3).

Components of the Behavioral Model of Health Services Utilization: Focus on Persons with HIV/AIDS

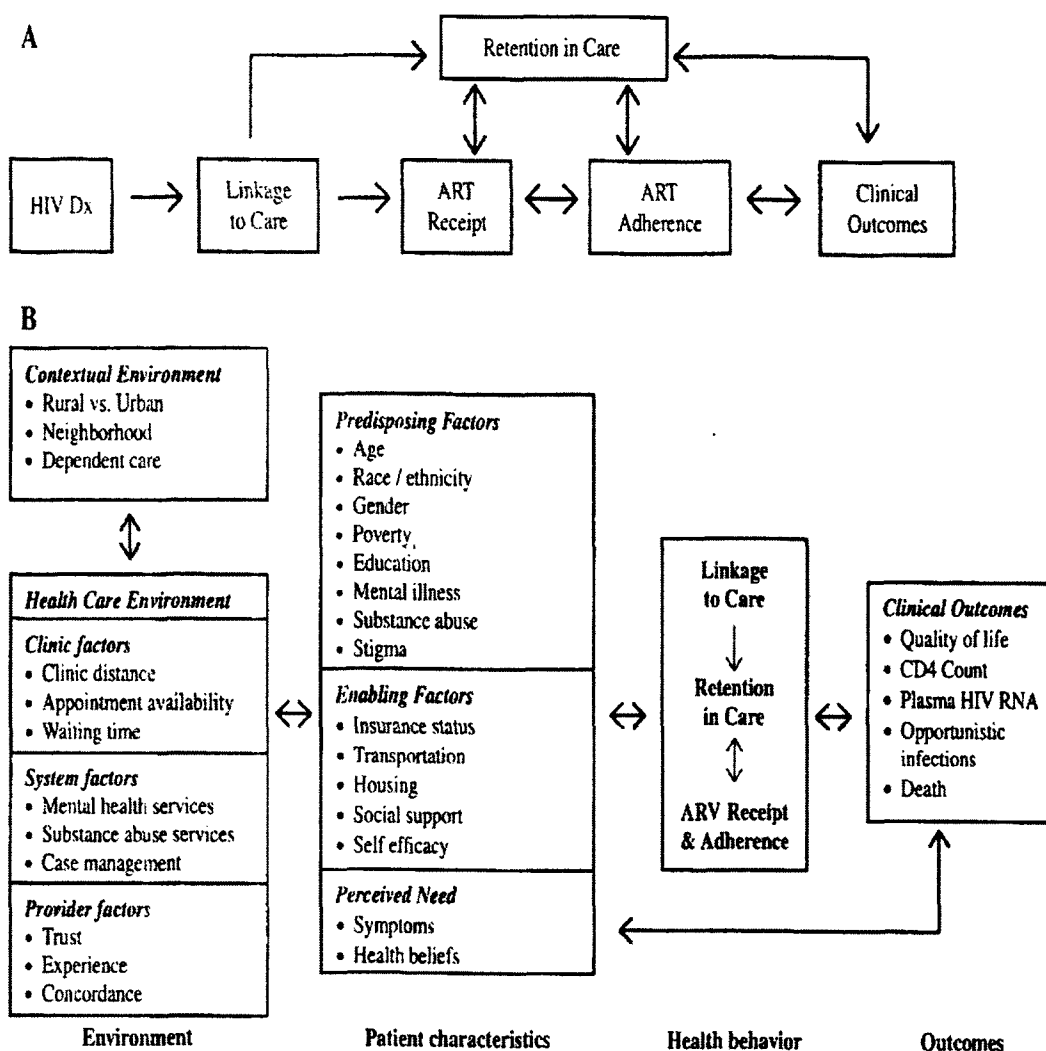
In the discussion that follows, components of the Behavioral Model of Health Services Utilization will be described with a specific focus on persons with HIV/AIDS. Predisposing, enabling and environmental factors will be discussed.

Predisposing Factors

Predisposing factors are characteristics of an individual that exist prior to illness. In this model, predisposing factors include three dimensions. These dimensions are demographics, social structure characteristics, and health beliefs (Mkanta & Uphold, 2006; Phillips et al., 1998).

Age. In 2009, new HIV infections were highest among persons 13–39 years old (39%), followed by those who were 30–39 years old (27%); 40–49 years old (27%), and 50+ years of age (11%). The average person with HIV was between 20 and 44 years of age (CDC, 2011d).

Cunningham et al. (2006) completed a study comparing multisite samples from the Targeted Outreach and Intervention Initiative, a multisite special project of national significance, under the Ryan White CARE Act of underserved persons with a national probability sample (HIV Costs and Services Utilization Study [HCSUS]) of persons receiving care. A logistic multivariate analysis of persons younger than 35 years of age demonstrated the outreach participants were less likely (AOR = 0.60, 95 % CI = 0.48-



*Figure 3. Blueprint for HIV Treatment Success. From “The therapeutic implications of timely linkage and early retention in HIV care” by Ulett et al. (2009), *AIDS Patient Care and STDS*, p. 42, Used by permission of author, J. Mugavero and publisher Libert Publishing.*

0.75) to have low ambulatory medical visits (fewer than two visits in the last six months).

Whereas, in the HCSUS sample, participants between the ages of 35 and 49 were more likely (AOR= 1.32, 95% CI = 0.92–1.89) to have low ambulatory medical visits. Studies

by Cunningham et al. (2006) and Giordano et al. (2005) suggest that persons over 35 years old were more successful in establishing and remaining in care. This was a slightly different finding from a study performed by Molitor et al. (2006) of persons who had never been linked in care. Results of this study indicated that persons over the age of 35 were more likely to have been without medical care for over 12 months ($X^2 = 18.64, p < 0.001$).

On the other hand, younger age has been associated with poor adherence to antiretroviral medications and difficulty in establishing care (Giordano et al., 2005). Univariate analysis of study results by Giordano et al. (2005) indicated that higher CD4 cell counts and younger age were also indicators of difficulty establishing care. Multivariate analysis suggested that individuals who were injection drug users and younger had difficulty establishing care. This group also had poor antiretroviral medication adherence. Fattal et al. (2005) found that older patients in psychiatric care, even those who had not been diagnosed with HIV/AIDS, were more likely to be compliant than younger patients in taking all of their medications and keeping scheduled appointments.

Although the incidence of HIV among older individuals is increasing, older Americans do not perceive themselves as being at risk for HIV and do not take extra precautions (Jacobs, 2008). It was found that women over the age of 50 are less likely than younger women to have accurate information on HIV transmission (Jacobs, 2008; USDHHS, 2009). According to Uphold and Mkanta (2005), the rate of AIDS cases among persons age 50 and older increased to 12.3% between 1996 and 2000. CDC (2008) reported that persons aged 50 and older accounted for 24% of people living with

HIV/ AIDS, and this was an increase of 17% since 2001; and 15% of the increase was due to the introduction of HAART. Given that older persons are becoming infected later in life, and those with AIDS are living longer due to advances in therapy, it is expected that the reported rate of infection will increase among those age 50 and older .

Gender. Study results on HIV/AIDS by gender have been mixed. Older women are sexually active, and a misconception exists that women know how to avoid HIV infections (Jacobs, 2008). Men who have sex with men (MSM) are a group that is disproportionately affected by HIV (CDC, 2011d). This group only represents 2% of the U.S. population, but during 2006–2009, it accounted for more than 50% of all new infections (CDC, 2011d).

Uphold and Mkanta (2005) found that women used more supportive services, had more frequent emergency rooms visits, had higher hospitalization rates, and were less likely to receive antiretroviral medications. Compared to men, women often were inaccurately diagnosed, accessed primary health care providers who knew little about HIV infection, and sought care later in the course of their illness (Anthony et al., 2007; Uphold & Mkanta, 2005). These factors were related to women having increased role demands, such as childcare and family responsibilities, which may prevent them from obtaining the best health care (Anthony et al., 2007; Uphold & Mkanta, 2005). Also, women with HIV infections are often members of disenfranchised groups, such as injection drug users and racial minorities, who have restricted access to health care as well as insufficient economic resources to combat the problems related to the disease (Uphold & Mkanta, 2005).

Race. African Americans represent 14% of the U.S. population, and 44% of those affected with HIV (CDC, 2011b). Lopez, Simone, Madariaga, Anderson, and Swindells (2009) conducted a retrospective cohort study to examine the impact of race/ethnicity on HIV disease progression and mortality; they also studied potential confounders such as socioeconomic status, presence of comorbidities, and stage of HIV infection. The study was performed in an HIV clinic in a midwestern academic setting. This clinic was Ryan White-funded and was also the only HIV clinic in the region. Eight hundred and seventy patients were included in the study. Fifty-three percent of the patients were White, 29% were African American, and 15% were Hispanic. Lopez et al. (2009) found that “Black patients with advanced disease (CD4 cell count, $100/\text{mm}^3$ and/or HIV viral load $> 100,000$ copies/mL) had poorer prognoses than other racial/ethnic groups, even after controlling for confounders” (p. 989). Survival outcomes between the ethnic groups were not statistically significant, but outcomes were somewhat lower for African American patients.

With respect to race, Giordano et al. (2005) found that once indigent African American and Hispanic patients had access to care in a particular health care system, they remained in treatment and received the same level of care as White patients. Uphold and Mkanta (2005) stated that variations in utilization patterns by race and ethnicity have been consistently noted in “people of color” (p. 476). When the HIV epidemic began, as well as in later years, hospitalization rates were disproportionately high for individuals from racial minority groups (Uphold & Mkanta, 2005). People of color had longer lengths of hospital stays, more emergency department visits, and were less likely to use outpatient health services and home health care (Uphold & Mkanta, 2005).

In a study of the California Bridge Project, Molitor et al. (2006) found that race/ethnicity was the only significant factor related to linkages in medical care ($X^2 = 9.52, p = 0.009$). In this study, 325 clients met the criteria of self-reporting no prior history of HIV medical services, with almost 75% of the clients (29% African American and 45% Latinos) being “people of color” (Molitor et al., 2006, p. 456). Whites were less likely than Latinos or African Americans to have documented medical care after receiving interventional contact by peer-based staff that could link them to services. After contact from the outreach workers, African Americans were 3 times more likely than Whites to receive medical care (adjusted OR = 3.69, 95% CI 1.63–8.37, $p = 0.002$).

Age, Gender, and Race. In 2009, the estimated rate of new HIV infections among African American men was 6.5 times higher than that of White men; for African American women, the incidence rate was 15 times that of White women (CDC, 2011b). African-American men accounted for 70% of the estimated new infections among African Americans (CDC, 2011b). More new HIV infections occurred among young African American men aged 13–29 as a result of having sex with other men than of any other age range and racial group (CDC, 2011b). In 2009, African American women accounted for 30% of the estimated new infections among African Americans (CDC, 2011b). Jacobs (2008) found a relationship among HIV-risk behaviors among older African American women and lower educational levels, lower condom use self-efficacy, and less comfort when communicating with their partners about sex. African American women were twice as likely as White women to report nonuse of HAART (Lillie-Blanton et al., 2010).

Substance Use. In 2009, injection drug users accounted for 9% of the newly diagnosed cases of HIV, and African American represented the greatest number of infections by injection drug users compared to Whites at 2,140 and 1,290, respectively (CDC, 2011a). Sixteen percent of AIDS cases among older adults consist of injection drug users (USDHHS, 2009). Bradford (2007) completed a study on the use of outreach persons to reach HIV persons who are out of care. The participants were predominantly racial ethnic minorities (58%), and 46.2% had used illicit drugs or engaged in binge drinking within 30 days prior to the start of the study.

The HIV Surveillance Report (CDC, 2010b) stated, “In 2004, in response to an Institute of Medicine Report, the Centers for Disease Control and Prevention implemented the Medical Monitoring Project (MMP), a nationally representative, population-based surveillance system to assess clinical and behavioral outcomes among HIV-infected persons” (p. 5). These data are used to provide nationally representative estimates of clinical behavioral indicators among persons infected with HIV and receiving care in the U.S and to identify gaps in services. From January 2006 – August 2007, data were collected on patients in care during 2005. The results showed that 52% of respondents (468/899) reported using alcohol or noninjection drugs (illegal drugs not used for medical purposes), and 72% had used marijuana. Twenty-four percent of the participants stated that they had smoked or snorted cocaine, and 24% had used crack (CDC, HIV Surveillance Report, 2010b).

Giordano et al. (2005) completed a study of newly admitted HIV patients at a county clinic for uninsured persons. Twenty-five percent of the sample admitted to currently using alcohol, and 13% were found to be injection drug users. Of the illicit drug

users, 20% were current users and 17% were past users. The findings indicated that difficulty in establishing care was independently associated with a history of injection drug use. On the whole, the results from this study suggested that once patients entered care, substance use was a major barrier to remaining in care. Giordano et al. (2005) found when conducting multivariate analysis that past drug use was more predictive of difficulty establishing care than was current drug use. Injection drug users were more likely to use the emergency department and inpatient services and were less likely than other patients to obtain outpatient services, except for services related to mental health care (Sohler et al., 2007; Uphold & Mkanta, 2005). A greater percentage of injection drug users were also more likely to be without medical care for 6–12 months or longer than non-injection drug users (Anthony et al., 2007; Molitor et al., 2006).

Mental Illness. Depression and mental illness have been shown to be widespread conditions in the HIV/AIDS population (Beer et al., 2009; Bradford, 2007; Lopez et al., 2009; Knowlton et al., 2010). These factors can significantly affect resource use (Knowlton et al., 2010; Uphold & Mkanta, 2005). Moreover, patients with high depression symptoms and poor mental health status are more likely to miss health care appointments (Uphold & Mkanta, 2005). Pillai et al. (2009) analyzed self-reported surveys of HIV + women in New York City and found that approximately 47% ($n = 28$) of the 60 women in their study reported receiving mental health services within the last six months.

The diagnosis of depression was identified as the second-leading factor, after infections, associated with hospitalizations among HIV patients (Uphold & Mkanta, 2005). Symptoms related to depression can interfere with a person's motivation to seek

care and to maintain regular clinician visits (Uphold & Mkanta, 2005). If appropriate mental health treatments are undertaken, costs of health care services for persons with HIV/AIDS can be significantly reduced.

Stigma. Individuals living with HIV/AIDS face stigma as a result of their condition (CDC, 2010c). HIV/AIDS is viewed more negatively than many other physical health problems or mental illnesses. The stigma faced by PLWHA is both pervasive and multifaceted (Rao, Pryor, Gaddist, & Mayer, 2008), and it can affect those simply being tested for HIV/AIDS as well as those being diagnosed with the disease. Self-stigma is linked to lowered self-esteem and self-efficacy, depression, anxiety, and hopelessness (Rao et al., 2008). Kinsler, Wong, Sayles, Davis, and Cunningham (2007) completed a prospective study to evaluate the relationship between perceived stigma from a health care provider and access to care. Perceived stigma is defined as an individual's anticipated fear of society's negative attitudes and the potential discrimination that may be experienced because the individual has HIV (Kinsler et al., 2007).

The sample included 223 hard-to-reach underserved HIV-infected individuals. A face-to-face structured questionnaire was administered to a study sample that was 80% male, 46% African American, 40% Latino and 8% White; 61% were between the ages of 35 and 49 years of age. Findings at baseline indicated that approximately 25% of the participants reported perceived stigma by the health care provider, particularly in the following areas: the health care provider had been uncomfortable with them (20%); preferred to avoid them (19%), or refused them service (19%). At the 6-month follow-up, 19% of respondents reported perceived stigma in one of the four areas examined. At the one-month and six-month follow-up, approximately 57% reported less access to care

or the ability to get care when needed and find conveniently located medical care facilities. When completing the bivariate analysis, perceived stigma from a health care provider was significantly associated with low levels of access to care at baseline, bivariate analysis unadjusted OR=3.29; 95% CI [1.55, 7.01] at baseline. This relationship was not statistically significant at the six-month follow-up, but those reporting perceived stigma from a health care provider also reported lower levels of access to care. With the multivariate analysis, perceived stigma was significantly associated with low level of access to care at baseline, adjusted OR= 3.29, 95% CI [1.55, 7.01] and at the 6-month follow-up, adjusted OR=2.85; 95% CI [1.06-7.65].

Rao et al. (2008) conducted a study to explore cross-cultural differences in HIV stigma. The authors examined ethnic/racial differences in responses to items on the HIV stigma scale. This instrument assesses the level of perceived and experienced stigmatization of PLWHA. Study participants were recruited from AIDS Service Organizations (ASO), Ryan White Title II/III clinics in South Carolina, and Department of Public Health clinics in Iowa. The race/ethnicity composition included 224 Black non-Hispanics and 317 White non-Hispanics. Sixty-seven percent were men and 33% were women.

All participants completed the HIV stigma scale. The results indicated that Black participants did not feel more stigmatized than White participants, but rather experienced stigma differently. For example, items that were more relevant to Black respondents' senses of stigmatization reflected concern about discrimination by others or being morally judged. Items that were more relevant to White respondents' senses of stigmatization reflected concern about keeping their status a secret and fears of

interpersonal rejection. It was suggested that maybe “Black PLWHA were more familiar to concepts of discrimination and had a higher probability than the Whites of indicating greater stigmatization on items that described experiences in which they felt morally judged or discriminated against” (Rao et al., 2008, p. 271).

The researchers believed that the findings provided preliminary evidence about the notion that PLWHA with different cultural backgrounds experience different types of HIV stigma. Black participants were more likely to endorse certain items while White participants were more likely to endorse other items. However, when the items scores were summed to obtain the subscale scores, the racial/ethnic differences cancelled each other out thus making it less likely that significant mean differences would be found across groups at the subscale level (Rao et al., 2008).

When PLWHA face stigmatization, the need to overcome or decrease barriers to care is essential (Katz et al., 2001; Rao et al., 2008; Wong, Cunningham et al., 2004). Persons facing HIV stigma may not get tested for HIV in a timely manner; have lower self-esteem; experience depression, anxiety, or hopelessness; and may have poor antiretroviral compliance (Rao et al., 2008; Zukoski & Thorburn, 2009). Bradford et al. (2007) stated that persons with HIV who experience barriers to care access also may have increased health disparities related to co-occurring mental and substance abuse disorders. Barriers include a lack of knowledge about how to access necessary service needs, resulting in patients receiving fragmented services; pay for care; obtain convenient locations and times for appointments; and develop a level of trust in the health care system and health care providers. Bradford et al. (2007) stated, “The ability to manage multiple interactions may be impacted by distrust of the health care system due to

negative personal experiences, reports from others or ineffective patient-provider communications” (p. S-49).

Bradford et al. (2007) conducted a study to look at the effectiveness of outreach interventions to engage and retain underserved persons with HIV in stable, primary medical care. The study examined whether efforts to reduce barriers to care improved health outcomes in the study population. The authors assessed interventions designed to improve engagement and retention at baseline by studying structural, financial, and personal barriers at 6 months and at 12 months of persons with HIV who were not fully engaged in HIV primary medical care or were at risk of falling out of care. Participants were predominantly male (77%), Black (44%), and Hispanic (23%), and 31% had less than a high school education. Summary variables for total worry, concern, and stigma were combined to determine whether an individual experienced any barriers related to stigma. At baseline, 437 individuals were enrolled in the study. Stigma was measured as a personal barrier to receiving care by the participant answering questions related to eight health beliefs and eight HIV-related worries or concerns about seeking care. The presence of this variable (stigma) was correlated with participants’ level of engagement in care and was consistently associated with HIV interruptions in continuity of care by PLWHA (Bradford, 2007). These variables (total worry, concern, and stigma) were reduced by one third at 12 months from the baseline.

Enabling factors. Enabling factors are community and personal resources that help individuals utilize health services. These factors that are most relevant for the person living with HIV/AIDS are insurance status and social support.

Insurance Status. Having insurance is a reasonable indicator that is expected to affect success in receiving care (Anthony et al., 2007). In a study by Giordano et al. (2005), more than 90% of the clinic patients were covered by Ryan White CARE Act funds, which meant that at least 90% of the patients did not have insurance. Uphold and Mkanta (2005) indicated that insurance status was found to be one of the strongest factors associated with utilization patterns among patients with HIV infection. Individuals with health insurance (public or private) had higher utilization of outpatient services, received more HIV-related treatments, and obtained more care for HIV-related symptoms; they also used the emergency room less often than uninsured persons (Anthony et al., 2007; Laurencin, Christensen, & Taylor, 2008; Uphold & Mkanta, 2005).

Social Support. A good support system may motivate patients to take personal responsibility for maintaining their level of health by accessing and using health care services appropriately (Fattal et al., 2005, Uphold & Mkanta, 2005). Pillai et al. (2009) completed a study of HIV + women in New York City and implemented strategies to achieve entry into and retention in medical care by incorporating integrated care facilities and case management services. Sixty HIV+ women responded to questions on a self-administered survey that assessed the effectiveness of case management and supportive services in New York City. Sixty-six percent ($n = 39$) of the women identified themselves as Black, and the mean age of the women was 46.81 years. Participants were asked five questions using a Likert scale ranging from strongly disagree to strongly agree to determine their access to HIV care. The findings indicated that individuals who lived alone self-reported lower scores with access to care ($t(57) = 2.05, p < 0.05$). More

specifically, those who lived with others reported a score of 20.47 (SD =2.92) to those women living alone indicated a score of 18.86 (SD = 3.10).

Several findings from research studies indicated that persons who had social support (spouse, significant other, or family members) were more likely to take their antiretroviral medications and keep outpatient medical appointments (Cote, Godin, Garcia, Gagnon, & Rouleau, 2008; Mosack & Petroll, 2009). A study was conducted by Mosack and Petroll (2009) to investigate the patient perspective on informal caregiver involvement in treatment planning. Forty-two African Americans who were HIV+ and indicated that they were in a committed romantic relationship were recruited. In this qualitative study, a semi-structured interview was conducted and recorded. One initial question was related to having someone present during one or more medical appointments when the participant received the HIV+ diagnosis.

Based on this probe and the response of the participant, additional questions were asked related to the decision to include or not to include others in services needed, satisfaction with others' involvement, relationship of the other persons to the treatment planning process, and if the inclusion of others impacted adherence to care. The findings indicated that 73% of the individuals had "no one" physically present with them at the time of diagnosis. And of those who were present at the time of diagnosis, seven were partners or ex-partners, four were friends, and three were family members. Even after the diagnosis, few had others present with them at the time of their initial treatment planning appointment. The participants identified pros and cons related to involving others.

The participants identified more advantages than disadvantages to the involvement of other individuals in their treatment. Themes related to the benefits of

having someone present were improved information communication, development of stronger relationships, improved family health, and enhanced treatment outcomes (Mosack & Petroll, 2009). Successful treatment outcomes were identified as improved treatment plan compliance, such as consistent appointment attendance and medication adherence. Some of the disadvantages of involving others were that family members would sometimes dominate the conversation due to anger (e.g., related to the mode of transmission). This type of communication negatively affected patient-provider communication. The participants' emotional response to others' involvement included being less honest or less willing to discuss certain topics (Mosack & Petroll, 2009).

Health Behavior

Andersen (1995) identified health behavior in his model as personal health choices and use of health services. Health behavior is defined as the individual's personal health practices that influence the use of health services and health outcomes (Andersen, 2008). This behavior can be related to triggers or circumstances that result in an interpersonal crisis, interruptions of valued social activities, and demands that medical care is needed by significant others (Anderson, 1973). Health practices include such factors as the amount of time that lapses before an individual links with care when diagnosed with HIV/AIDS, adherence to scheduled medical appointments, retention in care, and use of prescribed medications (Ulett et al., 2009). Factors that can interfere with health behaviors relate to the individual's personal choices (e.g., use of illicit drugs and/or alcohol and diagnosis of mental illness).

Lillie-Blanton et al. (2010) conducted the Women's Interagency HIV study (WIHS) to examine racial/ethnic differences in the use of HAART to determine whether

these differences were attributable to substance use or insurance status. Approximately 58% of the sample was African American, 28% was Hispanic, and 14% was White. Twenty-nine percent of the women who were clinically eligible for HAART reported not using it. The relative risk indicated that African Americans and Hispanic women had a higher proportion of nonuse of HAART than White women. A higher proportion of nonuse was also identified among uninsured women versus women with Medicaid insurance (Lillie-Blanton et al., 2010). The unadjusted odds ratios of not using HAART were higher for African American women (OR=2.06; 95% CI [1.39, 3.07]), and even after adjustment for potential cofounders, nonuse of HAART for African Americans was twice that of White women.

Cunningham et al. (2006) conducted a comparison study between the HIV Costs and Services Utilization Study (HCSUS), which was a nationally representative study of persons with HIV infections who were receiving care from a HIV provider to a Targeted HIV Outreach and Intervention Initiative (Outreach) study of hard to reach underserved persons. The researchers wanted to examine factors related to low ambulatory utilization. The outreach study had more Blacks (59% versus 32%, $p = 0.0001$) and patients with an annual income of less than \$10,000 (75% versus 45%, $p = 0.0001$). Also, the outreach sample included more patients who were unemployed, lacked stable housing and insurance, and used illicit drugs (58% versus 47%, $p = 0.05$). Participants in the outreach sample were more likely to have fewer than two ambulatory visits (26% vs. 16%, $p < 0.0001$), more likely to have emergency room visits or hospitalizations in the prior 6 months, and less likely to take antiretroviral medications (82% vs. 58%, $p < 0.0001$).

Health Care Environment

In the Behavioral Model of Health Services Utilization, the environment is comprised of system factors and provider factors. System factors include referrals or treatment by mental health and substance abuse service providers and case management. Provider factors are those related to demographics and characteristics of providers, trust of patients of providers, and patients' perception of their level of engagement with providers.

System Factors. Anthony et al. (2007) studied the system factor related to case management and completed a study about the importance of using case management services in facilitating recently diagnosed persons with HIV who needed linkages of care with a HIV primary care provider. At the time of this study, little was known about variables that facilitated or hindered entry into clinical care (Anthony et al., 2007). The sample involved 270 HIV-positive persons enrolled in the Antiretroviral Treatment Access Study (ARTAS) study. ARTAS was a randomized controlled trial comparing active case management involvement with clients who were HIV-positive with passive referral in linking persons to care. Seventy-four percent of the persons had not seen an HIV care provider before enrolling, and 26% had only one prior visit. Results suggested that persons who received the case management intervention were 4 times as likely to have seen a provider as compared to those who received a passive referral. Thus, encounters with a case manager appeared to significantly improve linkage to HIV care among disadvantaged persons.

The study by Anthony et al. (2007) was limited because the sample was not randomly selected and statistically constructed to represent a specific population.

Moreover, participants were recruited from providers that predominantly serviced individuals of a lower socioeconomic status. Another limitation was the study's six-month time frame; consequently, results could have been different had the utilization time frame been longer. The authors cautioned readers not to generalize findings to a larger population because the persons in this study were recently diagnosed with HIV and had little or no prior experience using HIV-related health services.

Bradford et al. (2007) performed a study on using a patient navigation model to assess the effectiveness of outreach interventions to engage and retain underserved populations living with HIV to assess the continuity of care. According to Bradford et al. (2007), "Navigators assist HIV patients to make better use of available resources, develop effective communication with providers, sustain HIV care over time, and navigate the complexities of multidisciplinary treatment" (p. S-30). This study focused on four conceptual areas: (a) structural barriers (availability, organization, and transportation); (b) use of services (program contacts); (c) mediators (having a case manager and engagement with health care provider), and (d) outcomes (health insurance status, viral load, health-related quality of life, and receipt of appropriate HIV primary care).

In particular, the study examined the effectiveness of interventions used by nonclinical persons who acted as client navigators to assist persons with HIV achieve access to care. Criteria to be a navigator were knowledge of local HIV and related resources, bachelor's degree in a social science discipline or health care, and experience working with diverse communities associated with HIV. The interventions of coaching, skills-building, and education were used by the navigators to improve the desired outcome of increased engagement and retention in HIV health care. Participants in this

study were at-risk persons with HIV who were not fully engaged with HIV primary medical care or were at risk for discontinuing care.

A longitudinal study design was used and involved a face-to-face interview and medical record review to facilitate data collection. Linkage to case management was one of the mediating factors. At baseline, 437 persons who were not connected to care with HIV primary care provider were enrolled. Seventy-seven percent were male, 44% were Black, and 23% were Hispanic. Approximately one third of the participants had less than a high school education, 40% did not live in their own homes, 20% did not have health insurance, and 40% did not have case managers. Eighty-eight percent (88%) had received some HIV primary medical care in the previous six months; 37% of those enrolled reported at least one missed HIV primary medical care visit in the past 6 months prior to study enrollment; and approximately two thirds of those enrolled had an optimal number of two or more visits in the six months prior to enrollment.

Results of this study suggested that the intervention by navigators helped to decrease the financial, structural, and personal barriers of PLWHA. With the use of navigation-like interventions, almost 75% of those enrolled received appointment and other service coordination interventions. Health care referrals were received by 30% and 40% were accompanied to their health care appointments. With the use of the navigators' interventions, relationship building was constant during the study period, and this was reported for 86% of all contacts made. All barriers decreased significantly at 6 months and 12 months as compared to baseline measures. Both mediator variables (linkage to case managers and engagement with health care providers) showed significant improvement at 6 and 12 months. At baseline, 58% had a case manager. At 6 and 12

months, 72% had case managers and a significant improvement was seen in the participants' engagement with the health care provider. There was an increase in the proportion of patients who had two or more visits in the previous six months from 64% at baseline to 87% at 6 months and 79% at 12 months. Both of these changes were statistically significant at $p < 0.001$.

In another study examining the effectiveness of the Behavioral Model of Health Services Utilization to explain system factors, Katz et al. (2001) assessed the effect of case managers on unmet needs for supportive services among HIV-infected persons. The use of case management has been promoted as a strategy to decrease unmet needs for supportive services, improve utilization of outpatient services, and avoid costs related to hospitalizations of HIV-infected persons (Katz et al., 2001). In this study, unmet needs for supportive services included unemployment; not receiving public assistance; a lack of insurance; unstable housing; and a need for home health care, mental health counseling, and substance abuse services (Katz et al., 2001).

The study was conducted by using baseline and follow-up interviews of HIV-infected adults who were randomly selected for the HIV Cost and Services Utilization Study, a national multistage probability sample. Katz et al. (2001) used obtained their final sample in three stages: first, they randomly selected the metropolitan statistical area; next, they randomly selected the providers known to care for patients with HIV in urban and rural areas; and lastly, they randomly selected anonymous patients from lists of eligible patients. Baseline interviews were completed for 2,864 of the 4,042 (76%) selected patients. The follow-up interview with 69% of the surviving sampled group was on the average of 243 days later. At baseline, participants were asked if they had a case

manager, and if the response was affirmative, then they were asked the number of times they had seen or spoken with their case manager in the previous six months.

Katz et al. (2001) reported that case managers appeared to keep persons from becoming unstably housed. Although case managers do not write prescriptions for medications, it was noted that case managers helped patients to overcome their fears about treatment, helped them to adhere to medication regimens, and acted as their advocate to get physicians to initiate treatment on their behalf. Findings of this study suggested that sustained contact with a case manager (identified a case manager at baseline and had a case manager at follow-up) was strongly associated with increased utilization of medications ($p \leq 0.05$) and decreased unmet needs ($p \leq 0.05$). Having sustained case management services was associated with preventing patients from becoming unstably housed (OR, 0.58, CI 95%, 0.40 to 0.82, $n = 2248$), but not with a lack of insurance (OR, 1.28, CI 95%, 0.75 to 2.17, $n = 1895$). Sustained contact with a case manager showed an increase in the use of the emergency room ($p \leq 0.05$). Therefore, the authors did not find improved utilization of medical care with patients who had contact with case managers and this was attributed to HIV case managers focused on linking clients to services rather than serving as a “gate-keeper.”

Provider factors. Prior studies have indicated that engagement with a health care provider is important to medical treatment and quality of care (Atlas, Grant, Ferris, Chang, & Berry, 2009; Beach, Keruly & Moore, 2006; Bradford et al., 2007; Fattal et al., 2005; Knowlton et al., 2010; Lima et al., 2009). Not attending to health care needs through engagement with a health care provider becomes an extra burden to the individual, community, and society.

The Knowlton et al. (2010) sample consisted of individuals who had been in the Intervention for Seropositive Injectors-Research and Evaluation (INSPIRE) study. The INSPIRE study was a secondary HIVF-prevention intervention study conducted between 2001 and 2005 in Baltimore, Miami, New York City, and San Francisco. The purpose of Knowlton et al. (2010) study was to identify multilevel factors associated with HAART use among active injection drug users. One of those factors was related to the engagement of IDUs with the primary care provider. The authors stated that studying this relationship was important because many injection drug users are individuals from disadvantaged, minority populations who may be distrustful of the medical system (Knowlton et al., 2010).

Eligibility criteria of the participants were a self-report of being HIV+, injecting drugs in the prior year, and having had sex someone of the opposite gender sex within the prior three months. The other two factors were individual-level variables (baseline CD4 lymphocyte count, current illicit drug use, depressive symptoms) and structural-level variables (current enrollment in a methadone maintenance treatment, health insurance, or unstable housing). Assessments were given to the HIV+ injection drug user via an audio computer-assisted self-interview before the first intervention session. Knowlton et al. (2010) identified baseline assessment or six-month assessment predictors of HAART use and then six months later (i.e., at the 6- or 12-month assessment) with the full sample and among a subsample that reported HIV primary care in the prior two years.

The sample consisted of 1,161 participants, and 62% were male, 75% were current drug users, and 75% were non-Hispanic Blacks. Prior to the intervention session, the majority of the participants had stable housing (93%) and approximately 36% had

reported four or more HIV primary health care visits in the six months. The authors incorporated the Engagement with Health Care Provider tool as one of their measurement tools with a subset of the sample who reported any HIV primary health care visit in the two years prior to the baseline interview.

The study findings indicated that when the HIV+ injection drug user had frequent visits and better engagement with the HIV primary care provider, the individual had higher odds of taking HAART. Participants with better engagement with their primary care provider also had 45% higher odds of using HAART six months later as compared with those with low provider engagement (AOR, 1.45, 95% CI [1.09-1.93]). An analysis indicated that HAART use by injection drug users was independently predicated by patient-provider engagement and more HIV primary care visits.

Atlas et al. (2009) performed a study to see if quality of care was better when patients and physicians were connected than when connectedness was not present. Connectedness was described as the closeness of the relationship between a patient and an individual physician on the basis of a model predicting how likely a physician is to identify the patient as his patient. A primary care physician is usually considered to be the first source for individuals to receive prevention and chronic illness care. The authors stated that remaining in care is both the patient's and the physician's responsibility (Atlas et al., 2009). The study design was a population-based cohort study. Data were obtained from an electronic record base of patients who received most of their primary care from a specific physician or from different physicians in a specific practice.

Several of the patient's characteristics in this study were similar to the ones in the predisposing, enabling, and environmental factors used in the Health Services Utilization

Model by Ulett et al. (2009). Patient characteristics included date of birth, sex, race or ethnicity, number of outpatient visits in the previous years, and insurance status. Provider variables included age, sex, practice location, and years since medical school graduation. All patients were identified who attended the 13 practices with a total of 181 primary care physicians from January 2003 to December 2005. The total number of patients seen out of 994,431 visits was 169,024. Only 155,190 patients were eligible for the study. The provider had to designate which patients they considered to be “my patient” (Atlas et al., 2009). Of the 155,190 eligible patients, approximately 60% were connected to a specific physician (physician-connected); 34% were connected to a practice; and 6% were not connected to a specific physician or practice. Physician-connected patients were significantly older and more likely to be women, non-Hispanic Whites, and persons insured by a managed care plan or Medicare. Practice-connected or unconnected patients were more likely to be uninsured or insured by Medicaid ($p < 0.001$). The study showed that patients who were connected to a community health center were less likely to be connected to a physician than patients seen by private physicians (56.8% and 60.4% respectively, $p < 0.001$). Another finding was that racial and ethnic minorities were less likely to be physician-connected and less likely to receive guideline-adherent care. It was stated that “patients without a close relationship with a specific physician are less likely to complete recommended testing for preventive and chronic illness care” (Atlas et al., 2009, p. 331).

An earlier study by Bakken et al. (2000) examined the relationship between perception of engagement with the health care provider and demographic characteristics of the HIV-infected individual, their health status, and adherence to a therapeutic regimen

by persons with HIV/AIDS. For the purpose of the study, a tool was developed to measure the perception of engagement of the HIV/AIDS client with the provider of care since one had not been developed to meet their conceptualization. Bakken et al. (2000) stated the following:

Engagement with health care provider was conceptualized as including dimension of access to health care provider, information sharing, involvement of client in decision making, and self-care activities, respect and support of the provider for the client's choices, and management of client concerns (p. 190).

Findings revealed that 79% of the care was provided by primary care physicians, while nurse practitioners provided 16% of the care, and physician assistants provided 4%. The mean score for the Engagement with Health Care Provider survey was 18.6 (SD, 7.9) with a possible range of 13–52. A lower score was considered indicative of engagement with the health care provider. Participants who had current or past injection drug use had higher scores, suggesting less engagement with a health care provider. No significant differences were found between the engagement of the participant with the provider in regard to age (authors did not reflect statistic), gender ($p = 0.467$), or ethnicity ($p = 0.0374$).

Care by specialists. Care for persons with HIV/AIDS is provided by primary care physicians as well as by physician specialists. The question is whether access to treatment and care services is best achieved through the use of a primary care physician or a physician specialist. One study found that patients cared for by the most experienced providers used more antiretroviral medications and were twice as likely to receive primary care visits in a given month compared to patients of less experienced physicians.

On the other hand, patients with HIV/AIDS who did not have a regular primary care provider used costly emergency rooms more often (Uphold & Mkanta, 2005).

Wong, Asch, Andersen, Hays, and Shapiro (2004) conducted a study to examine the racial and ethnic differences of patients with HIV/AIDS and their preferences for initial care by specialists using a survey with three hypothetical situations administered to patients waiting to be seen by their care provider in an academic general internal medicine practice. The survey asked the respondents if given a choice to see their primary care physician or a specialist who would they choose based on the hypothetical situations presented to them. The study consisted of 646 participants: 48% were Caucasians, 29% were African-American, 9% were Latino, and 9% were Asian. Variables such as educational level, annual family income, and Medicaid insurance were used to determine whether a particular ethnic group was advantaged or disadvantaged. The findings of this study suggested that Asians were the most advantaged racial group, while African Americans and Latinos were the most disadvantaged with respect to access to specialist care. In addition, African Americans were most likely to have multiple chronic conditions and were one of the two ethnic groups (the other being Latinos) who had the greatest worry about illness ($p < 0.0001$).

When adjusting for other covariates in the study, African Americans were still less likely to prefer a specialist as a provider than Caucasians. The authors stated that a potential reason why African Americans had less preference for specialists was they may have more negative views about physicians, less experience with specialists, or different health views, but the reasons are unclear in the study (Atlas et al., 2009, p. 618). Pillai et al. (2009) found that in 2006, African American and Hispanic women accounted for

almost 90% of women living with HIV/AIDS in New York City. The purpose of the study was to examine access to and satisfaction with health care by HIV+ women who received case management and supportive services at AIDS service organizations (ASOs) using key demographic variables and a service delivery model.

Surveys were administered using audio computer-assisted self-interview (CASI) software to 60 HIV+ women. Based on the survey, 65% of the women identified themselves as Black, while 28% identified themselves as Latina. Various services were included by the ASOs, including medical services for various specialists, such as dentists, optometrists, group therapists, mental health service providers, chiropractors, substance abuse treatment providers, and nutritionists. Access to care was analyzed in relationship to demographics, type of health care, and service delivery model. Pillai et al. (2009) reported that access to care for these women was not related to race, age, years HIV+, or income, but to the presence of social support versus living alone. However, there was a significant difference in reported access to medical specialists for non-HIV+ care needs ($F_1 = 4.064, p = 0.05$) based on the service delivery model. HIV+ women reported having greater access to medical specialist services in a non-medical model ($n = 35$) than those who reported received services from medical model agency ($n = 25$). These differences did not appear when individuals were compared by race, thus supporting the finding that the differences were related to the service delivery model. Nonmedical model agencies provided services and referred patients to outside resources for their medical ancillary needs; whereas, medical models were ASOs that provided medical care, case management, and other supportive services at the same location.

Trust of health care provider. Whetten et al. (2006) examined the association among trust of health care providers, government and health services use, and outcomes. As part of the Coping with HIV/AIDS in the Southeast study, researchers interviewed 611 HIV positive individuals who received care at one of eight infectious disease clinics in five states in the Deep South: North Carolina, South Carolina, Georgia, Alabama, and Louisiana (Whetten et al., 2006). These states and clinics were selected because AIDS cases increased 29% from 2000 to 2002 in these locations as compared to an increase of 9% across the other southern states and less than 1% across the remainder of the country (Whetten et al., 2006). Approximately 70% of the participants were African American. Trust of care providers was one of the areas included as part of the attitudinal assessment.

Trust in care providers was associated with increased HIV-related outpatient clinic visits, increased use of antiretroviral medications, and improved reported physical and mental health. Differences in trust were statistically significant ($p < 0.001$) depending upon the minority group. Ten percent of those interviewed reported not trusting their provider or clinic to provide them with the best care possible. The student *t*-test showed that minorities who distrusted their provider were less likely to visit their provider more than three times ($p < 0.5$). Nonminority persons were 1.13 times more likely to visit their provider more than three times.

Regression analysis demonstrated that trust in one's provider was significantly associated with five of the six outcome variables (clinic visits, fewer emergency room visits, greater likelihood of taking antiretroviral medications, better mental health and better physical health). The study showed the importance of patients trusting their provider or clinic, which led to an increase in adherence and number of service visits.

The findings by Whetten et al. (2006) are similar to findings by Beach et al. (2006) and Bradford et al. (2007). Both of those studies attested to the role of effective patient-provider communication to build trust and the need of patient self-centeredness. Patient-centeredness was defined as the understanding that each patient is a unique individual (Beach et al., 2006).

Summary of Literature Review

This chapter presented the evolution of The Behavioral Model of Health Services Utilization developed by Andersen (1968). The model and has evolved over time and has been expounded upon by other researchers (Andersen 1968; Andersen, 1995; Andersen, 2008; Aday & Andersen, 1974; Andersen et al., 1983; Phillips et al., 1998; Ulett et al., 2009). In 2009, Ulett et al. adapted the model to include implications of timely linkage and early retention in HIV care to health services use. The review of literature revealed that the key components of Andersen's original model have not varied significantly despite the many studies conducted to test and expand the model. These factors provide the foundation for this current study. The Behavioral Model of Health Services Utilization is used in this research study because of its explanatory value and its ability to provide researchers with data on adherence to outpatient follow-up (Andersen, 1995).

The focus of the literature review also was to analyze research conducted on health services utilization with special attention given to predisposing, enabling, and environmental factors that may explain nonadherence to medical outpatient follow-up of patients with HIV/AIDS. Results of the review of literature suggest that the Behavioral Model of Health Services Utilization is a well-developed and frequently used theoretical framework for examining health care utilization patterns of persons with HIV/AIDS

(Andersen, 2008; Uphold & Mkanta, 2005). Researchers using the model make basic assumptions related to the predisposition to use services, ability to obtain services, and the medical need for services (Andersen, 2008; Uphold & Mkanta, 2005). Predisposing factors (demographic and social structure characteristics) are considered fixed and are perceived to effect service use directly and indirectly through the enabling and need variables (Aday & Andersen, 1974; Andersen et al., 1983; Andersen, 2008; Uphold & Mkanta, 2005).

Enabling characteristics focus on the individual's ability to pay for care and the level of community support individuals are able to receive when seeking and obtaining care (Aday & Andersen, 1974; Andersen et al., 1983; Andersen, 2008; Uphold & Mkanta, 2005). The review of literature also confirmed an increase in HIV/AIDS in the African American community (Alleyne & Wodarski, 2009; CDC, 2011b; Jacobs, 2008; Lopez et al., 2009). Alleyne and Wodarski (2010) declared, "In 2000, HIV/AIDS was among the top three causes of death for African American men ages 25 through 54 years and among the top four causes of death for African American women ages 25 through 54 years" (p. 144). Lopez et al. (2009) stated the influence of gender, race, and ethnicity on health services outcomes for people with HIV is an area of interest and may explain disparities in health care.

According to the literature, maneuvering the health care system is not easy for persons who have a chronic illness and requires coordinated care from many specialties. Persons with HIV/AIDS have been identified as experiencing various types of barriers, such as other illnesses, lack of social support, alcoholism, illicit drug use, and mental illness (Cunningham et al., 2006; Cunningham et al., 2007). Utilizing a multidisciplinary

team focus to care for patients with HIV/AIDS is important due to the diverse characteristics and needs of persons diagnosed with HIV/AIDS (Cunningham et al., 2007). Over the years, researchers have discovered those who have HIV/AIDS who have someone to advocate for them have beneficial outcomes (Bradford et al., 2007; Katz et al., 2001). When the necessary level of services is not obtained by persons with HIV/AIDS, patient health and quality of life is affected. Therefore, the ability of persons with HIV/AIDS to receive assistance in navigating the health care system may be a factor in increasing adherence to their scheduled appointment.

When patients were asked about whom they would prefer to see initially, most persons stated they wanted to see their primary care physician. In the study by Wong et al. (2004), African Americans were much less likely to prefer initial care by a specialist than Whites. The researchers also suggested that African Americans considered the use of a specialist when there was more certainty about what tests and treatments were needed and the patient had seen a specialist in the previous year. Once this is understood by the patient, the specialist becomes the provider of choice for the initial visit (Wong, Asch, et al., 2004). African-American patients with HIV/AIDS may be more willing to remain engaged in treatment if they understand more about the treatments and services that could be obtained from a specialist.

Furthermore, it is important patients with HIV/AIDS have an open relationship with their provider, a sense of trust, and a level of comfort that leads to open communication. Fostering a positive relationship may enhance patient adherence to a prescribed medical regimen and prevent missing scheduled appointments (Atlas et al., 2009; Robinson, Callister, Berry, & Dearing, 2008; Saha, Jacobs, Moore, & Beach,

2010). According to Robinson et al. (2008), “Research has shown that patient-centered interactions promote adherence and lead to improved health outcomes” (p. 600). Patient-centered care was defined as patient involvement in care and the individualization of patient care (Robinson et al., 2008). HIV and AIDS are chronic conditions, and therefore, health-promotion activities can occur only if the patient is receiving care. In conclusion, little research was found that used a mixed methodology approach to examine factors that explained the inability of patients diagnosed with HIV/AIDS to adhere to outpatient medical appointments. Also, little research was found on adherence by African Americans utilizing services specifically provided by providers who specialize in the care of this population. Based on the literature reviewed and the patient population served, permission was granted to modify the conceptual framework of Ulett et al. (2009).

Patient characteristics, health care environmental factors (system and provider factors), and health behaviors were examined by the researcher in this study. Predisposing factors were age, race/ ethnicity, gender, income, education, medical characteristics (CD4 and viral load), mental illness, substance abuse, and stigma. Enabling factors were insurance status and social support in relationship to marital status. Systems factors were use of mental health services and substance abuse services and case management. Provider factors were related to the engagement of the patient and provider. The variables examined were provider specialty, ethnicity/race, and number of patient visits during a two-year time frame. All of these factors were examined in relationship to the health behavior of nonadherence to outpatient medical follow-up in an infectious disease clinic specializing in treating persons with HIV/AIDS. The need to study the

impact of these factors on African Americans with HIV/AIDs is supported by the dearth of literature identifying predictors for why African Americans have lower levels of adherence to scheduled outpatient appointments and treatment once they have initiated care in an outpatient infectious disease clinic.

CHAPTER 3

METHODOLOGY

In this chapter, the methodology used to conduct this research study will be reviewed. The focus will be on the identification of factors that may explain non-adherence in outpatient medical treatments at an infectious disease clinic by African Americans diagnosed with HIV/AIDS. The chapter presents research design, setting, subjects, and methods. The protection of human rights, and statistical analysis will also be discussed.

Research Design

This study was an explanatory, theory-testing , correlational research design that used a mixed methods approach. The quantitative data was supplemented by collecting additional data via open-ended questions. The study design was intended to test the Behavioral Model of Health Services Utilization by describing, correlating, and explaining behaviors associated with non-adherence to HIV/AIDS outpatient treatments. Nieswiadomy (2008) explains the use of this design: “In descriptive studies, phenomena are described or the relationship between variables is examined” (p. 145). In correlational studies, the researcher examines the strength of association between variables by determining how changes in one variable are associated with changes in another variable (Nieswiadomy, 2008).

The Behavioral Model of Health Services Utilization is one of the most frequently used frameworks for examining patient utilization of health care services (Phillips et al., 1998). This framework uses an open systems approach to integrate a range of individual, environmental, and provider-related variables associated with decisions to seek care

(Phillips et al., 1998). In the operation of the model, the explanatory methods of studying the variables that facilitate the measurement and the complex relationships are examined (Phillips et al., 1998). According to Phillips et al. (1998), this explanatory method contributes to a better explanation of the role of the contextual variable. The model depicts feedback loops so that individual characteristics can be examined in relationship to their influence on utilization and vice versa (Phillips et al., 1998).

The study used retrospective medical record reviews and surveys completed with subjects who attended the outpatient infectious disease clinic. A retrospective chart review was used to identify factors related to subjects' non-adherence to outpatient infectious disease appointment. Surveys were distributed by the researcher through face-to-face encounters and completed in the researcher's presence. The surveys were used to explore specific barriers, obstacles, and difficulties that the subject experienced related to adhering to their scheduled medical appointments.

A mixed methods approach allowed for the examination of variables related to adherence and nonadherence from two perspectives (historical data and concurrent data). According to Mkanta and Uphold (2006), medical record chart reviews are considered one of the best methods of obtaining valid information on utilization patterns. An EMR provides a historical perspective of the linkage to care and retention of persons who were scheduled to receive care within the designated time frame selected for this study. Since data about environmental factors related to provider or system factors that impact adherence could not be discerned from the EMR, the researcher wanted to obtain concurrent data from subjects who come to the clinic due to not keeping a scheduled appointment.

Setting

The outpatient infectious disease clinic that served as the setting for this study is located in the southeastern Virginia. The infectious disease clinic is part of an educational institution which provides an array of health care, educational, and research services to the local community, state, and nation. Other infectious diseases clinics operate within this same institution. However, the HIV/AIDS infectious disease clinic is designated for persons needing specialized services due to a confirmed diagnosis of HIV/AIDS. This infectious disease clinic was chosen due to its location in an urban area, its affiliation with a teaching institution, and its specialization of services provided to a unique group of subjects who are diagnosed with HIV/AIDS. The clinic is staffed with a medical director specializing in infectious diseases, other physicians, physician assistants, nurse practitioners, and registered nurses who have received additional training, certification and education to aid in providing quality services to this specialized population. The clinic also has the ability to refer subjects to necessary service providers, such case managers, social workers, and mental health counselors. Another reason that this clinic was selected was due to its ability to provide services to subjects who are uninsured or have inadequate financial resources to pay for required services; thus, some subjects are eligible for and receive Ryan White subsidies.

Sample

The sample in this study included all subjects who initiated care at an outpatient infectious disease clinic between August 2007 and January 2007; and were diagnosed with HIV/AIDS. All subjects during those time frame medical records were accessed

because a data base of only African Americans who attended the outpatient infectious disease clinic during that period could not be provided.

Study Subjects' Retrospective Electronic Medical Record Review. The subjects for the retrospective medical record review were persons affiliated with an outpatient infectious disease clinic in southeastern Virginia. Subjects included individuals who were diagnosed with HIV/AIDS between the ages of 18 and 89 years who attended the clinic and initiated care between August 2007 and January 2008. Also, the subjects would have not received care with another provider within six months prior to their initial appointment at the outpatient infectious disease clinic. This delimitation is important in establishing that baseline information is the same for all subjects in the study. The electronic medical record (EMR) was instituted in August 2007 by the medical school with which the clinic is affiliated.

Exclusion criteria for the medical record review were subjects (a) who were seen prior to initiation of the EMR; (b) who were less than 18 years of age or greater than 89 years of age; (c) who previously received outpatient HIV treatment elsewhere within six months of initiating care at this outpatient infectious disease clinic; (d) who missed their appointment due to inpatient hospital admission; and (e) who expired within the two-year period of their first attended visit.

Several demographic variables could not be located in the clinical documentation of the EMR and had to be extracted from other data files. The ethnicity and subjects' marital status were extracted from another spreadsheet that was provided by the office staff. Educational level and amount of income were not recorded in the clinical medical record, nor could it be extracted from other files. The majority of the records did not list

if the subject was employed or unemployed. If employment was documented, it was not consistently stated if the subject was employed part-time or full-time.

Surveys. Subjects were recruited to complete surveys that were administered by the researcher at the “walk-in” clinic between July 31, 2010 and October 31, 2010. These subjects were identified by the office staff as nonadherence with their regularly scheduled medical appointments. Inclusion criteria for the subjects to complete the surveys included (a) ages 18 and older and less than 89 years of age; (b) able to speak and understand English; (c) acknowledged the ability to read English; and (d) able to provide an informed consent, and (e) African American. Exclusion criteria for the subjects to complete the surveys were (a) race other than African American, (b) primary diagnosis other than HIV or AIDS, (c) age less than 18 or older than 89, and (d) unable to speak or understand English. If the subject acknowledged an inability to read English, the information was read to the subject.

Sampling

A nonprobability convenience sampling method was utilized for both the electronic medical review and the completion of the survey tools. Data were collected from the electronic medical record and the information from the surveys resulted in two unlinked data sets. The medical record data were not linked to survey data.

Convenience sampling allowed the researcher to recruit the most available persons as study subjects (Nieswiadomy, 2008; Polit & Beck, 2008). Sampling conducted in this manner for the EMR review increased the likelihood that all ethnic groups who initiated care at this clinic during the designated time frame were represented. Data could provide more descriptive information related to adherence and non-adherence.

The advantage of convenience sampling for this portion of the study was the ability to readily choose available subjects (persons with HIV/AIDS) within the planned time frame for completion of the surveys and to select persons who had not been keeping their scheduled HIV/AIDS appointments. Subjects recruited to complete the surveys were persons who came to the “walk-in” clinic to receive services and were not able to be placed on regularly scheduled appointments because of their past non-adherence in keeping scheduled appointments.

Data Collection

A list of patients who initiated care with the infectious disease clinic during the interested time frames was provided to the researcher from a request made by the researcher to the Medical Director of the infectious disease clinic. All data came from subjects who were or are still in care at the infectious disease clinic. Data were collected from a retrospective review of medical records of subjects establishing primary HIV/AIDS care at the infectious disease clinic from August 2007 to January 2008. The researcher recorded data during the designated time frame, beginning from the patient’s initiation of care and following subjects’ over the duration of a two-year period.

Electronic Medical Record (EMR) Implementation. The TouchWorks™ Electronic Health Record (EHR) from Allscripts was implemented at this research site in the summer of 2007. This EHR was implemented throughout the medical school for use by over 150 physicians in departments ranging from family and internal medicine and medical and surgical specialties to obstetrics and radiation-oncology (EVMS Health Services, 2010). The system installed included the following TouchWorks™ modules: Charge Capture, RxPlus, Scan, Note, Dictate, Order/Results, Forms, and Analytics.

Additionally, the medical school integrated the iHealth™ online personal health record for patients, which is actively promoted on the medical school's website (EHR, 2009).

AllScript TouchWorks™ software “is a modular electronic medical used to automate the most common physician activities including prescribing, dictating, capturing charges, ordering labs and viewing results, providing patient education, and documenting clinical encounters” (Allscripts, 2008). Security to the system is accessed via the Internet network connection. The user has to have a unique login, and then the user creates a unique password. Only authorized persons are granted access to the EHR. Secure records can be viewed at any time from anywhere since AllScript TouchWorks™ is a web-based application. Health care providers can see the notes of each health encounter visit made by the patient even if it was not directly related to their clinic service (e.g., patient with HIV/AIDS who also attends the obstetrics clinic).

A unique login was requested by the Medical Director of the infectious disease clinic of their Information Technology (IT) Department in order for the researcher to access the EMR. After providing required information to the IT department, the researcher received a unique login code. The research nurse educator in the practice provided a training session to the researcher on how to access the required records and how to locate information. IT help was also available to the researcher around-the-clock.

Electronic Medical Record (EMR) Data Collection Tool. A tool (see Appendix E) to facilitate the collection of data from the electronic medical records was developed based on the predisposing, enabling, and environmental factors of the Behavioral Model of Health Services Utilization, as identified through the review of literature. Questions were devised by the researcher after completing a review of the literature of persons with

HIV/AIDS and after discussing the nonattendance with the director of the infectious disease clinic. The Medical Director, nurse practitioner, and research nurse educator in the infectious disease clinic who specialized in the care of persons with HIV/AIDS were asked to review the document for completeness and validity. They were also encouraged to make suggestions as to questions to be added or deleted as well as comment on the overall organization of the tool.

The EMR data collection tool (see Appendix E) was comprised of four sections. The first section contained 11 items designed to collect data related to socio-demographic variables, such as age, gender, ethnicity, highest education level, employment, insurance, marital status, and income. Section two contained four items to facilitate data collection related to treatment for HIV/AIDS, such as CD4 lymphocyte count, HIV Viral Load, and receipt of HAART medication. A third section contained six items for data collection about medical (mental health and substance use) conditions and referrals for additional services (alcohol, substance use, and case management services). The final section contained four items that pertained to the subject's office visits including date, provider and/or specialty, and if documentation existed of written information provided to the subject.

Medical Records Data Collection

Once the researcher accessed the electronic medical record system via the use of an unique identifier, the following procedure was used to gather the data from the electronic medical record of each subject who initiated care at the clinic between August 2007 and January 2008.

1. Entered the subject's medical record number.

2. Collected demographic data
 - a. Year of birth
 - b. Age
 - c. Confirmed that the medical record # matched the subjects name
 - d. Confirmed the current insurance status
3. Selected appointments from a tab. A table was under this tab that had information related to the appointment. The information included if the patient arrived for the appointment, cancelled the appointment, or no show. With each appointment scheduled, the date and the name of the provider that the patient was scheduled to see or did not see due to cancellation or no show was included.
4. Confirmed that the patient was eligible for the study. Ineligible criteria were:
 - a. Deceased
 - b. Over 89 years of age
 - c. Younger than 18 years of age
 - d. Less than 2 years of data from initial date selected for the review of the record

Initial date began August 2007 to January 2008 due to the initiation of the EMR in August 2007.
5. Selected “Encounter “for the first initial date used in the study. In selecting “Encounter” this confirmed important data.
 - a. Confirmed subjects diagnosis of HIV/AIDS
 - b. Confirmed the site for the study, since there were also satellite sites.
 - c. Confirmed other diagnosis related to mental health, substance abuse/use and alcohol abuse/use.

- d. Confirmed insurance status of that initial visit.
- 6. Selected “Notes” tab. This is the tab where providers documented notes when the visit occurred. All of the following information was located under this tab.
 - a. Confirmed that the visit was for HIV/AIDS.
 - b. The subject’s subjective data “what the subject stated the reason of the visit” for the first encounter was used in the study.
 - c. The provider’s objective data for the first encounter used in the study.
 - d. Reviewed the medication list for the initiation of HAART/ARV.
 - e. Reviewed the active problem list.
 - f. Reviewed the review of system (ROS).
 - g. Reviewed the assessment made by the provider.
 - h. Reviewed the plan. This is also where information was obtained if the provider addressed the treatment of mental illness, substance abuse or alcohol treatment (if warranted) from the subject’s subjective information or objective findings from the provider.
- 7. Selected the Tab for CD4 count and Viral Load. Selected the results that were close to the initial date of service.

The records were reviewed in the office of the institution or at the researcher’s home. The length of time to review each record was approximately 30 minutes.

Supplemental Data Collection

Questions that were asked to the subjects on the survey for the open-ended-questions were related to components of the Behavioral Model of Health Services Utilization. Questions were devised by the researcher after completing a review of the

literature of persons with HIV/AIDS and after discussing the nonattendance with the director of the infectious disease clinic. Socio-demographic data were collected including: age, gender, highest education level, employment, insurance, marital status, income, and living situation. Four structured open-ended questions were included to solicit data to identify issues that subject experiences and that may keep the subject from coming to scheduled appointments. Subjects need to attend their appointments in order to receive adequate treatment for their HIV/AIDS; and to have more positive outcomes.

Two questions were designed to elicit responses regarding factors the prevented the subject from adhering to his/her scheduled appointment in the infectious disease clinic (see Appendix F).

1. What barriers/obstacles/difficulties have prevented you from coming to your scheduled outpatient treatment appointments?

2. What measures can this office take to help you come to all of your scheduled appointments?

The third question was designed to identify strategies which can facilitate adherence to prescribed medical regimen and appropriate follow-up care.

3. What else do you believe that you need to keep you in medical care?

The last question was designed to solicit data about perceived HIV/AIDS related stigma.

4. How do you feel that others treat you because you have HIV and/or AIDS?

When conducting a qualitative inquiry, it is essential that trustworthiness be established. Lincoln and Guba (1985) developed criteria for the trustworthiness of qualitative inquiry. The four criteria are credibility, dependability, confirmability, and

transferability. Credibility is the confidence in the truth of the data and interpretations of them. The concept involves carrying out the study in manner that enhanced believability of the findings. Dependability is the stability (reliability) of data over time and over conditions. Lincoln and Guba (1985) believed that credibility cannot occur in the absence of dependability. Confirmability transpires when findings reflect the subjects' voice and not the biases of the investigator. And lastly, transferability is the ability to generalize the data or apply the data to other settings or groups. With the consistency used in the established protocol with subjects answering the questions, it is hoped that credibility, dependability, confirmability, and transferability are established. Face and content validity for the open-ended survey were established by seeking input from experts in HIV/AIDS care, including the medical director of the outpatient infectious disease clinic, nurse practitioners who specialized in chronic diseases and who work with patients with HIV/AIDS, and a nurse educator who worked with patients with HIV/AIDS.

In order for these subjects to re-establish care and keep regularly scheduled appointments at the clinic, the subjects had to demonstrate recommitment by attending at least three consecutive scheduled "walk-in" appointments. It was at one of these visits that the subject completed the two surveys. The researcher arrived 15 minutes before potential research subjects were scheduled to arrive in order to (a) establish which exam room would be utilized for that session, (b) introduce self to providers, and (c) ensure that office staff had an adequate amount of recruitment letters to provide to subjects who met the criteria of the study. Once the office staff determined that the potential subject met the eligibility criteria for study participation, the potential subject was given the recruitment letter and was directed to the location of the researcher.

The researcher introduced herself, and explained the purpose of the research study. Each potential subject was asked if he/she would consider participating in the study. If the potential subject agreed to participate, the researcher engaged the potential subject in the informed consent process; reading the consent form while the potential subject read along from the copy that was provided to him/her. After study related questions and concerns about the study was addressed, the subject signed a copy of the consent and was given a copy to take home.

The researcher then completed the demographic data portion of the survey. Obtaining the demographic information took approximately two to three minutes. Next, the open-ended structured questions on the survey were given to the subject. In the last component of the session, the subject was asked to complete the Engagement with Health Care Provider tool developed by Bakken et al. (2000).

The entire session occurred in an exam room located within the infectious disease clinic. The subject sat in the chair next to a desk, and the researcher sat adjacent to the subject and was at eye level. The researcher was not in the path of the doorway if the subject decided to leave, and the door to the exam room was closed for privacy. Each session lasted approximately 15 to 20 minutes, depending on the subjects speaking to the researcher as he/she responded to the surveys.

Engagement with Health Care Provider Questionnaire Tool. According to Bakken et al. (2000), no existing scale measured all the dimensions of engagement that were conceptualized in their study; therefore they developed, “The Engagement with Health Care Provider” tool (see Appendix G). The tool was developed to examine the relationships between perception of engagement with health care providers, demographic

characteristics, health status, and adherence to therapeutic regimen in persons with HIV/AIDS (Bakken et al., 2000). Validity assures the degree to which an instrument measures the variable of interest and captures the meaning of the construct in which the investigator is interested (Nieswiadomy, 2008). Bakken et al. (2000) stated, “The scale was submitted to a principal component factor analysis with Varimax rotation” (p. 191). A one-factor solution emerged with an Eigenvalue of 8.6 and 66.5% of the variance explained (Bakken et al., 2000). Scales that involve summing item scores are almost always evaluated for their internal consistency, and the Cronbach’s alpha is the most widely used method for measuring internal consistency (Nieswiadomy, 2008). The Cronbach’s alpha reliability estimate was 0.96% for this tool. A correlation coefficient above .70 is considered satisfactory (Nieswiadomy, 2008).

The tool is divided into two sections. In the first section, the subject is asked to select the health care provider who was seen on a regular basis and then complete the remaining questions with this provider in mind. The providers that could be selected were doctor, nurse, nurse practitioner, physician assistant, and other with a line for the subject to place a response. These selections also corresponded to the providers who were employees in the outpatient infectious disease clinic in this study. The next section had 13 items in which the subject had to rate the degree to which each of the statements about the provider was true as experienced by the patient. The 13 items were listed as “My health care provider listens to me,” “cares about me,” “answers my questions,” “spends enough time with me,” “involves me in decisions,” “respects my choices,” “deals with my problems,” “engages me in my care,” “is helpful to me,” “respects me,” “supports my decision,” and “sees me when I ask,” and “provides me with information.”

These 13 items were rated on a 4-point Likert-type response scale with responses defined as “1=always”, “2=usually”, “3=sometimes”, and “4=never” or not applicable. Appendix H show permission to use the tool was granted by the author.

Protection of Human Subjects

Initially, the researcher met with the medical director of the infectious disease clinic to discuss the feasibility of performing the research with the infectious disease clinic population. Several meetings were held with the medical director, and it was agreed that the researcher could proceed forward to obtain necessary Internal Review Board (IRB) approvals from Old Dominion University (ODU) and Eastern Virginia Medical School (EVMS). Applications to conduct this study were submitted to the Institutional Review Boards (IRB) at ODU and EVMS. Approval to proceed with the research was obtained from both review boards.

Consents. A request was submitted to the EVMS IRB Committee for waiver of subject’s consent to participate and a waiver of authorization for Protected Health Information (PHI) for the electronic medical record. The applications for waivers of consent and PHI were needed due to the transient nature of the patient population. It was anticipated that many subjects were no longer in the program at this clinic, lost to follow-up, relocated, or deceased if their disease progressed. For this reason, it was impractical to seek consent from each subject whose electronic medical record was reviewed.

The application for waiver of authorization for the use of PHI was requested since the researcher would have access to the name, medical record number, year of birth, dates of service and other identifiers recorded for each patient. The case was made that this research could not be conducted in a practical manner without access to and use of the

PHI, given that de-identified data sets for this patient population were not available.

Names and medical record numbers were needed to keep track of data collection progress and to identify subjects in the case there were missing data. Dates of services were also needed to follow disease progression and to determine intervals between visits.

Subjects' participation in the open-ended survey portion of this study was voluntary. Informed written consent was obtained from each subject by the researcher after the subject was informed of the purpose of the research study and agreed to participate (see Appendix J and Appendix K). Each subject was advised that he/she had the opportunity to withdraw from the study at any time and that their responses would remain anonymous. Anonymity was achieved in that there were no attempts to associate any responses with specific subjects. The subjects were assured of confidentiality of their responses since the data would be reported in aggregate form. Likewise, subjects were assured that any subsequent publications will not identify individual subjects or study setting. The researcher was available throughout the period of data collection and analysis to answer inquiries or questions about the study, data collection procedure, or results reporting.

Data Management

Health Insurance Portability and Accountability Act (HIPAA) guidelines related to handling of PHI were followed (HIPAA Guide, 2007). All information obtained during this study was kept private to the extent required by law. All information gathered was reported as aggregate data. All hard copies of data collection forms were kept in a locked file at the researchers' office. Once the data were transferred from the tools to an Excel spread sheet, the Excel spread sheet was password protected on the investigator's

personal computer. Direct identifiers such as name and medical record number were recorded on separate sheets and stored in a separate folder in the same area as the locked file cabinet.

Statistical Data Analysis

These analyses were performed for the whole sample of all race/ethnicities and then also only for those of African American race/ethnicity. Analyses were performed with Stata/SE, version 11. Variables of interest within the Behavioral Model of Health Services Utilization were initially examined with descriptive statistics. For continuous variables in the EMR, descriptive statistics included the mean and standard deviation values and for the categorical variable frequencies and percentages were used. Inferential statistics for the continuous variables were conducted with analyses of variance (ANOVA). When the continuous variables had a skewed distribution, the Mann-Whitney test was used instead. Categorical variables were computed with either the Pearson chi-square test or the Fisher's exact test (when cell size was less than 5).

From the above results, any variables that were significant from these inferential analyses with "nonadherence" (whether continuous or categorical), those variables were considered as an independent variable in a univariate binary logistic regression analysis with the outcome variable being nonadherence.

In the structured open-ended question survey, the demographic characteristics were analyzed using descriptive statistics with mean and standard deviation for the continuous variables and frequency and percentages for the categorical variables. The responses from subjects to the four open-ended questions were written as provided by the subject to the questions asked. The Engagement with Health Care Provider questionnaire

was scored by adding together all the subjects' scores from the Likert scale for each of the 13 items and then finding the mean and the standard deviation for each item.

Variables

Variables were selected *a priori* based on review of the literature. Key variables from the adaptation of the Behavioral Model of Health Services Utilization used by Ulett et al. (2009) in their study of retention in HIV care were used. Variables analyzed included predisposing factors of sociodemographics (age, race/ethnicity, and gender) and medical history (substance use, alcohol use, HAART medication initiation, medication time, and mental disorders) as shown in Table 2.

Age was measured as a continuous variable, and the age used was the subject's age at the time of initiating care. Medication time was a continuous variable and defined as the number of days that lapsed between the date medication was ordered and the date of initiating treatment. Several predisposing variables were dropped in the analysis due to a lack of retrievable data from the EMR. The two variables were education level and income level. Employment variables (employed and employment status) were not used in the analysis due to a lack of data in the EMR. Enabling factors included marital status and insurance status. Marital status was a categorical variable. Insurance was also a categorical variable (see Table 3).

Table 2

Predisposing Variables Category and Level of Measurement.

Variable	Category	Level of Measurement	Statistical Analysis
Age	Age at time of study (continuous)	Ratio	M/SD *ANOVA
Gender	Male; Female	Nominal	Frequency / % **Pearson Chi-Square
Race/Ethnicity	White African American Latino/Hispanic Other	Nominal	Frequency / % **Pearson Chi-Square
Education	Less than High School High School Graduate Some College College Graduate or >	Ordinal	Frequency / % **Pearson Chi-Square
Employed	Yes; No	Nominal	Frequency / % **Pearson Chi-Square
Medication Time	Days (continuous)	Ratio	M/SD *ANOVA
Substance Use	None Past Current	Ordinal	Frequency / % **Pearson Chi-Square
Alcohol Use	None Past Current	Ordinal	Frequency / % ** Pearson Chi-Square
Mental Disorder	Yes; No	Nominal	Frequency / % **Pearson Chi-Square
HAART HAART HARRT	Never ordered—No Not applicable—reason provided as to why it was not ordered Yes—Med ordered	Nominal	Frequency / % **Pearson Chi-Square

M = Mean; SD = Standard Deviation; % = Percentage; *Mann Whitney U if distribution skewed

** Fisher's Exact Test if less than 5 in the cell

Table 3

Enabling Variables Category and Level of Measurement.

Variable	Category	Level of Measurement	Statistical Analysis
Annual Income			
< \$10,000	Yes; No	Nominal	Frequency / % *Pearson Chi-Square
Marital Status	Married Never Married Separated/divorced/ Widow	Nominal	Frequency / % * Pearson Chi-Square
Insurance	Private Medicaid Medicare Ryan White	Nominal	Frequency / % * Pearson Chi-Square

= Percentage

* Fisher's Exact Test if less than 5 in cell

Environmental factors included health care provider(s) and system variables (see Table 4). Health care provider variables included race/ethnicity, specialty, and number of providers. Specialty was operationalized as type of provider seen by the study subject and was a categorical variable. The categories were physician, nurse practitioner, physician assistant, and office nurse. This category was only applicable in the analysis if the subject had seen only one provider during their visit.

Table 4

Environmental Category and Level of Measurement.

Variable	Category	Level of Measurement	Statistical Analysis
Specialty	Physician Nurse Practitioner Physician Assistant Office Nurse	Nominal	Frequency / % *Pearson Chi-Square
Number of Providers	1 provider 2 provider >2 providers	Nominal	Frequency / % *Pearson-chi square
Referral for Mental Health Services	Yes; No	Nominal	Frequency / % *Pearson Chi-Square
Referral for Illicit Drug Use	Yes; No	Nominal	Frequency / % *Pearson Chi-Square
Referral to Case Management Services	Yes; No	Nominal	Frequency / % *Pearson Chi-Square
Referral for Alcohol Use	Yes; No	Nominal	Frequency / % *Pearson/Chi-Square

M= Mean; SD= Standard Deviation

% = Percentage;

* Fisher's Exact Test if less than 5 in the cell

System variables included referral for use of mental health services and substance use/abuse services. Illicit drug use treatment recommendation (s) and alcohol treatment recommendation (s) were coded as "0" for no referrals given (and the person had a problem documented); "1" (s) for not applicable/not relevant (the person did not have a documented issue or it was a past issue and not current); and "2" when a referral was given due to current use of illicit drug or alcohol use. Any variable statistically significant with $p < 0.05$ from the univariate analysis was entered into a multivariate binary logistic regression analysis for the categorical outcome of nonadherence.

Outcome Variables

Retention in care was categorized as adherence or non-adherence in care based on keeping the scheduled appointments. It was measured as the number of 6-month blocks during which at least one clinic visit was attended over the 2-year period following an initial attended visit, with a range of 1 to 4 visits. For instance, one six month time frame was considered as 1 visit until 4 visits were accounted for within the 2-year period. The presence of any missed appointment for any of the four 6-month follow-up visits categorized an individual as non-adherence. An individual attending all 4 six-month follow-up visits was categorized as adherence. The dependent variable used for all analysis was the outcome variable of adherence (coded as 0) versus nonadherence (coded as 1).

Research Questions

1. Which predisposing factors (age, race, gender, education, medical history (visit times, visit scheduled, time for initiating HAART medication, substance use/abuse, alcohol use, and mental disorders] among African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia will best explain nonadherence to outpatient medical follow-up appointments?
2. Which enabling factors (support by family/significant others, and insurance) among African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia will best explain nonadherence to outpatient medical follow-up appointments?
3. Which environmental factors (provider: race/ethnicity, gender, and specialty; system: referral or use of mental health services, substance abuse services, and

case management services) among African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia will best explain nonadherence to outpatient medical follow-up appointments?

4. For African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia is there a difference in predisposing, enabling, and environmental factors for those who adhere to their outpatient medical follow-up appointments and those who do not adhere to their outpatient medical follow-up appointments?
5. For African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia, what are relevant factors related to engagement with the provider in understanding nonadherence to outpatient medical follow-up appointments?
6. Which health care environmental and personal factors are barriers to medical appointments for African Americans with HIV/AIDS?

SUMMARY

This chapter described the methodology that will be used to conduct this research using an explanatory theory-testing correlational research design that used a mixed methods approach. This research design will be used to test the Behavioral Model of Health Services Utilization by describing, correlating and thus explaining behaviors associated with nonadherence to outpatient medical follow-up by African Americans with HIV/AIDS. A retrospective medical record review will be conducted along with supplemental data obtained from surveys of subjects who have been nonadherent to their regularly scheduled appointments and come to the “walk-in” clinic to receive services.

CHAPTER 4

RESULTS

This chapter will focus on the retrospective EMR review of African American subjects. Supplemental data collected from the Engagement with the Health Care Provider Tool and open-ended questionnaire will also be reviewed. Demographics related to African Americans from the EMR and the supplemental data are presented.

In the EMR, 65% (n = 82) of the sample of (N=125) was African American. Fifty-five percent of the African Americans were males and 45 % were females. Ages ranged from 19 years to 64 years of age. The mean age was 38.7 (SD =11.8). Of the 62 African American subjects whose marital status was recorded, approximately 87% were divorced. All subjects had some form of insurance, and the majority had Ryan White insurance (42.5%). Table 5 shows the demographics of African American subjects.

Table 5

African Americans' Demographics of the Electronic Medical Record.

	N	Percentage (%)
Gender	82	
Male		54.9
Females		45.1
Marital Status	62	
Single, never married		11.3
Married		1.6
Divorced		87.1
Insurance	80	
Private Commercial		21.3
Medicaid		22.5
Medicare		13.7
Ryan White		42.5

Demographics of the survey subjects ($N = 20$) are presented in Table 6. Fifty-five percent of the sample was male and 45% female. Ages ranged from 25 –57 years, and the mean age was 38.5 ($SD = 9.30$). Seventy-five percent were unemployed and had an income of less than \$10,000. All of the subjects had some form of insurance. Forty percent had less than a high school education.

Research Question 1

Which predisposing factors (age, race, gender, education, medical history [initial treatment date, substance use, alcohol use, HAART medication initiation, mental disorders] and laboratory data [baseline CD4 and plasma HIV viral load]) among African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia will best explain nonadherence to outpatient medical follow-up appointments?

Predisposing factors. The variables used were age, visits scheduled, CD4 count at baseline, and medication time. Descriptive statistics were used to calculate means and standard deviation values (see Table 7). Inferential statistical analysis, using as appropriate either the analysis of variance (ANOVA) for non-skewed variables or the Mann-Whitney test for skewed variables were calculated for the continuous variables of age, visits scheduled, CD4 count at baseline, visit time and medication time for all 82 EMRs, only visits scheduled was significant ($p = < 0.001$) as a predisposing factor of adherence versus nonadherence with attendance to outpatient appointments. Of the 82 persons who had scheduled visits, 12 persons ($M = 2.8$; $SD = 1.29$) were adherent with the schedule of attending at least one visit every six months and 70 persons were nonadherent ($M = 11.7$; $SD = 5.19$) as depicted in Table 6.

Table 6

Demographics of Survey Subjects.

Demographics (N = 20)	N	%
Predisposing Characteristics		
Gender		
Male	11	55
Female	9	45
Age (Mean 38.5; SD 9.30)		
18-30	4	20
31-40	9	45
41-50	5	25
51-60	2	10
Employment Status		
Unemployed	15	75
Employed	5	25
Full-time (n =4)		
Part-time (n=1)		
Enabling Resources		
Insurance		
Private/Commercial	4	20
Medicaid	6	30
Medicare	4	20
Ryan White	6	30
Income		
< \$10,000	15	75
> \$10,000	5	25
Education		
Less than HS	8	40
Graduate HS	6	30
Some College	6	30
Marital Status		
Single, never married	11	55
Married	4	20
No longer married	5	25
Living Situation		
Homeless	1	5
Relative/ Friend	7	35
Home/apartment/owned/rented	12	60

In examining the categorical variables of adherence versus nonadherence with non- attendance, there were various sample sizes gathered from the 82 EMRs due to missing data. Missing data occurred with illicit drug use (N=58), alcohol use (N=57), and viral load (N=73). The categorical variables used for the predisposing factors were gender, mental illness, illicit drug use, alcohol use, HAART medication initiation, and viral load at baseline. Descriptive statistics used for the categorical variables were frequencies and percentages (see Table 7). Inferential statistical analysis, using as appropriate either the Pearson chi-square tests or the Fisher's exact test was used for these categorical variables for predisposing factors.

Table 7

Predisposing Factors (Continuous Variables)—Adherence Versus Nonadherence with Attendance.

Characteristic	Adherence Number M (SD)	Nonadherence Number M (SD)	<i>p</i> Value
Age (N = 82)	12 37.5 (13.45)	70 38.9 (11.64)	0.71
Visits Scheduled (N = 82)	12 2.8 (1.29)	70 11.7(5.19)	< 0.001*
CD4 count (baseline) (N = 79)	10 291.2 (192.56)	69 396.9 (308.21)	0.30
Visit Time (N = 82)	12 40.7 (62.51)	70 19.5 (44.63)	0.47
Medication Time (N = 82)	12 2.3 (7.79)	70 5.0 (18.34)	0.74

Note: M = Mean, SD = standard deviation

A significant statistical finding ($p = .02$) was related to HAART medication initiated ($N = 82$) as depicted in Table 8. Those subjects who were adherent with scheduled visits had greater percentages of "no." The provider did not order HAART medication nor state the reason why HAART medication was not initiated versus when applied "not applicable," and the provider wrote the reason why the HAART medication was not initiated.

Table 8

Predisposing Factors (Categorical Variables)—Adherence Versus Nonadherence with Attendance.

Characteristic	Adherence Number Percentage (N)	Nonadherence Number Percentage (N)	<i>p</i> Value
Gender (N = 82)	12	70	0.32
Female	58.3 (7)	42.9 (30)	
Male	41.7 (5)	57.1 (40)	
Mental Illness (N = 82)	12	70	0.17
None	58.3 (7)	77.1 (54)	
Present	41.7 (5)	22.9 (16)	
Illicit Drug Use (N = 58)	9	49	0.55
None	55.6 (5)	67.4 (33)	
Past	33.3 (3)	14.3 (7)	
Current	11.1 (1)	18.4 (9)	
Alcohol Use (N = 57)	9	48	0.42
None	88.9 (8)	88.3 (40)	
Past	11.1 (1)	4.2 (2)	
Current	0.0 (0)	12.5 (6)	
HAART Medication			
Initiated (N = 82)	12	70	0.02*
No	41.7 (5)	12.9 (9)	
Not applicable	0.0 (0)	24.3 (17)	
Yes	58.3 (7)	62.9 (44)	
Viral Load (baseline)			
N = 73	9	64	1.00
Detected	77.8 (7)	73.4 (47)	
Undetected	22.2 (2)	26.6 (17)	

Research Question 2

Which enabling factors (support by family/significant others, and insurance) among African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia will best explain nonadherence to outpatient medical follow-up appointments?

Enabling factors. The two variables analyzed were insurance and marital status. Descriptive statistics used for the categorical variables were frequencies and percentages (see Table 9). Inferential statistical analysis, using the Fisher's exact test, for these categorical variables found that both insurance and marital status had p values that were not significant for the comparisons among African Americans with HIV/AIDS adherence and nonadherence to outpatient medical follow-up appointments as shown in Table 8.

Table 9

Enabling Factors—Adherence Versus Nonadherence with Attendance.

Characteristic	Adherence Number Percentage (N)	Nonadherence Number Percentage (N)	p Value
Insurance (N = 80)	12	68	0.55
Private/Commercial	16.7 (2)	22.1 (15)	
Medicaid	8.3 (1)	25.0 (17)	
Medicare	16.7 (2)	13.2 (9)	
Ryan White	58.3 (7)	39.7 (27)	
Marital Status (N = 60)	8	54	1.00
No	100.0 (8)	98.15 (53)	
Yes	0.0 (0)	1.85 (1)	

Research Question 3

Which environmental factors (provider: race/ethnicity, gender, and specialty; system: referral or use of mental health services, substance abuse services and case management services) among African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia will best explain nonadherence to outpatient medical follow-up appointments?

Health care environmental factors. The health care environmental factors examined were provider and system factors. Provider factors included race/ethnicity, specialty, and the number of providers seen by the patient for the visits scheduled. Systems' factors included referrals for mental health, illicit drug use, and/or alcohol treatment. Descriptive statistics used for the categorical variables were frequencies and percentages (see Tables 10 and 11). Inferential statistical analysis using the Fisher's exact test, for these categorical variable found no statistical significance for any of these variables as shown in Tables 10 and 11. The EMR documentation did not provide consistent data related to case management services referral; therefore, this variable could not be analyzed.

Table 10

Health Care Environmental Factors (Provider)—Adherence Versus Nonadherence with Attendance.

Characteristic	Adherence Number Percentage (N)	Nonadherence Number Percentage (N)	<i>p</i> Value
N = 82			
Provider Ethnicity	12	70	0.14
White	16.7 (2)		15.7 (11)
Black	58.33 (7)		31.4 (22)
Other or >1 Provider	25.0 (3)	52.9 (37)	
Provider Type	12	70	0.08
Physician	16.7 (2)	8.6 (6)	
Nurse Practitioner	66.7 (8)	42.9 (30)	
> 1 Provider	16.7 (2)	48.6 (34)	
Provider Number	12	70	0.09
1 Provider	83.3 (10)	50.0 (35)	
2 Providers	16.7 (2)	28.6 (20)	
> 2 Providers	0.0 (0)	21.4 (15)	

Table 11

Health Care Environmental Factors (System-Referral Services)—Adherence Versus Nonadherence with Attendance.

Characteristic	Adherence Number Percentage (N)	Nonadherence Number Percentage (N)	<i>p</i> Value
Mental Illness Treatment (N=82)			
No	12	70	0.18
Not applicable	8.3 (1)	1.4 (1)	
Yes	58.33 (7)	75.7 (53)	
Yes	33.3 (4)	22.9 (16)	
Illicit Drug Treatment (N=58)			
No	9	49	0.41
Not applicable	11.1 (1)	4.1 (2)	
Yes	88.9 (8)	83.7 (41)	
Yes	0.0 (0)	12.2 (6)	
Alcohol Treatment (N=57)			
No	9	48	1.00
Not applicable	0.0 (0)	4.2 (2)	
Yes	100.0 (9)	87.5 (42)	
Yes	0.0 (0)	8.3 (4)	

Research Question 4

For African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia, is there a difference in predisposing, enabling, and environment factors for those who adhere to their outpatient appointments follow-up appointments and those who do not adhere to their outpatient medical follow-up appointments?

Logistic regression analysis was used to predict the odds ratio of dichotomous variables to determine the independent effect of significant factors in the bivariate analysis. Simultaneously, these factors were entered into a multivariate analytical model. Of the continuous variables, only visits scheduled were significant. Of the categorical variables, only HAART medication initiation was significant. These variables were placed in the logistic regression model. In the univariate logistic regression model, only visits scheduled was statistically significant. With an increase in visits scheduled, the patient is 5 times more likely to be nonadherent as shown in Table 12.

Table 12

Logistic Regression of Significant Factors to Nonadherence (Univariate Analysis).

Variables	OR	Univariate 95% CI	p Value
Visits Scheduled (N = 82)	5.0	[1.52, 16.15]	0.008*
HAART Medication Initiated (N = 65)			
No (reference)	1.00		
Not applicable	empty**		
Yes	3.5	[0.90, 13.51]	0.70

Note. OR = odds ratio, CI = confidence interval

**Every single subject was nonadherent

Results of Surveys

The researcher received demographic data on each subject referred to the study, and then collected data from 20 subjects via the structured open-ended questionnaire (see Appendix F) and Engagement with Health Care Provider Tool (see Appendix G). Subjects invited to complete the surveys were persons identified by the clinical staff as being nonadherence to their regular scheduled appointments because they had missed three or more appointments.

Research Question 5

For African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia, what are relevant factors related to engagement with the provider for understanding nonadherence to outpatient medical follow-up appointments?

Data analysis. Thirty-five percent of the study subjects reported seeing the doctor, and 60% reported seeing the nurse practitioner on a regular basis. The other subject (10%) reported seeing the physician assistant on a regular basis. The seven subjects, who rated the 13 items for the physician, rated all 13 items as “always.” Differences were seen between the 12 subjects in rating the nurse practitioner. The lowest scores on the tool were for indicator “sees me when I ask” ($M = 1.65$; $SD = 1.03$); and “deals with my problems” ($M = 1.40$; $SD = .94$). The subjects based their response on the provider that they saw on a regular basis. This tool used a Likert measure (1 = always; 2 = usually; 3 = sometimes; and 4 = never) for the subject to rate 13 statements related to engagement activities with their provider. Table 13 outlines the descriptive statistics (mean and standard deviation) for all subjects’ responses on the 13 items of the Engagement with Health Care Provider tool.

Table 13

Descriptive Statistics Engagement with Health Care Provider.

1= Always	2 = Usually	3 = Sometimes	4 = Never
	M	SD	
My health care provider: (N = 20)			
Listens to me	1.10	0.45	
Cares about me	1.25	0.64	
Answers my questions	1.00	0.00	
Spends enough time with me	1.00	0.00	
Involves me in decisions	1.10	0.31	
Respects my choices	1.20	0.70	
Deals with my problems	1.40	0.94	
Engages me in my care	1.00	0.00	
Is helpful to me	1.05	0.22	
Respects me	1.05	0.22	
Supports my decisions	1.30	0.66	
Sees me when I ask	1.65	1.03	
Provides me with information	1.25	0.72	

Note. M = mean; SD = Standard Deviation

Research Question 6

Which health care environmental and personal factors are barriers to medical care appointments for African Americans with HIV/AIDS?

These data were collected via four structured open-ended questions. The responses provided from the subjects' supplements the data of the quantitative study. The goal of obtaining this information was to describe the barriers and the facilitators that may have an impact on nonadherence to outpatient infectious disease appointments as described by subjects who came to the "walk-in" clinic to be seen. Below are subjects' responses to each sub-question to gather information for research question six.

Question 1: What barriers/obstacles/difficulties have prevented you from coming to your scheduled medical outpatient treatment appointments? Participants' written responses included the following:

- Work, school, transportation
- Denial, work a lot
- Scheduling conflicts. Starts feeling good- I don't need to go. If I can't make appointment during last visit because schedule does not go out that far. I get home and don't call back.
- Emergencies. Process of moving; transition of moving; single parent. Lack of support; lack of reminder due to appointment may be so far in advance; areas- don't want to be seen; sign says what it is far and some people don't want to be seen walking in or out of the office.
- Frustration; appointment conflict.
- Coming to clinic about 2 years. Sometimes do not have money or transportation. I drank my pain away. Don't want to be bothered with it. I have a lot of stuff going on. Family about to be evicted because I have a criminal record. Do not like how medications make me feel.
- Out of town.
- Rough night. Not enough sleep. Forget appointment. They used to send letter and remind of appointments. Have received phone calls, not letters.
- Seeing someone different every time. Keep changing meds. Call Medicaid cab too late.
- Transportation worked out but do not show up.
- Kids, daughter just started school. Husband shares care .He is military and it is difficult to get to appointment.
- I have to reschedule when I couldn't meet my doctor on the original day.

- Everyday stuff-dealing with life. Work. Slip my mind. Stuff going on at home. Dealing with relationships.
- Personal matters.
- 4 subjects just wrote the word transportation

Question 2: What measures can this office take to help you come to all of your scheduled appointments? Participants' written responses included the following:

- Nothing.
- No they're fine. They call and remind me. They are why I came to Virginia.
- Reminders the day before.
- Reminders. When staff rescheduled appointment with doctor, didn't call and I did not know doctor was not coming in. Better communication concerning appointments. Need to break down information related to medication.
- I know if I don't come, I will be buried beside my wife.
- I like the doctors. I hate when they change my doctor.
- Letter and phone calls as reminders. If doctor schedule is not in, I am to give a call in two weeks. I forget to call back. The receptionist does not have schedule of doctor.
- Stop switching doctor and meds. I just want one doctor.
- Office does call and make sure that I keep my appointment.
- They pretty much are doing everything. They could call home and keep me updated on my scheduled appointment.

- Staff is friendly, open and available. I can call with any question- always willing to answer my questions.
- I'm not sure. They make sure they send phone calls to follow-up appointment. They always seem pleasant.
- They are friendly.
- If they can give some kind of transportation if you can't make it.
- They already provide an appointment card. They call two days before your appointment time.
- Nothing else, they do call and they give you a card.
- Any help with transportation.
- People are sweet in here. They show you a lot of respect. Can't nobody do this for me. I have to do this for me.

Question 3: What else do you believe that you need to keep you in medical care?

Participants' written responses included the following:

- I want to get better and stay healthy. Up to date with any changes in my health.
- Will to live.
- Knowing that I need the quality of life. Center in the community to educate people.
- Know what is going on with my body.
- I come back when I get sick.
- To keep me alive, I have to come.
- The doctor is a good person.

- Lab values. Want to keep one doctor. Switching doctor and they do not get to know you.
- To get to know more about my medications.
- I have to take these medications for life, so I need to come.
- I care about myself. I want to see what's going on and make sure that I am on the right track.
- I want to achieve my goals in life.
- Knowing that I need to see the doctor to keep up with my health and HIV.
- To make sure the status of my HIV is in control and that I have my prescription for me to take my medications every day.
- Staff that is concerned about my condition.
- If I don't get the tests, then I won't know how I am doing.
- Concerned about my health.

Question 4: How do you feel that others treat you because you have HIV and/or AIDS? Participants' written responses included the following:

- Without education, people feel like they are getting coodies. More protective of themselves. Some things are not the same in that we do not do things we use to do together.
- Few people know and they have HIV as well.
- Only a few people know. Close friends have been supportive. In the past they treated us like we had leprosy.

- Look at you in a certain way. Nurse acted like I was contagious and if she would touch me that she would catch something. People in office have nose in the air and shows lack of concern.
- I am not worried about it. I accept it and my family accepts it.
- Isolated from me. One friend when found out that I had HIV, the friend did not talk to me. Have secluded self.
- I don't tell people. Have had a problem with a pastor. I wanted to get baptized with my daughter and the pastor would not allow it. Pastors don't know or they don't want to know.
- People do not treat me differently.
- Provider act they don't want to touch you. Make you feel nasty. Do not make you feel welcome.
- When you say HIV, people treat you differently. I don't date. When disclose self to people, they back away from you. I really do not trust other people.
- They acted differently and asking me a whole bunch of questions. Did not want to be around me.
- They don't know. They treat you with stigma.
- Changed now. Over the past 15 to 16 years it has been different. When I first found out, people treated me like I had a plague.
- People who knows my status treat me as if was HIV negative.
- No change.
- They don't treat me no different than a normal person.

- No one really knows that I am. Not even my sons. I don't hang with no one.
- Honestly, I don't think no one cares. They do not put off on me.
- Same, don't nobody knows.

Summary of Research Question Analyses

Research question 1. Which predisposing factors (age, race, gender, education, medical history [initial treatment date, substance use, alcohol use, HAART medication initiation, and mental disorders] and laboratory data [baseline CD4 and plasma HIV viral load]) among African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia will best explain nonadherence to outpatient medical follow-up appointments?

Results. Statistically significant findings were related to visits scheduled and medications ordered. Those who were nonadherent had a significantly greater number of visits scheduled. With HAART medication ordered, those subjects who were adherent had greater percentages of “no” (for never ordered) responses than those who were not adherent. Those who were nonadherent were more likely to have “not applicable/not relevant.”

Research question 2. Which enabling factors (support by family/significant others, and insurance) among African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia will best explain nonadherence to outpatient medical follow-up appointments?

Results. The enabling variables were not significant factors related to adherence versus nonadherence with attendance at the outpatient infectious disease clinic.

Research question 3. Which environmental factors (provider: race/ethnicity, gender, and specialty; system: referral or use of mental health services, substance abuse services, and case management services) among African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia will best explain nonadherence to outpatient medical follow-up appointments?

Results. No significant findings were found related to environmental factors.

Research question 4. For African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia, is there a difference in predisposing, enabling, and environmental factors for those who adhere to their outpatient medical follow-up appointments and those who do not adhere to their outpatient medical follow-up appointments?

Results. The two factors were visit scheduled and medications ordered. These factors that were found to be significant in the bivariate analysis were analyzed with logistic regression for univariate analysis. A statistically significant finding was related to visits scheduled. Subjects who had increased visits were more likely to be nonadherent to their outpatient follow-up appointment. Therefore, the number of visits scheduled remained a factor in nonadherence to outpatient medical follow-up appointments and in identifying the predisposing, enabling, and environmental factors of those who adhere or do not adhere to their outpatient appointment.

Research question 5. For African Americans with HIV/AIDS at an outpatient infectious disease clinic in southeastern Virginia, what are relevant factors related to engagement

with the provider for understanding nonadherence to outpatient medical follow-up appointments?

Results. Twenty subjects who visited the “walk-in” clinic to re-establish their regularly scheduled appointment completed the Engagement with Health Care Provider tool. The mean score was between 1.00 and 1.65, and the standard deviation was between 0.00 and 1.03. Overall, the subjects rated their engagement with their provider in a positive manner.

Research question 6. Which health care environmental and personal factors are barriers to medical appointments by African American with HIV/AIDS? This information was collected via four structured open-ended questions.

Results.

Question 1. What barriers/obstacles/difficulties have prevented you from coming to your scheduled medical outpatient treatment appointments? The main issues that were recorded by subjects were transportation and lack of family support. Other barrier/obstacles/difficulties were related to forgetfulness and scheduling conflicts with other appointments. Some personal comments were related to denial of the severity of illness, not wanting to deal with the severity of HIV, not liking the side effect of medication or medications being switched too frequently.

Question 2. What measures can this office take to help you come to all of your scheduled appointments? Quite a few comments were recorded as the provider’s office needs not to make any changes. As stated by one subject, “everything here is nice and good.” Several subjects stated that the office could not implement any other measures because their recovery was up to them, and not the office’s responsibility. A measure that

was mentioned that could help in keeping their scheduled appointment was notification when the schedule was changed due to the provider's change of schedule. Another communication was related to the office taking initiative to call the subject to schedule an appointment when the appointment is unable to be scheduled at their last visit. The appointment was not able to be scheduled because the provider's schedule did not extend to the recommended time frame to return for a scheduled visit.

Question 3. What else do you believe that you need to keep you in medical care?

Most of the subjects comments were related to having a better by keeping up with changes in their health, obtain health status information, and to have a positive outlook on life.

Question 4. How do you feel that others treat you because you have HIV and/or AIDS? The responses to this question were varied. One set of comments related to subjects selectively choosing which persons to inform of their HIV/AIDS status, and those persons who were informed were supportive. Another set of comments related to family and friends treating them differently, as well as health care providers not making them feel welcome. The last set of comments related to subjects isolating themselves from others due to not wanting to experience stigma or being treated differently.

CHAPTER 5

DISCUSSION, CONCLUSION, IMPLICATIONS, RECOMMENDATIONS

In this chapter, the discussion, limitations, conclusions, implications, and recommendations will be presented. The purpose of this study was to examine nonadherence to medical follow-up at an infectious disease medical clinic among African Americans diagnosed with HIV/AIDS using Andersen's Behavioral Model of Health Services Utilization as adapted by Ulett et al. (2009). Specifically, this model was used to describe and explain predisposing, enabling, and environmental factors that influenced African Americans with HIV/AIDS adherence to their outpatient medical follow-up appointment versus African Americans with HIV/AIDS who do not adhere to their outpatient medical follow-up appointments. A mixed-methods approach was used that included a retrospective medical record review of records of subjects diagnosed with HIV/AIDS who presented to an outpatient infectious disease clinic and initiated care in the summer of 2007 and a survey of African Americans with HIV/AIDS who received care at a walk-in clinic. This chapter will provide a synthesis of the study analyses.

DISCUSSION

The adapted version of Andersen's Behavioral Model of Health Services Utilization was appropriate to describe the predisposing, enabling, and environmental factors that best explained nonadherence to outpatient medical follow-up among African Americans with HIV/AIDS. It is important to remember that following diagnosis, it is critical for people living with HIV/AIDS to adhere to their outpatient medical appointments (Anthony et al., 2007; Beach et al., 2006; Cunningham et al., 2006; Knowlton et al., 2010; Ulett et al, 2009) . People living with HIV/AIDS cannot have

optimal outcomes without obtaining adequate medication coverage and comprehensive services for their illness through regularly scheduled appointments with a health care provider. The use of the adapted version of Andersen's Behavioral Model of Health Services Utilization provided a means by which to focus on the population having disproportionate outcomes related to having HIV/AIDS.

Patient Characteristics

The predisposing factors of age, race/ethnicity, gender, mental illness, and substance abuse were not significantly related to adherence in this study. Except for race/ethnicity, these results were different than those reported in other studies. Age has been found to be a significant factor, persons over the age of 35 who were more successful in establishing and remaining in HIV care and treatment when compared to persons who were of a younger age (Cunningham et al, 2006; Giordano et al., 2005; Ulett et al., 2009). Sixty-five percent of the persons in the current study were < 40 years of age (mean age of 38 years); approximately 15% (12/82) of this group were adherent to outpatient HIV/AIDS appointment (($p = 0.71$), thus the relationship between age less than 35 and adherence did not hold true in this sample. These subjects may have received care at other clinics or have used other types of services (emergency departments, primary care physicians, or not in care at all). This trend bears further examination.

The results regarding the influence of race/ethnicity were similar to a study found by Giordano et al., 2005. They concluded when African Americans had access to care, they remained in care. Other studies have found that race/ethnicity as a factor in

adherence to outpatient care for HIV/AIDS (Uphold & Mkanta, 2005; Molitor et al., 2006; Ulett et al., 2009).

Gender was not a factor of adherence in this study. In other studies, there were mixed findings about the correlation of gender and adherence to outpatient appointments (Anthony et al., 2007; Uphold & Mkanta, 2005). Continued examinations of the newly infected may reveal patterns specific to gender, specifically among high-risk groups, such as men who have sex with men and/or older women.

The predisposing factors mental illness and substance use (illicit drug use and alcohol use) were not significant findings of adherence in this study. Ulett and colleagues (2009) found that those with a history of mental health disorders were more likely to be retained in care while those with a history of substance abuse were less likely to be retained in care. Others have also concluded that persons with a history of substance abuse are less adherent with their outpatient appointment for their HIV/AIDS (Anthony et al., 2007; Knowlton et al., 2010; Molitor et al., 2006). Mental illness services have long been established around a multidisciplinary focus and subjects may respond to the “wrap-around-services” that are provided by their mental health specialists and the community outreach efforts. In this research study, the inconsistent documentation in the EMR regarding subjects’ alcohol and illicit drug use may have impacted the study results and therefore statistical significance was not found.

Stigma was mentioned by subjects when they described how other treated them because they had HIV and or AIDS. Subjects provided supporting comments about the stigma they experienced by others including clergy and health care providers. These findings about stigma are similar to findings in other studies (Foster & Gaskins, 2009;

Kinsler, et al, 2007). Foster and Gaskins (2009) found that participants were selective in whom they revealed their HIV status and the need for HIV/education to be in communities. Kinsler and colleagues (2007) discussed how patients described that their health care provider as being uncomfortable with them or treating them in an inferior manner.

The enabling factors that were studied were insurance status and social support. In the current study, insurance status and social support were not significant. These findings are similar to a finding from another study because persons with insurance coverage were more likely to adhere to outpatient appointments (Laurencin et al., 2008). Every person in the sample had insurance, public or private, and approximately 40% of the sample had Ryan White insurance. Therefore, it would be difficult to know the impact of persons not having insurance with nonadherence to their outpatient infectious disease appointments based on this study.

Social support was operationalized as marital status of the individual. Sixty-eight percent of the sample had documented marital status, and 88% of those were divorced. Findings were different compared to other studies than that showed that lack of social support decreased nonadherence to follow-up (Fattal et al., 2005; Pillai et al., 2009). Social support is more than marital status and points to the need for medical records to include more clinical relevant defining characteristics related to other types of social support. When persons are experiencing a chronic illness, such as HIV/AIDS, having social support in the form of family, friends, faith-based organizations, and peer support may increase compliance to outpatient follow-up and required treatment regimen.

Perceived need factors related to symptoms and health beliefs expressed when subjects completed the surveys about system factors that kept them from adhering to scheduled appointments and created the need to re-establish care. Andersen (1995) stated the person's perceived need for care may be increased or decreased through health education programs. Persons mentioned the need of wanting to find out more about their disease status (e.g., severity, symptoms, and need to get back on medications). Some persons centered their health beliefs on becoming autonomous and believed it was not anyone else's responsibility to keep them in care. Another person stated nonadherence was due to not wanting to take responsibility for the severity of the illness. This finding is similar to the information reported in a focus group study (Beer et al., 2009). Persons return to care when their health care status is no longer under control based on their perception that they are getting sicker, lab values show that their disease status is becoming more severe, or they lack of understanding of what is happening to them in light of their knowledge about the disease. The reverse of this is true also in that when persons feel better and the lab values for CD4 and viral load support a healthier outlook, they will see themselves as being well and not adhere to their medical outpatient follow-up appointments. Neither of these extremes is beneficial to persons with HIV/AIDS who are in need of long-term care for this chronic illness.

Another aspect of this study was related to appointments scheduled and medication ordered in relations to nonadherence. The mean number of scheduled visits was significantly greater for persons who were nonadherent than those who were adherent. This finding is similar to Berg et al. (2005) in that the increase in missed appointments was due probably to the severity of the illness have more appointments and

more opportunities to miss their appointment. When subjects miss appointments, the office will call the patient to reschedule the appointment. If the office staff does not take the time to investigate on the reason for the nonadherence, then the subjects' pattern of nonadherence may continue, even in light of the rescheduled appointment.

Nonadherence was also statistically significant in relationship to medications ordered for HIV/AIDS by the provider. Subjects for whom the provider had not ordered medications or did not state reasons for not ordering medications had greater percentages of nonadherence to outpatient scheduled visits. This finding was similarly related to medication and adherence to outpatient appointment as found in the study completed by Lillie-Blanton et al., (2010). When there is a lack of continuity of care, providers may be reluctant to order medications. Another reason could be that providers are reluctant to order medications to subjects who use illicit drugs.

Environment

Health care systems and provider factors. One of the focused areas for this study was the outpatient environment in which health care services were provided to subjects with HIV/AIDS. Unfortunately, the EMR system used by the infectious disease clinic did not provide information about case management services. However, based on the data that were collected from the EMR, systems factors (referral to substance abuse services or mental health services) were not significantly related to nonadherence in keeping the outpatient appointment in this study. In other studies, mental health and substance abuse issues by patients with HIV/AIDS did affect patient adherence to follow-up (Giordano et al., 2005; Knowlton et al., 2010; Lillie-Blanton et al., 2010). Coordination of services is important to the patient with HIV/AIDS. Therefore, the

clinical record needs to reflect more integrated documentation of how these needs are met. It is critical that providers feel comfortable in challenging persons with illicit drug use about their use and educate patients on the impact of their “choices” for adherence

On the other hand, providers’ factors had statistically significant results. Provider type (physician, nurse practitioner, or other) was significant for adherence to outpatient appointments. Subjects were nonadherent when seen by more than one provider and nonadherent if seen by more than one type of provider. Subjects were also more adherent when seen by the physician versus the nurse practitioner. These findings about seeing the same provider and number of providers seen are the same as found in other research studies (Atlas et al., 2009; Beach et al., 2006; Knowlton et al., 2010). Providing patient-centered and continuity of care are important. The patient needs to believe that the provider “knows him or her” and that the subjects’ needs are being addressed. In doing this measure, a level of comfort with the provider may be experienced by the patient.

Building trust with the provider is an important characteristic which fosters adherence. African Americans have difficulty with trusting others, especially in health care due to past history of experimentation in research for the treatment of syphilis (Whetten et al., 2006). African American patients can begin to develop some cognitive level of appreciation that their providers have special knowledge about their care for HIV/AIDS; and this will translate into more adherences to attending their outpatient appointment. Patients also develop an ease with communication or may communicate differently with providers when there is continuity of services with the same provider (type and person). When nonverbal and verbal communication becomes more consistent over time, the provider and patient benefit from the interactions.

Limitations

Limitations of this study included the setting, sample, the sample size, operational definitions, and data collection procedures. Due to using only one site (setting) for the retrospective EMR data and for the surveys, the findings are not generalizable to all persons receiving HIV care in other outpatient infectious disease clinics or in other types of outpatient models for delivering care.

The sampling process used to abstract data from the electronic medical records was a limitation. Rigor could have been improved by developing a random selection process of the available records versus reviewing all the subjects who had received care within the designated time frame for collecting data. The study was limited to only African Americans with HIV/AIDS. When obtaining the supplemental data for the survey, and using just one racial/ethnic category and convenience sampling, the results cannot be generalized to other racial/ethnic groups. HIV/AIDS is such a devastating disease, and affects more than African Americans. African Americans do have sexual relationships with other racial ethnic groups; and therefore, the sample could have been inclusive of all racial ethnic groups. However, studying one racial ethnic group does support the validity of race/ethnicity because it limits the variation in the dependent variables that could be explained by patients' race/ethnicity.

Further limitation could be the small sample size ($N = 82$) and even smaller sample size obtained for the retrospective EMR of various variables such as persons who used alcohol ($n = 57$), illicit drug use ($n = 58$), or marital status ($n = 60$) and may have limited the ability to detect statistically significant differences in factors to explain nonadherence to the outpatient medical regimen. Among the information not found in the

EMR were education level, annual income, case management information, and marital status. Subjects' income and educational levels could not be ascertained from any database. Activities by case managers were not available in the EMR. Currently, the case management notes reside with the case manager, and the case manager communicates via EMR task link.

In this study, the enabling variable for support was defined as only the marital status and if the subject had insurance. The definition for support could have been broadened to include other types provided to persons living with HIV/AIDS. Support from family members, significant others, peer support, and case managers could have been broadened that area of review. Data collection for lab values related CD4 and Viral Load could have been across all four six month periods and not only the first recorded results. In doing this the clinical picture may have evolved to include further information for future studies.

The review of the EMRs presented challenges in examining factors related to patient characteristics and environmental factors (system and provider). The EMR was introduced at the outpatient infectious disease clinic in the summer of 2007. As with implementation of any new product, the staff had to learn new ways to input and extract information and to interact with their patients. With the implementation of the EMR, a huge time commitment by staff and learning curve was needed. When the infectious disease clinic began using EMR, they were using it only for the progress notes and medication documentation. The scanning of pertinent labs, medical history, and immunizations did not happen immediately after EMR initiation. Another challenge

occurred when patients had multiple providers. It was difficult to maintain medication records because patients did not always know the names and doses of medications.

Finally, the supplemental data that was obtained were from subjects' self-reporting. The self-reported responses may be unreliable because people may provide socially acceptable responses (Nieswiadomy, 2008; Polit & Beck, 2008). However, self-reporting has been found to be a valid source of data (Mkanta & Uphold, 2006) but the person could say social desirable responses and not report certain aspects, thus leading to bias. Despite these limitations, this study provides valuable information regarding factors that describes adherence to outpatient appointments.

CONCLUSION

The purpose of this study was to examine whether the Behavioral Model of Health Services Utilization explained nonadherence of African Americans to their outpatient infectious disease follow-up appointments. The Behavioral Model of Health Services Utilization offered a systematic and organized approach to examine factors related to nonadherence. An adaptation of the Behavioral Model of Health Services Utilization developed by Ulett et al. (2009) proved useful in examining relationships between patient characteristics (predisposing, enabling, and need factors) and the environment (system and provider factors) to describe the health behavior of nonadherence to HIV/AIDS outpatient appointments at an infectious disease clinic. The addition of nonadherence as a health behavior factor was added to this model and permission was granted (see Appendix L). This change was requested due to the fact that retention was not the focus of this study but rather nonadherence to scheduled outpatient medical follow-up appointments.

It was expected that the Behavioral Model of Services Utilization would explain nonadherence to outpatient follow-up visits by African Americans with HIV/AIDS. The model supported the examination of individual level factors as well as organizational level factors towards nonadherence of follow-up. Persons experiencing HIV/AIDS have multifaceted needs and nonadherence to care does not promote optimal wellness. This model has feedback loops to show that individual characteristics influences utilization and vice versa (Phillips et al. 1998). In this model, the feedback loops allows for flexibility in its use. This flexibility can be perceived as a positive or a negative factor based on the variables of interests. If other variables that are not listed in the mode are needed to support the research questions, then that flexibility becomes complimentary.

The Behavioral Model of Health Services Utilization did explain predisposing factors related to patient characteristics and nonadherence and factors of the health care environment related to nonadherence. In this study, stigma was related to nonhadherence and perceived need was related to nonadherence. The factors related to stigma showed that subjects provided pointed and descriptive examples of how stigmatization impacted their behaviors in not seeking care and in lack of socialization with others. When subjects do not feel accepted, nonadherence to outpatient follow-up becomes a negative component of wellness. According to Andersen (1995), perceived need is larger than how people view their own general health and functional state and how they experience symptoms of illness to be a driving force for seeking care. Perceived need also represents professional judgment about people's health status and the need for medical care. Subjects who believe that they are totally responsible for their own wellness instead of acknowledging the level of support that can be provided miss an integral component of

integrated services needed to care for patients diagnosed with HIV/AIDS. The model also had the capacity to explain a factor that was not considered in this study, transportation. Persons listed transportation on the survey as one of the barriers to adhering to care.

The Behavioral Model of Health Services Utilization explained environmental factors related to system factors and the provider's relationship with the patient. The relationships inferred by this model are that the environment in which HIV/AIDS care is provided is an important component related to nonadherence of patients to their outpatient infectious disease appointment and that system factors are important with patients' adherence to outpatient appointments. The factors related to providers helped to explain reasons why patients may not be adherent to their HIV/AIDS outpatient appointment due to the type of provider seen, number of providers seen, and relationship with the provider (e.g., trust and experience level of provider). The Behavioral Model of Health Services Utilization explained the importance of the patient-provider relationship. In this study, subjects were more adherent when seen by a physician (one provider type) and also when seen by only one provider versus multiple providers.

Nonadherence to outpatient appointments, as a health behavior, is related to the subjects' inability to be linked in care and receive and adhere to medications. Subjects discussed barriers, obstacles, and difficulties related to keeping their scheduled appointments. Responses depicted patient characteristics in the model for predisposing factors (stigma); enabling factors (transportation, social support), and need (health beliefs). The personal testimonies of African American re-establishing care by coming to the "walk-in" clinic revealed the importance of their need to adhere to their outpatient

appointments. Re-establishing care was a motivating factor for subjects. The person had to show up for three consecutive scheduled appointments. The need of continuity of seeing the provider was explained by the model with the provider factors, and subjects expressed the need to see the same provider.

Another factor that was not studied in this study was clinic factors. The Behavioral Model of Health Services Utilization could explain these factors when persons responded to the survey that was presented during their “walk-in” visit. In the Behavioral Model of Health Services Utilization, under the health care environment are clinic factors, such as clinic distance, appointment availability, and waiting time. One patient stated that it would be nice if the service provider was located closer to the subjects’ community. Others mentioned that waiting time was not a factor when they arrived at the clinic. Nonadherence was related to appointment availability because the administrative staff was not able to schedule appointments far in advance and could not recommend to the subjects when they could return for a visit.

IMPLICATIONS

Policy Implications

President Barack Obama, in an opening letter for the National HIV/AIDS Strategy for the United States (Office of National AIDS Policy, 2010), wrote the following:

Our country is at a crossroads. Right now, we are experiencing a domestic epidemic that demands a renewed commitment, increased public attention, and leadership. Early in my Administration, I tasked the Office of National AIDS Policy with developing a National HIV/AIDS Strategy with three primary goals:

1) reducing the number of people who become infected with HIV; 2) increasing

access to care and improving health outcomes for people living with HIV; and, 3) reducing HIV-related health disparities. To accomplish these goals, we must undertake a more coordinated national response to the epidemic. The Federal government can't do this alone, nor should it. Success will require the commitment of governments at all levels, businesses, faith communities, philanthropy, the scientific and medical communities, educational institutions, people living with HIV, and others. (p. i)

The findings of this study suggest that combined actions of the state and local governments are needed to increase adherence to scheduled outpatient appointments for African Americans living with HIV/AIDS. The findings in this study can contribute to policy development in the areas of examining the impact of enabling factors on nonadherence of follow-up outpatient appointments. Subjects in this study had some form of insurance (public or private), but policymakers can further explore the role patients' co-payments have on nonadherence. Policies are needed in examining patient characteristics, health behaviors, and health care environment related to the connectivity of PLWHA to providers of HIV/AIDS services. Service needs are best met for PLWHA when there are coordinated efforts. When local, state, and federal governments operate independently of one another, they are not able to provide more collaborative, comprehensive, and individualized services (Bradford, 2007). Therefore, policies are needed to guide the coordination of all services for HIV-infected individuals to increase their adherence to their outpatient scheduled appointments.

Policy can support increase education of providers to become more aware of providing culturally sensitive care to persons with HIV/AIDS. The education provided may help to foster adherence to the patient's medical regimen for treatment.

Policy is needed to expand the amount of support that patients can receive for the cost of transportation to and from needed services. Another implication is to promote linkages with other service organizations that provide psychosocial related services (transportation and mental health services) will enhance the availability of HIV prevention efforts. This is a definite challenge for HIV research in the need of policy to identify specific barriers and to develop strategies to improve linkage and retention in clinical care for African Americans who are disproportionately affected due to the diagnosis of HIV and who have greater health care disparities.

The Ryan White Comprehensive AIDS Resource Emergency (CARE) Act (now called the Ryan White HIV/AIDS Program) provides funds for Americans who have little or no insurance. Additional burden is placed on the Ryan White HIV/AIDS Program by individuals not eligible for Medicaid. Approximately 40% of the subjects had Ryan White insurance, and 18% had Medicaid, the leading payer for HIV care. To receive HIV coverage through Medicaid, a person living with HIV has to have a serious opportunistic illness or chronic condition. Coverage for non-disabled adults with HIV is limited to pregnant women and families with a gross income below the poverty level as specified by their state. As our country looks at the health care needs of the nation, the leaders need to consider budgeting for preventive strategies of PLWHA. Therefore, this study supports the re-enactment of this law to benefit those who otherwise would not

have insurance. Having insurance is one of those modifiable factors that can benefit people seeking health care.

Stigma experienced by subjects with HIV/AIDS was related to nonadherence. Policy to address education of providers related to their role in decreasing stigma is important. The CDC is partnering with other agencies in pursuing a high-impact prevention approach to advance the goals of the National HIV/AIDS Strategy and to maximize the effectiveness of current HIV prevention methods (CDC, 2011b). This study can support using a preventative approach as the CDC examines stigmatization related to health disparities among African Americans. Decreasing stigma for PLWHA will involve increasing the level of trust in the health care system and in the providers of care. Subjects also need to feel accepted and listened to by providers, because in the past, providers practiced paternalistic care. Today, patients are more interactive in their care, so the need to involve them in decision-making is critical for adherence. Policies to address culturally sensitive care are needed.

Practice Implications

In this study, subjects identified barriers, obstacles, and difficulties in adhering to their scheduled outpatient appointment. They also identified the level of engagement that occurred with their provider and if people treated them differently because of having HIV/AIDS.

Expanding community support to African Americans living with HIV/AIDS is critical. This support can come in the form of dialogue at community centers, peer-led interventions, and involving faith-based organizations. By providing dialogue in the community, information can be tailored to the needs of the participants, and fallacies

related to HIV/AIDS can be attended to. The dialogue should be seen as a partnership among community leaders, peer-educators, and the community at large. When providing peer-led interventions, African Americans with HIV/AIDS may be more accepting of the health message and the need to stay in care for their HIV/AIDS.

For African Americans, expanding social support to not only family members but also to the places of worship and other spiritual practices can be a form of support to assist persons living with HIV/AIDS adherence to their medical care regimen. Religion and spirituality are very much a part of African American lives. Incorporating faith-based organizations into providing support in education and prevention strategies are important. In the church setting, this can be accomplished by creating focused outreach ministries that provide support to those with HIV/AIDS.

Health care providers need to help individuals to recognize and manage the psychosocial aspects of their HIV/AIDS as well as the clinical aspects. Specialized case management services can assist in this endeavor by coordinating services among the various providers that the HIV/AIDS patients have to encounter and become an advocate for the patient; and then document their coordination in the electronic medical records. This level of support by providers will assist populating the medical record with the specific clinical information needed to care for these patients. African Americans need to feel connected to their health care providers. Increase in technology use is becoming prevalent in health care practices. However, African Americans with HIV/AIDS may not have access to modern technology, and therefore, more traditional ways of keeping persons connected may need to be used. Providers may need to create outreach

departments that coordinate care with community case managers and home health agencies.

In this study, subjects identified the need to have access to HIV/AIDS care within their community and not travel a long distance. When this is not possible, health care providers need to consider alternatives for care that are sensitive to the transportation limitations of the persons with HIV/AIDS. Health care providers may need to increase their awareness of community-based support programs in order to refer patients unable to travel to specialty clinics, and patients may need better education on available community services. Providers may also need to consider offering care in locations that are more accessible for patients with HIV/AIDS.

The health care practice can also improve the subjects' experience by implementing staff development programs focusing on providing unconditional/unbiased communication to those with HIV/AIDS. Perceived stigma was self-reported and persons living with HIV/AIDS need to feel comfortable in receiving health care from all level of providers of services. Adherence to the medical regimen is important for maintaining the health, well-being, and quality of life. Persons with HIV/AIDS are living longer due to HAART treatment. Yet, African Americans are still disproportionately affected with the disease than any other racial/ethnic group. Providers need to feel comfortable and competent talking to patients about stigmas, strategies to prevent stigmas, and how to discuss perceived differences in treatment with their provider.

In this study, subjects did not feel that it was their responsibility to educate the public on the difference between having HIV and having AIDS. Practices may want to involve outreach efforts to help with educating the public and the persons with

HIV/AIDS. Health care practices can network with community forums to provide education that is culturally sensitive and incorporates interpersonal needs of PLWHA. By becoming aware of the barriers that are faced by PLWHA and communicating with patients about overcoming those barriers, providers may increase the patients' feeling of connectedness to the practice, and thus enhancing their adherence to medical care.

RECOMMENDATIONS

Recommendations for Future Research

This study examined factors of nonadherence to outpatient infectious disease appointment by African Americans with HIV/AIDS. Based on the results of this study, future research on this topic should be explored to include studies about the influence of patient characteristics, health care environment, and health behaviors on clinical outcomes. Due to the health care disparities experienced among African Americans with HIV/AIDS, it is important that research continue in these areas so that there are improved outcomes for African Americans.

Future research should examine perceived experienced stigma through dialoguing of persons with HIV/AIDS collaboratively with the providers of services because it is important to acknowledge that stigma may have important effects on the use of services and remaining in care. Effective interventions to reduce stigma is still needed which could include education and modeling of nonstigmatizing behaviors by providers of services. A recommended component of this future research is to have persons who are experiencing HIV/AIDS teach providers about stigma, and this may increase providers' sensitivity to the needs of persons with HIV/AIDS. The researcher also recommends that studies be conducted to gain a better understanding about stigmatization and why persons

with HIV/AIDS remain silent about their disease. Based on this study, the researcher believes that until persons admit that they have a problem and actively participate in their care, optimal outcomes will not occur. PLWHA must feel comfortable in order to seek care and believe they deserve the best care.

Since multiple factors influence treatment adherence of African Americans to outpatient follow-up for HIV/AIDS, the researcher recommends that other mixed methods study approaches be conducted using more interpersonal variables related to communication styles, partnership with the practice, and health promotion. Using a mixed methods approach allowed more personal information to come forth from subjects who were identified as nonadherence with their regular scheduled medical appointments. Future research should include more qualitative studies so that the persons with HIV/AIDS can “tell their own story” and this will help to tailor interventions to engage them in treatment.

Future studies might also include expanding the research focus to include subjects that do not adhere to regular medical care and who are not African American. The potential data from these sources could provide an additional conceptual framework to compare and contrast the lived experience of stigma and nonadherence.

Another study can focus on these multifaceted areas: stigma (perceived and actual); individual barriers to care (perceived and actual); organizational barriers (perceived and actual); and expand those study to include a more in-depth component of both environmental factors (contextual and health care). The contextual environment would include the neighborhood. The health care environment would include the clinic, system, and provider factors. All of these factors are interrelated and could be detrimental

in persons needing care. HIV/AIDS is a chronic condition and people are living longer, but African Americans are still disproportionately affected by the disease. In this study, the predisposing factors related to age, gender, mental illness, and substance abuse were not significant. However, the general population is becoming older, and the past messages have been directed more towards homosexual men and rather than to women. Research is needed to identify strategies to educate older females on how to prevent HIV/AIDS.

Future research is also needed to examine institutional related factors in supporting this special need population to adherence in their medical regimen. In reviewing system related factors of how health care is delivered to persons with HIV/AIDS is crucial for efficient resource allocation. It was important that PLWHA perceived that their provider engaged them in their care. To this end, further research should be focused on identifying factors that will promote collaboration between patients and providers. Future studies should explore in greater depth the impact of environmental factors, such as clinic distance, appointment availability, and waiting times on African Americans with HIV/AIDS. Qualitative studies that are designed to better understand the lived experiences of persons with HIV/AIDS may prove useful in studying these issues.

Recommendations for Practice

To engage individuals, families, and communities around HIV/AIDS education is a complex challenge, especially for African Americans. The complex challenge is due to the impact of poverty, lack of trust in the health care system, stigmatization, incarceration, and the correlation of poverty to illicit drug use among African Americans. Variables related to the impact of substance abuse and mental illness can be studied

through focused groups that can be held in the community or at community services boards in cities.

When extending support to the person with HIV/AIDS to the church, more research is needed to develop culturally sensitive interventions for church leaders to recognize their role in helping support persons living with HIV/AIDS. This support may foster more compassion towards persons with HIV/AIDS, and the church partners with available community resources for persons with HIV/AIDS.

A community-based education program is proposed with the use of mobile van to go to communities since transportation was identified as an issue with nonadherence. Since the concept of the mobile library is already accepted in communities, using a mobile van may not seem threatening to the community and to African Americans. Education will be provided by trained professionals (laity and health care persons). At a minimum, the interventions should include the ability to talk with a case manager who specializes in the coordinating services of PLWHA, peer support (someone also living with HIV/AIDS), computer-assisted technology, and educational materials written at the appropriate literacy level. The physician, nurse practitioner, or physician assistant will be available to complete a physical examination and to answer health-related questions. The mobile service will also have the ability to link PLWHA to providers.

Recommendations for Dissemination

First, the findings of this study should be shared with the outpatient infectious disease clinic where the study was conducted. Results will provide direction for the medical director to examine practices within the clinic. Second, results should be shared with local hospitals, city agencies, and support organizations that offer programs and

provide services for persons with HIV/AIDS. Using the findings of this study to establish a dialogue about care for HIV/AIDS patients can help to advance the adoption of evidenced-based strategies that promote adherence to recommended treatments.

Additionally, results can be used to help educate policy makers on issues affecting care of persons with HIV/AIDS. Lastly, the findings of this research study should be presented at national conferences, such as the American Public Health Association and Association of Nurses in AIDS Care. Oral and podium presentations can be used as platforms to disseminate information about factors impacting nonadherence to HIV/AIDS care. Dissemination at a national level can also be accomplished through the publishing of study results in peer-reviewed journals, such as *Journal of HIV/AIDS and Social Services*, *Journal of the Poor and Underserved*, and *Journal of Nurses in AIDS Care*.

SUMMARY

In the United States, HIV/AIDS in the African American population has remained a national concern. Persons are now living longer, and this disease is seen as a chronic illness. It is critical that all measures are undertaken to understand how to impact adherence to prescribed medical regimen among African Americans. To take advantage of the current treatment, persons with HIV/AIDS need to enter and stay connected to the health care system.

The present study suggest that nonadherence to outpatient follow-up is multi-layered; and dynamic. Non adherence could be based on several factors such as stigmatization experienced from others and self-imposed isolative behaviors, relationship to the provider, office procedures, and the severity of symptoms experienced by persons with HIV/AIDS. This data may prove helpful to health care planners involved in

scheduling appointments in redesigning systems so that increased dialogue with the person experiencing HIV/AIDS occur with the initial assessment in the office about the barriers that may be faced in adhering to the recommended scheduled appointments and their prescribed treatment. In this way, a proactive and supportive plan could be implemented that may increase adherence and better quality outcomes.

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APPENDIX A
PERMISSION GRANTED TO USE ANDERSON MODEL
(OCTOBER 3, 2010)

CYNTHIA B BANKS

From: Ron Andersen [randerse@ucla.edu]
Sent: Sunday, October 03, 2010 1:56 PM
To: CYNTHIA B BANKS
Subject: Re: Permission to use

Dear Cynthia,

You have my permission to use the figure depicting the Behavioral Model in your dissertation.

Best wishes for completion of your Ph.D.,

Ron Andersen

At 05:15 PM 10/2/2010, you wrote:

Dr. Andersen,
I am a PhD student at Old Dominion University in Norfolk Virginia in their Health Services Research program. I would like to copy your "original" figure of the model used in your Dissertation Research. I would like to use that figure as I discuss the historical perspective in my literature review. My research study is concerning nonadherence of African Americans with HIV/AIDS to their outpatient medical outpatient appointments.

A Behavioral Model of Health Service Use (Andersen 1968).

Respectfully,

Cynthia B Banks, MS, RN
Associate Professor
Sentara College of Health Sciences
Room 121
Office telephone: 757-388-5872
Pager: 757-475-6782

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APPENDIX B

**PERMISSION GRANTED: RONALD ANDERSON (SEPTEMBER 2011) AND
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SUZANNE DUNCAN

From: Permission Requests - UK [permissionsuk@wiley.com]
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Attachments: image002.png; image004.jpg

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The Wiley Permissions Team

From: SUZANNE DUNCAN [mailto:SDUNCAN@sentara.com]
Sent: Friday, July 23, 2010 12:37 PM
To: Permissions - US
Subject: "NON-RIGHTSLINK" Permission to use figure in Dissertation

Hello,
I tried requesting permission on your website but keep getting an e-mail error message when I click submit. Below is the information you requested on your site. I am trying to get permission for one of the faculty members here at my college. She is earning her PH.D. at Old Dominion University.

First Name: Cynthia
Last Name: Banks
Name of Company or Organization: Old Dominion University
Street Address: 1551 Hampton Blvd.
City: Norfolk
State/Province: VA
Zip/Postal Code: 23529
Country: USA

Contact Phone Number: 757-237-7301
Fax: 757-226-0183
E-mail Address: cbank003@odu.edu

Wiley product/title from which you'd like to reprint: **Health Services Research**

Is this title a book or a journal? **Journal**
If this title is a journal, please provide the following:
Journal Month: Spring
Journal Year: 1983
Journal Volume: 18
Journal Issue Number: 1

Specific pages numbers, figures/tables, and/or total word count you wish to reproduce: **Figure 1 on page 51**

Maximum print run estimate: at
the most 10
Your Publisher: Myself
Title of Your Work: For my dissertation

APPENDIX C**PERMISSION GRANTED: K. PHILLIPS (SEPTEMBER 27, 2011) &****WILEY BLACKWELL (SEPTEMBER 21, 2010)**

SUZANNE DUNCAN

From: Permission Requests - UK [permissionsuk@wiley.com]
Sent: Tuesday, September 21, 2010 10:53 AM
To: SUZANNE DUNCAN
Subject: FW: NON-RIGHTSLINK Permission to use figure in Dissertation Request
Attachments: image004.png; image005.jpg

Dear Cynthia Banks,

"Permission is hereby granted for the use requested subject to the usual acknowledgements (author, title of material, title of book/journal, ourselves as publisher).

Any third party material is expressly excluded from this permission. If any of the material you wish to use appears within our work with credit to another source, authorisation from that source must be obtained.

This permission does not include the right to grant others permission to photocopy or otherwise reproduce this material except for versions made by non-profit organisations for use by the blind or handicapped persons."

Please note we are waiving our fee on this occasion. Future requests may incur a charge.

Best Wishes

Cassandra Fryer
 Permissions Assistant

Wiley-Blackwell | 9600 Garsington Road | Oxford | OX4 2DQ | UK
 | cfryer@wiley.com

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Best wishes,
The Wiley Permissions Team

From: SUZANNE DUNCAN [mailto:SDUNCAN@sentara.com]
Sent: Monday, September 20, 2010 3:53 PM
To: Permissions - US
Subject: NON-RIGHTSLINK Permission to use figure in Dissertation Request

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Top of Form

First Name: Cynthia
Last Name: Banks
Name of Company or Organization: Old Dominion University
Street Address: 1551 Hampton Blvd.
City: Norfolk
State/Province: VA
Zip/Postal Code: 23529
Country: USA

Contact Phone Number: 757-237-7301
Fax: 757-226-0183
E-mail Address: cbank003@odu.edu

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Is this title a book or a journal?
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If this title is a journal, please provide the following:
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Journal Year: 1998
Journal Volume: 33
Journal Issue Number: 3, part I

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Suzanne Duncan, MSLS
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APPENDIX D**PERMISSION GRANTED: J MUGAVERO (MARCH 2010) &****LIBERT PUBLISHING (APRIL 13, 2010)**

March 23, 2010

Michael J. Mugavero, M.D., M.H.Sc.
CCB 178, 908 20th Street South
Birmingham, Al 35294-2050

Dr. Mugavero,

I am a PhD (c) at Old Dominion University in Norfolk, Va. I am in the Health Services Research Program.

I would like to have permission to copy your Adaptation of the Behavioral Model of Health Service Utilization (B) that was printed in the article, "The Therapeutic Implications of Timely Linkage and Early Retention in HIV Care" in *AIDS PATIENT CARE and STDs*, Volume 23, Number 1, 2009. I am performing my dissertation research on Nonadherence of African Americans keeping their scheduled appointment at an outpatient infectious disease clinic.

Respectfully,

Cynthia B. Banks

Cynthia Banks
Cbank003@odu.edu

APPENDIX E**ELECTRONIC MEDICAL RECORD (EMR) DATA COLLECTION TOOL**

Date: _____ Information Collected by: Cynthia Banks, MS, RN

1. Name of patient: _____

2. MR #: _____

3. Date of Birth (year): _____

4a. Age: _____

4b. Gender (circle): Male Female Missing

5. Ethnicity (circle):

African American (Black)

White

Latino/Hispanic

Other

Missing

6. Highest Education level (circle):

Less than high school graduate

Some College

Missing

High School graduate

College Graduate or more

7. Employed (circle): Missing No Yes Missing

8. Status of employment (circle): NA Full-time Part-time

9. Insurance (circle):

Private

Medicaid

Medicare

Ryan White – uninsured

Missing

10. Marital Status (circle):

Single or never married

Married , has a partner or living as though married

Separated, Divorced or widowed

11. Annual Income < 10,000 (circle): No Yes NA Missing

12. Time from intake visit to first schedule provider visit (days): _____

13. Initial CD4 lymphocyte count (cells/mm3):

Date: _____

Result: _____

< than 51

51-200

201-500

> 500

14. Other CD4 Lymphocyte count (cells/mm3)

Date: _____ Result: _____

Date: _____ Result: _____

Date: _____ Result: _____

Date: _____ Result: _____

15. Initial HIV Viral Load result (copies/ml): HIV-1-RNA

Date: _____

Result: _____

<10,000

10,000 – 100,000

> 100,000

Missing

16. Other HIV Viral Load (copies/ml):

Date: _____ Result: _____

Date: _____ Result: _____

Date: _____ Result: _____

Date: _____ Result: _____

17. HAART Receipt (circle):

No

Yes

Missing

If Yes: Date prescribed: _____

18. Comorbid affective disorders (circle):

No

Yes

Missing

19. Admitted Illicit Substance (Drug) Use (circle):

Current illicit drug use

Past (no longer using)

None

20. Admitted Alcohol Use (circle):

Current alcohol use

Past but not current alcohol use

None

21. Referred to Resource for Substance Use (circle):

No Yes (Date or referral): _____

22. Referred to Resource for Illicit Drug Use (circle):

No Yes (Date of referral): _____

23. Referred to Case Management Services (circle):

No Yes (Date of referral): _____

24. Office visit date: _____

Provider/Specialty Seen (Circle): MD, NP, PA, RN, Case manager, other: _____

Written information provided: Yes No documentation in medical record

Office visit date: _____

Provider/Specialty Seen (Circle): MD, NP, PA, RN, Case manager, other: _____

Written information provided: Yes No documentation in medical record

Office visit date: _____

Provider/Specialty Seen (Circle): MD, NP, PA, RN, Case manager, other: _____

Written information provided: Yes No documentation in medical record

Office visit date: _____

Provider/Specialty Seen (Circle): MD, NP, PA, RN, Case manager, other: _____

Written information provided: Yes No documentation in medical record

Office visit date: _____

Provider/Specialty Seen (Circle): MD, NP, PA, RN, Case manager, other: _____

Written information provided: Yes No documentation in medical record

APPENDIX F

SURVEY TOOL (FACE-TO- FACE)

Date of interview: _____

Information Collected by: _____

1. Name of patient: _____

2. MR #: _____

3. Date of Birth (year): _____

4. Age: _____

4. Gender (circle): Male Female

5. Ethnicity (circle):

African American (Black) White
Latino/Hispanic Other

6. Highest Education level (circle):

Less than high school graduate High School graduate
Some College College Graduate or more

7. Employed (circle): No Yes

8. Status of employment (circle):

NA Full-time (35-40 hours/week) Part-time (less than 35 hours/week)

9. Insurance (circle):

Private
Medicaid
Medicare
Ryan White – uninsured

10. Marital Status (circle):

Single or never married
Married , has a partner or living as though married
Separated, Divorced or widowed

11. Annual Income < 10,000 No Yes NA

12. Living situation:

Homeless
With friend or relative
Therapeutic community (adult living, half-way house)
Room, hotel, motel
House or apartment (rented or owned)

Open-ended questions:

1. What barriers/obstacles/difficulties have prevented you from coming to your scheduled medical outpatient treatment appointments?

2. What measures can this office take to help you come to all of your scheduled appointment?

3. What else do you believe that you need to keep you in medical care?

4. How do you feel that others treat you because you have HIV and/or AIDS?

APPENDIX G

ENGAGEMENT WITH HEALTH CARE PROVIDER TOOL

Engagement with Health Care Provider

Your primary health care provider is probably your doctor. However, your health care provider might also be a nurse, nurse practitioner or physician's assistant.

Please check the type of health care provider that you see on a regular basis and then complete this page with that person in mind.

My primary health care provider is (please check one):

- ☐ Doctor
☐ Nurse
☐ Nurse Practitioner
☐ Physician Assistant
☐ Other, please describe: _____

Please rate the degree to which each statement is true for you:

1= Always 2= Usually 3= Sometimes 4= Never n/a= no experience

Always	Usually	Sometimes	Never	No Experience	My health care provider:
1	2	3	4	n/a	Listens to me
1	2	3	4	n/a	Cares about me
1	2	3	4	n/a	Answers my questions
1	2	3	4	n/a	Spends enough time with me
1	2	3	4	n/a	Involves me in decisions
1	2	3	4	n/a	Respects my choices
1	2	3	4	n/a	Deals with my problems
1	2	3	4	n/a	Engages me in my care
1	2	3	4	n/a	Is helpful to me
1	2	3	4	n/a	Respects me
1	2	3	4	n/a	Supports my decisions
1	2	3	4	n/a	Sees me when I ask
1	2	3	4	n/a	Provides me with information

APPENDIX H

PERMISSION TO USE ENGAGEMENT WITH

HEALTH CARE PROVIDER TOOL

From: Holzemer, Bill <bill.holzemer@nursing.ucsf.edu>
Date: Fri, May 1, 2009 at 12:50 PM
Subject: RE: Request Permission
To: Cynthia Banks <cbank003@odu.edu>

Yes, you have permission to use the instrument. Best wishes, Bill

William L. Holzemer, RN, PhD, FAAN
 Professor and Associate Dean, International Programs
 Lilham & Dudley Aldous Endowed Chair in Nursing Science
 School of Nursing, N531C
 University of California, San Francisco
 2 Koret Way
 San Francisco, CA 94143-0608 USA
 415 476 2763 work
 415 476 6642 fax
bill.holzemer@nursing.ucsf.edu

From: Cynthia Banks [<mailto:cbank003@odu.edu>]
Sent: Friday, May 01, 2009 9:30 AM
To: Holzemer, Bill
Cc: cbank003@odu.edu
Subject: Request Permission

Please see the attached requesting permission and a copy of your instrument: 13 item scale called "Engagement with Health Care Provider. I am a PhD student completing my dissertation on factors related to nonadherence to medical outpatient follow-up visits by African Americans with HIV/AIDS.

Thank-you.

Date: May 1, 2009

To: William L. Holzemer, R.N., Ph.D.

Department of Community Health Services

University of California, San Francisco

San Francisco, CA 94143-0608

bill.holzemer@nursing.ucsf.edu

Re: Permission Request

From: Cynthia Banks, MS, RN

PhD Student at Old Dominion University

Norfolk, VA 23529

I am working on this research project that is focused on Nonadherence to Outpatient Medical Follow-up Appointments. In my literature search, I came across your instrument called "Engagement with Health Care Provider". I am requesting a copy of your instrument and permission to use the instrument in my research study.

Thank-you.

APPENDIX I
RECRUITMENT LETTER

Recruiting Participants for the Study**Letter to the Patient of the Infectious Disease Walk-in clinic**

August 22, 2009

Dear Patient,

My name is Cynthia Banks. I am a doctoral student at Old Dominion University. I am working on a study to look at factors that may keep you from coming to your appointments at this clinic. It is very important that patients keep their appointments to stay as healthy as possible. If you choose to be in this study, it can help this clinic to provide you with services you may need to keep your appointments. There is little to no risk involved in this study. The information you share will remain private and confidential. If you decide not to be a part of this study, it will not affect your care at the clinic. Your participation will be your choice. The health educator nurse at this clinic, who is a member of the research team, will ask you to complete some questions and obtain your informed consent to participate. These questions would take about 15 minutes to complete.

If you have any questions, please ask this nurse in this clinic to contact me at 757-237-7301.

Sincerely,

Cynthia Banks, MS, RN

Doctoral Student, Old Dominion University

Recruiting Participants for the Study**Letter to the Patient of the Infectious Disease Walk-in clinic**

March 23, 2010

Dear Patient,

My name is Cynthia Banks. I am a doctoral student at Old Dominion University. I am working on a study to look at factors that may keep you from coming to your appointments at this clinic. It is very important that patients keep their appointments to stay as healthy as possible. If you choose to be in this study, it can help this clinic to provide you with services you may need to keep your appointments. There is little to no risk involved in this study. The information you share will remain private and confidential. If you decide not to be a part of this study, it will not affect your care at the clinic. Your participation will be your choice. If you agree to participate in this study, I will ask you to complete some questions and obtain your informed consent to participate. These questions would take about 15 minutes to complete.

If you have any questions, please ask this nurse in this clinic to contact me at 757-237-7301.

Sincerely,

Cynthia Banks, MS, RN

Doctoral Student, Old Dominion University

APPENDIX J
INFORMED CONSENT DOCUMENT
OLD DOMINION UNIVERSITY

INFORMED CONSENT DOCUMENT

OLD DOMINION UNIVERSITY

PROJECT TITLE:

Factors that Influence Nonadherence to Outpatient Medical Follow-up by African Americans with HIV/AIDS at an Outpatient Infectious Disease Clinic

INTRODUCTION

The purposes of this form are to give you information that may affect your decision whether to say YES or NO to participation in this research, and to record the consent of those who say YES.

The title of the research is "Factors that Influence Nonadherence to Outpatient Medical Follow-up by African Americans with HIV/AIDS at an Outpatient Infectious Disease Clinic" Your face-to-face interview will happen at Eastern Virginia Medical School in a private area during your visit.

RESEARCHERS

Karen Karlowicz, RN, MSN, EdD, Responsible Project Investigator
College of Health Sciences
Department of Nursing

Mrs. Cynthia Banks, MS, RN
PhD Student Old Dominion University
College of Health Sciences

~~Adrian P. Brown, PhD, LPC~~
~~Department of Counseling & Guidance~~

DESCRIPTION OF RESEARCH STUDY

Several studies have been conducted looking into the topic of factors that may affect why African American patients keep their prescribed medical treatment for HIV/AIDS. I am interested as why African Americans with HIV/AIDS do not keep their appointment visits at the infectious disease clinic.

You will be asked to share information about your past visits. You will be asked to rate how your relationship was with the person that you saw most when you came for care. You will also get to say what other things may have kept you from coming to your clinic visits.

If you say YES, then your participation will last for about 15 minutes. The interview will happen during this visit at the Eastern Virginia Medical School Outpatient Immune Deficiency clinic located at Hofheimer Hall. About 30 to 50 patients who come to the "walk-in" outpatient medical clinic will be participating in this study.

EXCLUSIONARY CRITERIA

To participate in this study, you should be an African American, 18 years or older, and with an ability to read and understand written English.

To the best of your knowledge, you should not have any difficulty in reading and understanding the questions. If you do have problems reading, the staff will read the information to you.

RISKS AND BENEFITS

RISKS: If you decide to participate in this study then you may face the following risks:

1. You may become emotional in answering the questions on the form about what you think about the person who gave you care when you visited the clinic.
2. You may become emotional when you think about why it was difficult to keep your follow up clinic appointments.
3. You may be concerned about your confidentiality.

The researcher tried to reduce these risks by:

1. Writing questions in a manner that will not cause you to become emotional.
2. Not using information that could identify specific patients or the name of the health care provider that you may be discussing.

Let us say, however, there is some possibility that you may be subject to some of these other laws and that you have decided

NOTE: There are no direct results to you being in the study. The study will allow you to share your thoughts about why you did not keep your medical appointments at the education centers, especially those by persons who have not been in the study. The results of this study may help explain and suggest explanations for why you keep your medical appointments and results in treatment. Other researchers reading about the best ideas, questions and thoughts may benefit by learning how to improve their relationship with their patients and what they like about their patients' thoughts in care.

2013 AND 2014

THE SUBSCRIPTIONS OF YOUR COMPANY WILL BE PAID FOR BY THE COMPANY. THERE IS NO NEED TO PREPARE A CHECK OR MONEY ORDER. YOU WILL NOT RECEIVE PAYMENT BY POSTAL ORDER.

THE FUTURE OF THE FIRM

*** The respondents to my questionnaire stated that they had never personally bought for their own personal use. They will give it to you.**

GOVERNMENT

[illegible]

1. 凡在本市行政区域内从事经营活动的个体工商户，均须依法向工商行政管理部门申请注册登记，领取营业执照后方可开展经营活动。

RECEIVED

to get to understand your participation in the study, at any time. If they develop potential problems with your continued participation, we will discuss them with you.

CONSTITUTIONAL LAW AND POLICY

[illegible]

YOU'VE GOT TO SEE THIS

that you are satisfied that your understanding of the issue, the research study, and its risks and benefits. The researcher should answer any questions you may have and obtain the permission. If you have any questions later on, then the researcher should be able to answer them.

Or Karen Robinson at 713-493-6363 or Crystal Smith at 713-231-7264

At any time you have difficulty in contacting us, please, have any questions about your rights in this form, then you should contact O'Connor Publishing, the current publisher, at 715-482-4828, or the Old Dominion Publishing Office at 715-482-4828, at 715-482-4828.

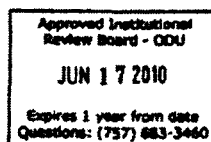
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Product Development Department, P.O. Box 100,
New York, N.Y. 10001.**

Subject's Printed Name & Signature	Date
Witness' Printed Name & Signature	Date

INVESTIGATOR'S STATEMENT

I certify that I have explained to this subject the nature and purpose of this research, including benefits, risks, costs, and any experimental procedures. I have described the rights and protections afforded to human subjects and have done nothing to pressure, coerce, or falsely entice this subject into participating. I am aware of my obligations under state and federal laws, and promise compliance. I have answered the subject's questions and have encouraged him/her to ask additional questions at any time during the course of this study. I have witnessed the above signature(s) on this consent form.

Investigator's Printed Name & Signature	Date
---	------



APPENDIX K
INFORMED CONSENT
EASTERN VIRGINIA MEDICAL SCHOOL

FORM DATE: 7/1/08

Questionnaire and Interview Consent Form
Eastern Virginia Medical School (EVMS) Institutional Review Board

Study Title:	Factors that Influence Nonadherence to Outpatient Medical Follow-up by African Americans with HIV/AIDS at an Outpatient Infectious Disease Clinic
Name of Investigator:	Edward C. Oldfield, III, M.D., F.A.C.P. LuAnn Gahagan, RN Judy Wessel, NP <i>Eastern Virginia Medical School, Infectious Disease Clinic</i> Agatha-Parks Savage, EdD, LPC <i>Eastern Virginia Medical School, Family Medicine Department</i> Cynthia Banks, MS, RN Karen Karlowicz, RN, MSN, EdD <i>Old Dominion University School of Nursing</i>
Sponsor:	none
Name of Subject:	

You are being asked to participate in a research study involving the collection of information in the form of a brief questionnaire and face-to-face interview. The purpose of the research project is to find out why African Americans, more than any other ethnic group, do not keep their HIV/AIDS treatment appointments at the EVMS infectious disease clinic. About 50 patients who come to the "walk-in" outpatient clinic will participate in this study.

Completion of the interview and questionnaire will require approximately 15 minutes of your time. During the fifteen minutes, you will be asked by the staff in the clinic to complete a short survey, and to answer four questions. The interview will happen in a private area of the clinic during this visit at the Eastern Virginia Medical School Outpatient Immune Deficiency clinic located at Hofheimer Hall. During the interview, you will be asked questions about your relationship with the person you see most when you come in for care. You will also be asked to talk about things that keep you from coming to your clinic visits.

You will not be reimbursed for your participation. There are no additional costs to you associated with taking part in this study.

Risks related to your participation are unplanned release of your information and possible psychological discomfort as you answer questions about your experiences with HIV/AIDS treatment. There may be other risks not yet identified. There may be other risks not yet identified.

You should not participate in this research unless you are an African American HIV/AIDS patient, aged 18 years or older or less than 80 years of age, with an ability to read and understand written English. If you do have problems reading the questions in our questionnaire, the staff can read the information to you.

Although the results of this research may not benefit you directly, they may be made available upon request.

Form DATE: 7/1/08

All protected health information will be maintained in strict confidence as required by law. However, your protected health information may be disclosed if required by law. Once your protected health information is disclosed for research, such as to the sponsor, federal privacy laws may no longer protect the information.

Your study records may be reviewed and/or copied in order to meet state and/or federal regulations. Reviewers may include, for example, an Eastern Virginia Medical School Institutional Review Board and/or an Old Dominion University Institutional Review Board.

Information learned from this research may be used in reports, presentations and publications. None of these will personally identify you.

Taking part in this study is your choice. If you decide not to take part, your choice will not affect any medical benefits to which you are entitled. You may choose to leave the study at any time. The investigator may decide to take you off this study if you revoke your authorization or if you are unable to complete the questionnaire and interview process.

We will tell you about new information that may affect your health, welfare, or willingness to stay in this study.

In the event of injury resulting from this research study, Eastern Virginia Medical School (EVMS) and Old Dominion University (ODU) provide no financial compensation plan or free medical care.

If you have any questions pertaining to this research you may contact Cynthia Banks at 757-237-7301. If you believe you have suffered an injury as a result of your participation in this study, you should contact the principal investigator, Dr. Edward Oldfield at (757) 446-8910. You may also contact Dr. Robert Williams, an employee of Eastern Virginia Medical School, at (757) 446-8423. If you have any questions pertaining to your rights as a research subject, you may contact a member of the Institutional Review Board through the Institutional Review Board office at (757) 446-8423.

<p>You will get a copy of this signed form. You may also request information from the investigator. By signing your name on the line below, you agree to take part in this study and accept the risks.</p>			
Signature of Participant/LAR	Typed or Printed Name	Relationship to Subject	MM/DD/YY

<p>I certify that I have explained to the above individual the nature and purpose of the study, potential benefits, and possible risks associated with participation in this study. I have answered any questions that have been raised and have witnessed the above signature. I have explained the above to the volunteer on the date stated on this consent form.</p>	
Signature of Investigator or Approved Designee	MM/DD/YY

<p>IRB APPROVAL DATE <u>10/22/2009</u> EXPIRES DATE <u>10/19/2010</u> IRB # <u>01-16-PB-0193</u></p>
--

Page 2 of 2

APPENDIX L**PERMISSION TO MODIFY ULETT'S MODEL**

[Start Page](#) [Mail](#) [Calendar](#) [Documents](#) [Sites](#)

[Search Mail](#) [Search the Web](#) [Show Mail](#)
[Create a filter](#)

[Compose Mail](#)

[Inbox \(2\)](#)

[Sent Mail](#)

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[Priority](#)

[4 more v](#)

[Contacts](#)

[Tasks](#)

[Chat](#)

Search, add, or invite

Cynthia Banks

[Set status here](#)

cbbanks

Finch, Sandy J.

Gahagan, LuAnn S.

Karlowski, Karen A.

Maihafer, George C.

Michael J Mugavero

Oldfield, Edward C.

phyllis.morgan

Sillman, Elizabeth A.

Wessell, Judy A.

[Options](#)

[Add contact](#)

Rotten Tomatoes: Movies - 97% [The Social Network](#) - 1 hour ago

[« Back to Inbox](#) [Archive](#) [Report spam](#) [Delete](#) [Move to](#) [Labels](#) [More](#)


Request for Modification of the model [Inbox](#) [X](#)


Cynthia Banks to Michael

Dr. Mugavero,
Please note the attached letters. One letter is one that I sent to you in March 2010.
This is a new request that I have concerning the model in the article by Ulett, et al

Thank you,
Cynthia Banks
Old Dominion University

2 attachments — [Download all attachments](#)

 **Dr. Mugavero.doc**
26K [View](#) [Download](#)

 **October 11 Dr. Mugavero.doc**
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Michael J Mugavero to me

Hi Cynthia,

This all sounds very reasonable to me. Best of luck with your continued studies

Best,
Michael

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From: Cynthia Banks [<mailto:cbank003@odu.edu>]

Sent: Monday, October 11, 2010 9:25 PM

October 11, 2010

Michael J. Mugavero, M.D., M.H.Sc.
CCB 178, 908 20th Street South
Birmingham, AL 35294-2050

Hello Dr. Mugavero,

Please let me take the time to re-introduce myself again. My name is Cynthia Banks. I am a doctoral student in Health Services Research at Old Dominion University in Norfolk Virginia. My research is focused on nonadherence with African Americans to their outpatient medical appointment. I sent you the attached email in March 2010 to obtain permission to photocopy your Adaptation of the Behavioral Model of Health Service Utilization. Thank you for giving me permission to photocopy the model. As, I continue to work on my research study, and with the focus on the African American population and nonadherence, I now realize that I need to request modification of the model that is referenced.

In the model, there are three areas under Health behavior (linkage of care, retention in care and ARV receipt and adherence). I would like to obtain permission to include "nonadherence" under that category. Another area on your adapted model is Provider Factors which include trust, experience and concordance. Also, I would like to obtain permission to examine the following factors of the provider, ethnicity and specialty areas such as physician, nurse practitioner and physician assistant as it relates to African Americans nonadherence to HIV/AIDS care. If you have any questions or concerns, I would be happy to contact you at your earliest convenience.

Respectfully submitted,

Cynthia B. Banks

Cynthia Banks
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VITA

CYNTHIA BURRELL BANKS

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EDUCATION:

Master of Science, Concentration: Nursing Case Management
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