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REHABILITATION SERVICE UTILIZATION AMONG AFRICAN AMERICAN WOMEN
LIVING WITH HIV/AIDS: USING THE BEHAVIORAL MODEL
FOR VULNERABLE POPULATIONS

A dissertation submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy in Health Related Sciences - Rehabilitation Leadership
at Virginia Commonwealth University.

by
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Abstract

REHABILITATION SERVICE UTILIZATION AMONG AFRICAN AMERICAN WOMEN LIVING WITH HIV/AIDS: USING THE BEHAVIORAL MODEL FOR VULNERABLE POPULATIONS

By Aisha E. Shamburger-Rousseau, Ph.D., CRC

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Health Related Sciences - Rehabilitation Leadership at Virginia Commonwealth University.

Virginia Commonwealth University, 2013

Major Director: Amy J. Armstrong, Ph.D., CRC, Department of Rehabilitation Counseling

African American women represent one of the largest groups disproportionately living with and affected by HIV/AIDS yet African American women have largely been unrepresented in the federal-state rehabilitation system. As pharmaceutical treatment options improve and individuals with HIV/AIDS are living longer and healthier lives, research exploring the appropriateness of rehabilitation services has increased. Accordingly, it has become more necessary to address the needs of this population. As the largest service provider for people with disabilities, the state-federal rehabilitation system has the potential to be a vital resource for African American women living with HIV/AIDS.

The purpose of this study is to identify and examine variables related to and predictive of the utilization of rehabilitative services among a sample of African American women living with HIV/AIDS in the United States who volunteered to complete the National Working Positive Coalition - Vocational Development and Employment Needs Survey (NWPC-VDENS). The

sample for this study was 313 African American women living with HIV/AIDS who were recruited from AIDS service organizations and national networks throughout the United States. Participants voluntarily completed the NWPC - VDENS, which explored their needs in the areas of education, training, employment, and health. The behavioral model for vulnerable populations was utilized as a framework to organize and examine predisposing, enabling and need constructs as they related to the utilization of rehabilitative services among African American women living with HIV/AIDS.

This study used descriptive, bivariate and binary hierarchical logistic regression statistical analyses to determine the extent to which the constructs were predictive of the use of vocational rehabilitative services. The bivariate analyses produced no statistically significant differences between users and non-users of vocational rehabilitation services for either the predisposing or need variables. Three enabling characteristics, receipt of income benefits, knowledge of services, and reasonable access were all found to have statistical significance in the bivariate analyses. At least one variable from each construct was statistically significant in the regression model. Receipt of income benefits and knowledge of rehabilitation services were found to be predictive of the utilization of vocational rehabilitation services. Study findings framed from previous research, study limitations, implications, and recommendations for future research were acknowledged.

Chapter 1: Introduction

Overview

The Americans with Disabilities Act of 1990 protects an individual considered to have a disability if he or she “has a physical or mental impairment that substantially limits one or more major life activities, has a record of such impairment, or is regarded as having such impairment” (Americans with Disabilities Act [ADA], 1990, p. 1). Whether symptomatic or asymptomatic, individuals living with HIV or AIDS are protected under the ADA and are therefore eligible for state-federal vocational rehabilitation services. The vocational rehabilitation system is multidisciplinary and serves as a vital component of the larger health care system in the United States. Rehabilitation counselors traditionally assist clients with physical, mental or emotional disabilities to obtain or maintain employment and self-sufficiency. The American Medical Association ([AMA], 2011) identifies rehabilitation counseling as a health care career in which counselors are required to draw on “knowledge from several fields, including counseling, psychology, medicine, sociology, social work, education and law” (p. 2). Vocational rehabilitation services have been found to improve health outcomes (Schur, 2002). Despite the fact that the incidence rate of HIV/AIDS is increasing, very few studies have examined health beliefs and vocational rehabilitation service utilization by women who self-identify as both African American and seropositive.

HIV refers to the human immunodeficiency virus that leads to acquired immunodeficiency syndrome, better known as AIDS (Centers for Disease Control and

Prevention [CDC], 2011a). HIV and AIDS both continue to be significant health burdens globally. Within the United States alone, an individual is infected with HIV every 9.5 seconds (Kaiser Family Foundation [KFF], 2009). Although there are widely accepted treatment options to prevent the virus from replicating in the body, there is presently no vaccine or cure for the virus (CDC, 2012a).

African American women have been disproportionately affected by HIV/AIDS, and the most disadvantaged women are often at the greatest risk for contracting the disease. In 2009, although African American women accounted for only 12% of the United States' female population, they comprised 57% of all new HIV infections among women in the United States (CDC, 2011b; KFF, 2011). In addition to having gender-specific needs, African American women additionally confront cultural and race-based issues. This study seeks to address the needs and rehabilitation utilization patterns of African American women living with HIV/AIDS. It uses the behavioral model for vulnerable populations, an iteration of the most widely used framework in allied health to describe service utilization, as the guiding theory for a nation-wide study of African American women living with HIV/AIDS.

This study will use the term *African American* to describe the racial group being examined. The CDC utilizes the terms *Black* and *African American* interchangeably, defining both as people having origins in any of the Black racial groups of Africa, including people who indicate their race as Black, African American, or Negro (CDC, 2012a). This study will follow the precedent established by the CDC to identify study subjects.

Women have distinctly different concerns and stressors compared to their male counterparts when coping with an HIV-positive status. Obstacles include a paucity of women's support groups, inadequate childcare, the dual role of being a patient and caregiver, the threat of

losing child custody if one's health status is disclosed, a dearth of possible guardians for their children and feelings of guilt surrounding the possibility of having transmitted the disease to the children (Hackl, Somlai, Kelly, & Kalichman, 1997). African American women living with HIV/AIDS face their own unique issues relative to the intersection of disability, race, culture and gender (Amaro, 1995; Mulenga & Conyers, 2003; Quinn, 1993; Sigel et al., 1998). While African American women are not more genetically predisposed to HIV/AIDS, research has identified that this group is more susceptible to additional factors contributing to health disparities such as poor medical access, social stigma, lack of community support, and fear of disclosure (Toldson, Essuon, & Woodson, 2009). Burkett's (2000) findings from the analysis of three major health journals further suggests that explanations for illness and mortality are limited to the individual behaviors of African American women and few address the context in which these behaviors occur.

Typically, women who are at the highest risk for contracting HIV/AIDS represent the most disadvantaged segment of society. Some are at higher risk because they are faced with challenges such as homelessness, physical violence, sexual abuse, low education, lack of health insurance, unemployment, drug addiction, and poverty (Mulenga & Conyers, 2003). Many of these circumstantial factors place African American women at greater increase for infection. Moreover, the high prevalence of HIV among African American men has resulted in increased HIV transmission risk for African American women, whether or not they personally engage in risky behaviors (Aziz & Smith, 2011).

Statement of the Problem

There is a paucity of research that examines the variables affecting the utilization of vocational rehabilitation services among African American women living with HIV/AIDS. It is

the goal of this study to focus on the utilization needs of African American women living with HIV/AIDS rather than examining the differences between African Americans and Whites. Current research literature suggests additional research aimed at understanding the utilization of vocational rehabilitation by African American women with disabilities is warranted (Catz, Gore-Felton, & McClure, 2002; Conyers, 2004a, 2008; Vetter & Donnelly, 2006; Whitmore, Satcher, & Hu, 2005). Understanding more about this group's experiences, needs, and concerns relating to access to services of African American women living with this disease may broaden the knowledge base to influence public policies, modify treatment strategies, increase successful outcomes, address health disparities, guide the development of effective healthcare interventions and impact future research into a rapidly growing population of people with disabilities.

Purpose of the Study

The purpose of this study is to identify and examine variables related to and predictive of the utilization of rehabilitative services among a sample of African American women living with HIV/AIDS in the United States who volunteered to complete the National Working Positive Coalition - Vocational Development and Employment Needs Survey (NWPC-VDENS).

Current research indicates that heterosexual African American women are the fourth largest group of newly HIV-infected individuals, preceded only by White, African American and Hispanic men who have sex with men (CDC, 2011b). It is estimated that, overall, 1 in 139 White women will be diagnosed with HIV in her lifetime; in contrast, it is estimated that 1 in 32 African American women will be diagnosed with HIV in her lifetime (CDC, 2011c). For the past decade, AIDS has been one of the top leading causes of death among African American women (National Center for Injury Prevention and Control [NCIPC], 2007).

This study focuses on African American women living with HIV/AIDS. It seeks to fill a gap in the knowledge specific to African American women accessing the vocational rehabilitation system. Many studies and subsequent public health initiatives have been directed toward addressing strategies to prevent infection in African American women (Collins, Whithers, & Braithwaite, 2007; DiClemente & Wingood, n.d., 1995; El-Bassel et al., 1995; Evergreen Health Services of Western New York, 2007; Kelly et al., 1994; The Women's Collective, n.d.). However, few studies have addressed the issue of culture- and gender-appropriate rehabilitative services following an HIV or AIDS diagnosis. This study is particularly critical because several researchers (Catz et al., 2002; Conyers, 2004a, 2008; Conyers & Datti, 2008; Vetter & Donnelly, 2006; Whitmore, Satcher, & Hu, 2005) have recommended additional studies to develop a better understanding of the needs of African American women living with HIV/AIDS in order to provide a more holistic approach to treatment.

The behavioral model for vulnerable populations is a framework for analyzing access to the health care system. It consists of five components, including policies, characteristics of the health care system, utilization of services, satisfaction of the consumer, and characteristics of the population at risk. This study focuses on the last of these components. The characteristics of the population at risk include elements related to predisposing, enabling, and need. Predisposing characteristics refer to the propensity of an individual to utilize health care services; enabling characteristics portray the resources available to an individual or that person's family; and need characteristics refer to an individual's self-perceived or professionally evaluated need for care based on that person's level of illness.

The behavioral model for vulnerable populations framework guided the selection of the study's three primary research questions. Research Question 1 sought to answer descriptive

questions related to predisposing, enabling, and need characteristics specific of African American women living with HIV/AIDS who completed the NWPC-VDENS. The results were used to characterize the sample. There were no accompanying hypotheses for Research Question 1. Research Question 2 sought to examine which predisposing, enabling and need characteristics distinguished African American women living with HIV/AIDS who completed the NWPC-VDENS who had utilized vocational rehabilitation (VR) services from those who had not utilized VR services. Eleven hypotheses accompanied Research Question 2. Research Question 3 was exploratory and was answered through an analysis of the overall data. There were three accompanying hypotheses. The three research questions and resulting hypotheses identified and examined the variables related to and predictive of the use of vocational rehabilitation services among African American women living with HIV/AIDS (see Appendix A). The study results were further used to compare the differences between the women who utilized vocational rehabilitation services and those who did not.

Background and Significance

The acronym HIV stands for human immunodeficiency virus, a condition that leads to acquired immunodeficiency syndrome (AIDS; CDC, 2011a). It is possible for an individual to live with the HIV infection for years before it develops into AIDS. The CD4 cell counts for an individual with a healthy immune system range from 500 to 1800 per cubic millimeter of blood (CDC, 2007). An individual is diagnosed with AIDS when their CD4 cell count falls below 200 or they contract certain opportunistic infections such as tuberculosis or *Pneumocystis carinii* pneumonia (PCP), according to the CDC. The Centers for Disease Control and Prevention estimate that more than 1 million people are living with HIV in the United States, with an estimated 20% of them unaware of their HIV-positive status (CDC, 2011d). It is estimated that

approximately 50,000 Americans become infected with HIV each year and more than 16,000 Americans die from AIDS each year (CDC, 2011b, 2011d).

Racial and ethnic minorities account for a disproportionate number of individuals living with HIV/AIDS in the United States. This health disparity is best evidenced in the changing trends in the first 20 years of the epidemic. The proportion of new cases in non-Hispanic Whites has consistently decreased from 60% in 1981 to 43% in 1996, and 31% in 2010 (CDC, 2012b; Osmond, 2003). However, the proportion of new cases among African Americans rose from 25% in 1981 to 50% in 2001 and slightly decreased to 44% in 2010 (CDC, 2012b; Osmond, 2003). HIV-positive African Americans also die at a younger age following an AIDS diagnosis compared to HIV-positive Whites (Hall, McDavid, Ling, & Sloggett, 2006).

The mode of transmission for African American women has also shifted over the last 20 years. In reported cases through 1990, 57% of African American women reported being infected through intravenous drug use versus 32% who were infected via heterosexual contact (Ickovics & Rodin, 1992). In contrast, in 2010, only 13% reported contracting the virus through intravenous drug use while 87% specified contraction through heterosexual contact (CDC, 2012b). This changing trend of mode of transmission for HIV is in large part due to several early public health initiatives to educate and prevent HIV infection via contaminated injection equipment (Wodak & Cooney, 2005). While the mode of transmission has shifted, the growing numbers of African American women contracting the virus continues to remain problematic.

In 2009, African American women accounted for 12% of the United States female population; in contrast, this demographic accounted for 57% of all new HIV/AIDS infections among American women (CDC, 2011b; KFF, 2011). In 2007, HIV infection was the sixth leading cause of death for all women aged 25 to 34 years, but the fourth leading cause of death

for African American women in the same age group (NCIPC, 2007). For all women aged 35 to 44, HIV infection was the fifth leading cause of death, but the third leading cause of death for African American women in the same age category (NCIPC, 2007). According to the CDC (2012b), the HIV infection rate among African American women is currently 20 times greater than that among White women.

African American women are over 20 times as likely to die from HIV/AIDS as their non-Hispanic White counterparts (CDC, 2008). Additionally, once diagnosed, African American women do not live as long as White women (Hernandez & Smith, 1991). Recent trials have identified some of the factors behind these statistics: late initiation of treatment, high prevalence of co-occurring conditions, lack of participation in HIV care, and differences in response rates to therapy (Smith, 2010). The Gender, Race and Clinical Experience (GRACE) study also noted statistically significant lower response rates to treatment by African American patients compared to White and Hispanic patients (Currier et al., 2010). The GRACE study also found minorities and women to have poorer virologic responses to Highly Active Antiretroviral Therapy (HAART) regimens (Currier et al., 2010) Whites and males. In a study conducted in a clinic in Tennessee, with a sample size of 2605, researchers found that the percentage of time African American patients received HAART treatment was significantly lower than that of Whites. Even within the African American group, the percentage of time receiving HAART treatment was found to be lower for women than for men (Lemly et al., 2009). Overall findings suggested African American patients and women in care were also more likely to die in care than Whites (Lemly et al., 2009).

State-Federal Vocational Rehabilitation System

Vocational rehabilitation is a specialized counseling service, which assists people with disabilities in preparing for, obtaining, and maintaining employment as well as reaching goals of independent living. The state-federal vocational rehabilitation system is the most widely used formal system of services for individuals with disabilities (Wilson, 2000). State-federal rehabilitation in the United States was originally established via the Smith-Hughes National Vocational Education Act of 1917. The Smith-Hughes Act made federal funds available to states to match in providing vocational education services. The state-federal vocational rehabilitation system, which continues to be funded by federal and state monies, is designed to “help persons with disabilities help themselves to prepare for, start and maintain a career” (OVR, 2001). The Vocational Rehabilitation Act of 1954 legislated funding to expand services for individuals with mental illness or intellectual disabilities, for research, and for the physical improvement of rehabilitation agencies (Elliott & Leung, 2005).

Over the course of the next 20 years, vocational rehabilitation continued to grow and evolve, eventually influencing the passage of the Rehabilitation Act of 1973, which expanded and revised the authorization of states to provide vocational rehabilitation services. The core mandates of the act were to (a) serve individuals with disabilities, (b) promote consumer-led rehabilitation plans, (c) stress program evaluation, (d) provide support for rehabilitation research, and (e) prohibit discrimination in employment toward people with disabilities (Rehabilitation Act of 1973). In essence, the act prohibited employment discrimination on the basis of disability in programs directly or indirectly funded by federal monies. The Rehabilitation Act of 1973 was a precursor to the Americans with Disabilities Act (ADA) of 1990, which provides federal civil rights protections to individuals with a protected disability. Both symptomatic and

asymptomatic individuals with HIV/AIDS are protected under the Americans with Disabilities Act.

Rehabilitation counselors traditionally assist clients with physical, mental or emotional disabilities to obtain or maintain employment and self-sufficiency. They are often responsible for providing case management services, evaluating medical and psychological reports, making appropriate referrals, coordinating medical and vocational services, and working with employers to identify suitable accommodations. Rehabilitation services are generally available to eligible individuals with physical disabilities, chronic diseases, developmental disabilities and psychiatric disorders. Services can include, but are not limited to, diagnostic assessments to determine eligibility, counseling and guidance, referrals to other agencies, job referrals, job placement and retention services, vocational and other training services, academic schooling beyond high school, physical and mental restoration services, transportation, on-the-job or other personal assistance services, interpreter services, maintenance of additional financial services while receiving rehabilitation services, adjustment training, technical and technological assistance, supported employment, and post-employment services to retain or advance in employment (Rehabilitation Act of 1973, as amended in 1992).

In particular, when controlling for race, rehabilitation counseling services have been found to be effective for those who use the services to the full extent (Hayward & Schmidt-Davis, 2003). Although the number of individuals living with HIV/AIDS who choose to access the formal rehabilitation system remains low (approximately 2100 per year) data from 2008 indicate that 42% of individuals living with HIV/AIDS were employed after completing services provided through the formal rehabilitation system (Datti & Conyers, 2010). This statistic is

promising in encouraging African American women living with HIV/AIDS to seek services through the vocational rehabilitation system.

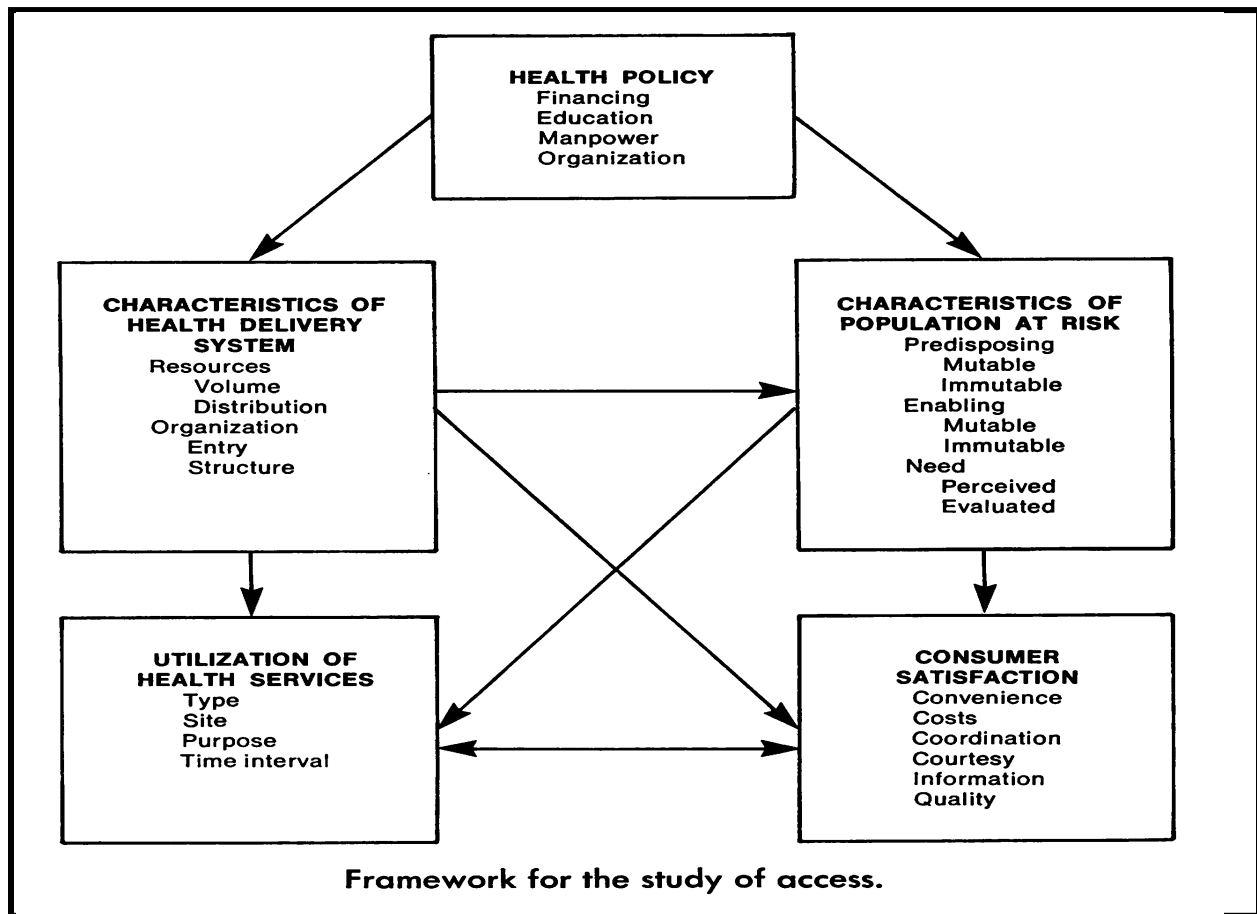
Theoretical Framework

A theory is a concise statement that explains the relationship between observed or approximated units in the empirical world, with the goal of answering how, when or why something occurs (Bacharach, 1989). A theory frames research problems and guides the research methods to explain newly obtained knowledge. The theoretical framework that is utilized in this study is the behavioral model for vulnerable populations. There are many variables that may arguable influence the use of the vocational rehabilitation system. The behavioral model for vulnerable populations consists of three primary components: predisposing, enabling, and need characteristics, which provided a theoretical approach to guide the selection of this study's predictor variables.

Andersen originally developed the behavioral model in 1968 as a framework to study the variations in the utilization of medical care by families. Through several revisions of the model, Andersen revised the model to focus on individuals instead of the larger familial unit (Andersen, 1995). The behavioral model has been the dominant model for analyzing health service utilization for more than 25 years (Calsyn, 2003).

The five components of the behavioral model's framework for access to health care are (a) health policy, (b) characteristics of the health delivery system, (c) utilization of health services, (d) consumer satisfaction, and (e) characteristics of the population at risk (Aday & Andersen, 1974; Gelberg, Andersen, & Leake, 2000; see Figure 1 for a visual display of the framework). Health policy, which is the first component considered when evaluating access to care within a system, includes systems of financing, education, manpower, and organization.

Figure 1. Behavioral Health Framework for the Study of Access.



Health planners and policy makers most often focus on this area of input into accessing health care. The characteristics of the health care delivery system and the population at risk are the inputs in the health care system that lead to the outcomes, which are health services utilization and consumer satisfaction.

The second component of accessing care within a system is evaluating the characteristics of the health delivery system, which includes resources and organization. With the unit or system of delivery as the focus, an emphasis is placed on the volume and distribution of medical resources including human labor, equipment, and the financial capital involved in the health care system (Aday & Andersen, 1974; Andersen & Newman, 1973; Gelberg et al., 2000).

Organization, which can include policies and procedures to coordinate provided services, describes what the system does with the resources at the point of entry into the health system and what happens to the patient beyond the initial entrance.

The third component, utilization of health services, depends on the type, site, purpose, and time interval of services provided. Researchers categorize the reasons for accessing the system as preventive, illness-related, or custodial care (Aday & Andersen, 1974; Gelberg et al., 2000). Preventive care refers to medical interventions to avert an individual from contracting an illness or disease. Illness-related care refers to returning individuals to their original state of health or stabilizing their current health condition (Aday & Andersen, 1974). Custodial care refers to providing medical services to an individual without providing treatment for the condition, illness or disease (Aday & Andersen, 1974), often described as palliative care.

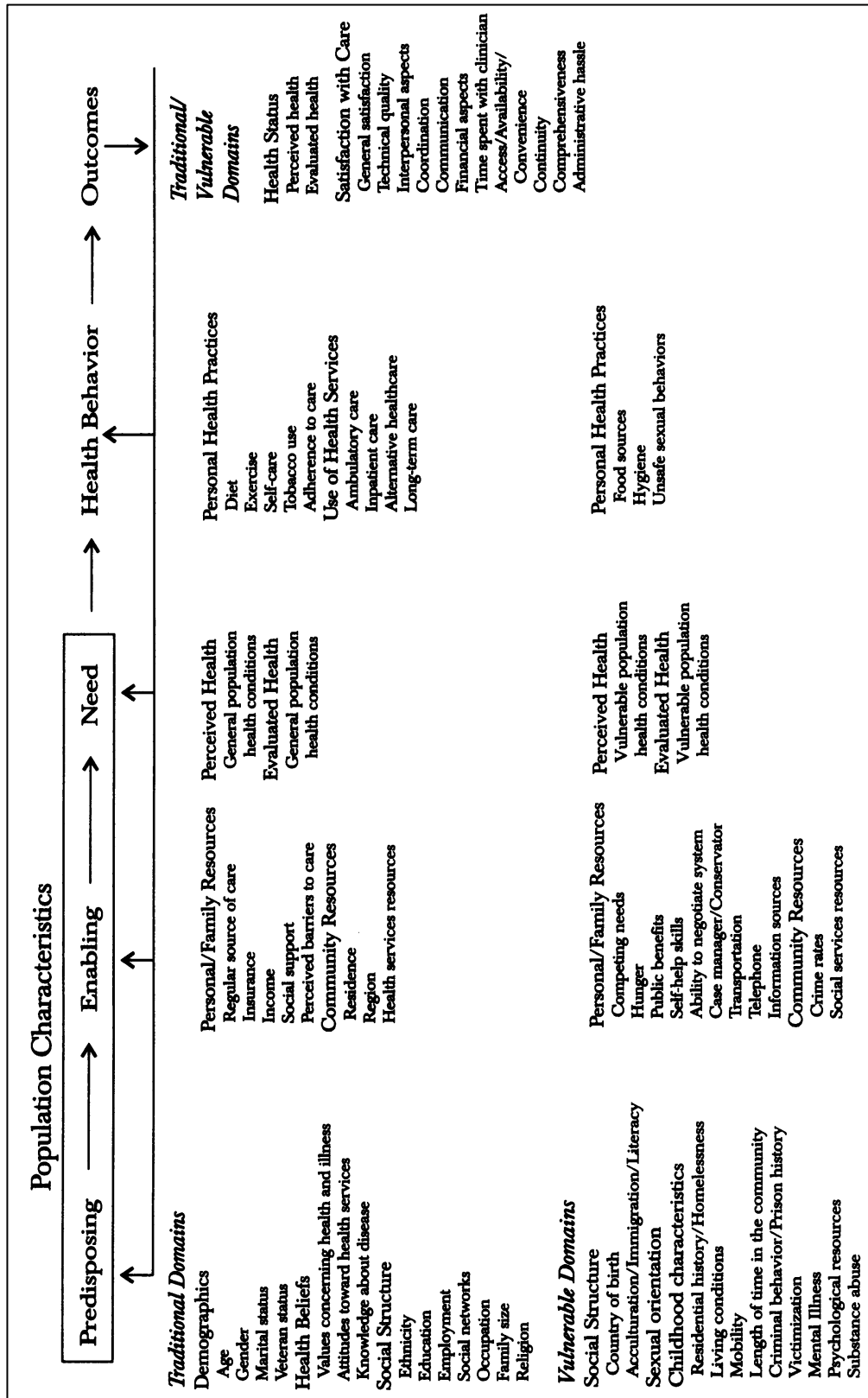
The fourth component, consumer satisfaction, is a measure of attitudes towards the health care system of those who have had direct contact. Commonly evaluated aspects include subjective perspectives pertaining to cost, coordination of services, ease of accessing services, and convenience (Aday & Andersen, 1974; Andersen & Newman, 1973).

The fifth component, characteristics of the population at risk, is the focus of this research project. The latest iteration, the behavioral model for vulnerable populations, is a major revision of the original Behavioral Model. Vulnerable populations are operationally defined as individuals at a higher risk for disease and injury than the general population, including, but not limited to minorities, people with disabilities, impoverished people, and individuals living with chronic illnesses (Gelberg et al., 2000). African American women living with HIV/AIDS would meet the definition of a vulnerable population. The five components specific to vulnerable populations are predisposing enabling and needs characteristics, health behaviors, and outcomes

(Gelberg et al., 2000). This study will focus on the predisposing, enabling, and need characteristics. Each of these characteristics describes various factors leading to a population's utilization of health services. These characteristics emphasize the individual as the unit of analysis, as opposed to the organization or health system providing rehabilitative services (Aday & Andersen, 1974; Andersen & Newman, 1973). Figure 2 displays the characteristics of the populations at risk. The predisposing, enabling, and need components predict service utilization. The model also includes a component to predict personal health behaviors as well as a component to evaluate the utilization of services on health outcomes. The predisposing, enabling, and need characteristics delineate two groupings of variables that can be described as either traditional or vulnerable domains. The traditional domains are derived from the behavioral model and the vulnerable domains from the expanded behavioral model for vulnerable populations.

Gelberg et al. (2000) describe predisposing characteristics as demographic, health belief, and social structure properties that exist prior to the onset of an illness and assist in indicating the likelihood that individuals will utilize health services. This component can also be operationally defined as the predisposition of the individual to use services (Andersen & Newman, 1973; Gelberg et al., 2000). Examples of predisposing characteristics include age, gender, marital status, education, race, ethnicity, occupation, family size, employment, religion, values, past illnesses, residential mobility and knowledge about health and health services (Aday & Andersen, 1974; Andersen, 1995; Andersen & Newman, 1973). The expanded model for vulnerable populations also includes social structure characteristics such as substance abuse, victimization, prison history, literacy, and acculturation (Gelberg et al., 2000).

Figure 2. Characteristics of Populations at Risk Accessing Health Care.



From "The Behavioral Model For Vulnerable Populations: Application To Medical Care Use And Outcomes For Homeless People," by L. Gelberg, R. M. Anderson, and B. D. Leake, 2000, *Health Services Research*, 34(6), p. 1278. Copyright 2000 by Blackwell Publishing. Reprinted with permission.

For the purpose of this study, the analyzed predisposing characteristics include age, children, internal and external stigma, and attitudes toward seeking professional services. According to the behavioral model for vulnerable populations, for predisposing components, age is further classified as a demographic variable; having children is a social structure variable; and internal stigma, external stigma and attitudes toward seeking professional services are health belief variables.

Enabling characteristics describe the resources at an individual's disposal that allow or encourage the utilization of health services. This component includes resources for the individual or family, such as health insurance, transportation, income, and sources of care. The enabling vulnerable domain characteristics include receipt of public benefits, the availability and use of information sources, and the availability of social services (Gelberg et al., 2000). This domain also describes community factors such as the attributes of a rural-urban setting and region-specific qualities of the United States, the price of health services, and ratios of health personnel and facilities to the population of the community (Aday & Anderson, 1974; Andersen & Newman, 1973). These personal and community enabling resources must be present for use of services to take place (Andersen, 1995). If individuals are insured, but live in a rural community without available facilities or are unaware of the facilities, their utilization of services is affected.

For the purpose of this study, the enabling characteristics included receipt of income benefits, source of support for self, source of support for the children, knowledge of vocational rehabilitation services, poverty status, reasonable access to vocational rehabilitative services, and self-efficacy as it relates to employment. In congruence with the behavioral model for vulnerable populations, all of the characteristics would be categorized as personal and family

resources, with the exception of access to vocational rehabilitative services, which is characterized as a community resource.

The need characteristic describes an individual's need for care based on his or her level of illness. Need can either be self-perceived by the individual accessing the health system (perceived need) or based on needs evaluated by a professional within the healthcare delivery system (evaluated need). Examples of perceived needs include symptoms experienced within a certain timeframe, self-report of overall health or symptoms, disability, or limitation of activities. Examples of evaluated need characteristics include clinical evaluations of symptoms or diagnosis, or the physician's rating of urgency of the condition or subsequent treatment (Aday & Andersen, 1974). Gelberg et al. (2000) posit that an individual's perception of health status or a clinician's evaluation of an individual's health status may be influenced by the patient's level of vulnerability. Correspondingly, individuals' perceptions of their health may be directly related to the factor that has made them most vulnerable such as their disability. For the purpose of this study, the illness level characteristics are health beliefs and need for rehabilitative services. Both characteristics are categorized as perceived needs.

Summary

HIV/AIDS is one of the leading causes of death among African American women. African American women represent the fourth largest group newly diagnosed with HIV. Individuals living with HIV/AIDS are protected under the Americans with Disabilities Act and eligible for state-federal vocational rehabilitation services. The benefits of utilizing vocational rehabilitation services have been well established. This study seeks to identify and examine the variables related to and predictive of the utilization of rehabilitative services among African American women living with HIV/AIDS.

The behavioral model for vulnerable populations is the latest iteration of the most dominantly used model for analyzing health service utilization over the last 25 years. The behavioral model for vulnerable populations was used to frame the predisposing, enabling, and need characteristics of the study participants. These characteristics have been identified as principal areas in understanding the use of health services.

Chapter 2: Literature Review

Introduction

This chapter provides an overview of research on the history of HIV/AIDS in the United States; including the stigma of living with HIV/AIDS, the perspectives of women with the disease; HIV/AIDS as a health disparity; and the experience of African Americans, and more specifically, African American women, who are accessing the vocational rehabilitation system. The concluding section, reviews how African American women living with HIV/AIDS share particular characteristics as a vulnerable population. This discussion is framed by the theorized characteristics described by Gelberg et al. (2000).

The broader behavioral health framework for access to health care, which encompasses the behavioral model for vulnerable populations, describes five components for analyzing access to the health care service, namely: health policy, characteristics of the health delivery system, utilization of health services, consumer satisfaction, and characteristics of the population at risk (Aday & Andersen, 1974). According to Gelberg et al. (2000), the characteristics of the population at risk can be classified as predisposing, enabling, and need. The variables included in the predisposing characteristics component for this study are: age, children, internal and external stigma, and attitudes toward seeking professional services. The variables included in the enabling characteristic component for this study are: income benefits, source of support for self, source of support for the children, knowledge of vocational rehabilitation services, poverty status, reasonable access to vocational rehabilitative services, and self-efficacy as it relates to

employment. Finally, the variables for the need characteristic component are health beliefs and the need for rehabilitative services.

The review begins with a chronological history of HIV/AIDS in the United States in order to provide a context for how the disease grew within a short span of 20 years to become an epidemic. This historical perspective also establishes the backdrop for explaining the stigma, which became attached to individuals living with HIV/AIDS.

HIV/AIDS in the United States

HIV is the human immunodeficiency virus that can lead to AIDS, the acquired immunodeficiency syndrome (CDC, 2011a). The CDC (2011a) estimates that more than one million people are living with HIV in the United States, with 1 in 5 being unaware that they are infected. Indeed, an estimated 56,300 Americans become infected with HIV each year, and more than 18,000 people with AIDS still die annually in the United States (CDC, 2011b).

While there are no firm guidelines for identifying the phases of HIV infection, the most widely accepted criteria include three phases. The first is the early or acute phase, where symptoms are subtle or nonexistent (CDC, 2007). As the HIV infection progresses to the clinical latency phase, the manifestation of symptoms may range from asymptomatic to chronic (CDC, 2007). Finally, in the last stage, a diagnosis of AIDS occurs when patients' CD4+ T-lymphocyte (CD4) cell count falls below 200 or when the individual develops certain cancers or opportunistic infections such as tuberculosis or *Pneumocystis carinii* pneumonia (PCP; CDC, 2007).

The first news of acquired immunodeficiency syndrome (AIDS) in the United States came in mid and late 1981, when medical journals began reporting several unusual incidences of young gay males in Los Angeles, New York, and San Francisco being diagnosed with a rare lung

infection called *Pneumocystis carinii* and a relatively benign cancer, Kaposi's sarcoma (KS), which had been most commonly diagnosed in older adults (CDC, 1981). These cases were particularly unusual, because the young adults presenting with the diseases were not known to be otherwise immunosuppressed. Subsequent reports pertaining to infections began to emerge among injection-drug users, Haitians, and individuals diagnosed with hemophilia (A timeline, n.d.; CDC, 1982; Masur et al., 1981). By July 1982, the CDC had received a reported total of 452 similar cases in 23 states (CDC, 1982).

As more instances of infections resulting in death were reported there was a strong desire to identify and place the responsibility for the spread of the disease on at-risk populations. One respected psychologist advised the passage of legislation for the “incarceration of homosexuals until and unless they can be cleansed of their medical problems” (Brandt, 1985, p. 183). Haitian Americans were another group that received a considerable amount of blame from the medical community. In 1982, Dr. Bruce Chabner of the National Cancer Institute surmised that “homosexuals in New York take vacations in Haiti, and we suspect this may be an epidemic Haitian virus that was brought back to the homosexual population in the United States” (as cited in Farmer & Kim, 1991, p. 207). Such rhetoric tended to fuel speculations that Haitian-Americans were originators of the disease due to sacrificial animal blood activity, ritualized homosexuality, and voodoo rituals (Farmer & Kim, 1991). As fears, discrimination, anxieties, and numbers of AIDS-related deaths continued to increase, the federal government was slow to request funding to research a disease that was seen as largely affecting morally controversial groups such as gays and injection-drug users. Thus the authorities confused a disease entity with behavior. In 1982 and 1983, the Reagan administration did not request *any* funding for AIDS

research, and in subsequent years the White House administration consistently requested less money for AIDS research than was actually appropriated by Congress (Brandt, 1985).

By September 1982, the CDC began to formally refer to the disease as AIDS. Although the virus that causes AIDS had not yet been identified, the four known risk factors for contracting the disease were: male homosexuality, intravenous drug use, Haitian origin, and hemophilia A (CDC, 1983). It was not until March 1983 that females with male sexual partners infected with AIDS were identified as a fifth risk group (CDC, 1983). Because of the ongoing uncertainty about the etiology of AIDS, anxiety became widespread both in the United States and abroad. Since the method of transmission of the disease had not yet been identified, fear resulted in such practices as banning children infected with AIDS from school (“A Timeline,” n.d.), closing public swimming pools to prevent interactions with infected individuals (“Speaking of the Plague,” 1991), removing individuals infected with AIDS from airline flights for fear of spreading the disease (Gallagher, 1993), and suggestions of quarantining or visibly marking those infected with the virus (United States Public Health Service [USPHS], 1988).

In 1984, the human immunodeficiency virus (HIV) was identified as the cause of AIDS. In 1988, in the first national mailing of its kind, the United States Surgeon General and the CDC sent out a brochure titled *Understanding AIDS* to all households to educate the public about the disease. The brochure confirmed that the disease could not be spread through casual contact and identified homosexual and bisexual men as well as male and female intravenous drug users practicing high-risk behaviors as the most commonly infected individuals (USPHS, 1988). The report also accurately predicted that heterosexual transmission would increase in the future (USPHS, 1988).

While the disease has progressed over the course of the last 20 years, there is still no known cure or vaccine. The trend associated with the most widely infected populations has shifted over time. Although AIDS was initially identified as a disease effecting gay men, by 1992 AIDS was the leading cause of death for all American men aged 25 to 44 (KFF, 2012). Within two years, AIDS grew to be the leading cause of death for all Americans aged 25 to 44 (KFF, 2012). By 1996, while the disease was no longer the leading cause of death for all Americans aged 25 to 44, it remained the leading cause of death for African Americans in the same age demographic (KFF, 2012). In 2010, while the African American population made up approximately 13% of the U.S. population, it comprised 44% of the HIV and AIDS cases in the United States (CDC, 2012c; Humes, Jones, & Ramirez, 2011). With the widespread growth of the disease also came the attachment of stigma.

HIV/AIDS-Related Stigma

Herek, Widaman, and Capitanio (2005) coined the term *AIDS-related stigma* to describe, “the social devaluing of people perceived to have AIDS or HIV as well as the individuals, groups, and communities with which they are associated” (p. 16). This definition was largely framed by a classic theory of stigma developed prior to the onset of HIV/AIDS in 1963 by sociologist Erving Goffman (Goffman, 1963; Herek, Capitanio, & Widaman, 2002; Herek et al., 2005). AIDS-related stigma (hereafter referred to as *HIV/AIDS stigma*) has been consistent and ongoing since the disease was first identified in the early 1980s. HIV/AIDS has become the health scourge of the 21st century, similar to leprosy and the plague in the Middle Ages.

Three characteristics have been identified that are likely to evoke HIV or AIDS stigma (Herek, 2002). The first stigmatizing characteristic is the attachment of an individual’s HIV-positive diagnosis to a virus that is commonly thought to be contracted as a result of the

individual's immoral behavior (Herek, 2002). As a consequence, feelings of disgust, anger, or blame are projected as opposed to feelings of empathy or concern (Herek, 2002). In a study consisting of a sample of 5,600 adults, 1 in 5 Americans held value-laden reactions about people living with the disease, agreeing with the statement that "people who got AIDS through sex or drug use have gotten what they deserve" (CDC, 2000, p. 1).

Although the trajectory of HIV disease has changed from a life-threatening illness to a chronic condition (El-Sadr, Mayer, & Hodder, 2010), many people still regard HIV as a condition leading to death (Herek, 2002). The second characteristic of stigma is that HIV/AIDS carries a greater stigma than many other illnesses because it is attached to a condition that is often regarded as leading to death (Herek, 2002). Indeed, in the initial years of the disease, prior to the introduction of antiretroviral drugs, it was likely for the disease to result in a quick death. Herek (2002) notes that, in spite of the scientific advancements of drug treatments that frequently offer hope such as HAART regimens, most Americans still perceive AIDS as a degenerative and fatal malady. Healthy individuals may attempt to distance themselves from people living with HIV/AIDS because they believe it will protect them from the virus (Herek et al., 2002).

The third characteristic is an increased stigma toward those illnesses or diseases that are perceived as contagious (Herek, 2002). While public education pertaining to the contraction of HIV/AIDS has been extensive (dating back to 1988), the history of HIV/AIDS is wrought with panic, anxiety, and fear of the unknown. These attitudes have resulted in ostracization and discrimination against individuals living with HIV/AIDS. In spite of medical research, many Americans still retain fears about being in close proximity to an individual diagnosed with HIV or AIDS. In 2002, a study found that nearly 1 in 5 Americans reported fear of someone diagnosed with AIDS (Herek et al., 2002). In the same study, 1 in 6 Americans described

feelings of disgust towards people living with AIDS and supported the idea of publicly identifying people living with HIV/AIDS (Herek et al., 2002). Even family members or volunteers assisting those living with HIV/AIDS may experience *courtesy stigma*, the phenomenon of being unjustly rejected or experiencing bias because of their association with an individual living with HIV/AIDS (Herek, 2002).

All these characteristics, coupled with a social history of HIV/AIDS being primarily attributed to populations often labeled as immoral and worthy of being ostracized (Brandt, 1985; USPHS, 1988), have contributed to the perpetuation of HIV/AIDS stigma. In 1982 when Haitian origin was originally defined as a risk factor, there was considerable resistance from the Haitian community due to the resulting stigma. Haiti's ambassador protested that Haiti, a part of the African Diaspora, was being used as a "scapegoat for a mysterious ailment" rooted in a history of "world discrimination" toward the country (Sherman, 1983). One journalist suggested that Haitian-Americans had been labeled as presenting "pre-existing characteristics of an already non-normative character. They are Black, tend to be poor, are recent immigrants and the association of Haiti with cult-religious practices fuels the current tendency to see deviance in groups at-risk for AIDS" (Albert, 1986, pp. 174-175).

Although, historically, AIDS stigma has focused on male homosexuality, and many Americans still equate HIV/AIDS with homosexuality (Herek et al., 2005), the stigma of living with the disease has continued to impact other affected groups, such as women. While the perspective of men living with HIV/AIDS has some overlap with that of women, there are also distinctively dissimilar experiences.

Women Living With HIV/AIDS

Women account for over one quarter of all new HIV/AIDS diagnoses, with the vast majority of them ranging in age from 15 to 29 years (CDC, 2007). In 2007, HIV infection was the sixth leading cause of death for women ages 25 to 34 and the fifth leading cause of death for women ages 25 to 44 (NCIPC, 2007). Despite these staggering statistics, HIV-positive women are also less likely to access therapy compared to HIV-positive men (Hall et al., 2006).

At the onset of the HIV/AIDS epidemic in the early 1980s, prevention measures were primarily directed towards White gay males (Sutton et al., 2009). This was largely due to reported cases of infection. Cases of HIV/AIDS in women were reported as early as 1981; however, it was not until nearly 10 years later, in 1991, that women began to be routinely included in clinical studies and attention was focused on gender-specific HIV issues (Nakajima & Rubin, 1991). As a result, the evolution of prevention and treatment programs geared to the needs of women has lagged behind considerably.

Women have distinct concerns and stressors relating to coping with an HIV-positive status, such as a paucity of women's support groups, inadequate childcare, the dual role of being patient and caregiver, the threat of losing custody of children if the health status is disclosed, a dearth of possibilities of guardians for their children, and feelings of guilt surrounding the possibility of having transmitted the disease to the children (Jenkins & Coons, 2002). Research has shown that sociocultural factors such as poverty, low literacy, stigma, unemployment, homelessness, racism, homophobia, and being underinsured or uninsured contribute to the high death rate among women living with HIV/AIDS (Sumartojo, 2000). Additionally, women who reported experiencing HIV discrimination were found to have significantly more adverse health outcomes such as greater stress and suicidal ideations, more depressive symptoms, and episodes

of unprotected vaginal intercourse, as well as lower self-esteem and poorer reports of quality of life (Wingood et al., 2007).

In addition to the aforementioned challenges experienced by women living with HIV/AIDS, African American women living with HIV/AIDS are confronted with additional complicating factors. In the aforementioned study by Wingood et al. (2007), while White women were more likely to report HIV discrimination, an analysis of the data indicates a differential relationship between HIV discrimination and the range of adverse health outcomes observed for African American relative to White women. Strong and consistent associations were observed between HIV discrimination and adverse health outcomes among African American women; however, no such associations were identified for White women (Wingood et al., 2007). The researchers suggest this difference may be partially due to African American women attributing discrimination to racial prejudice rather than to an HIV-positive status or the social inequities routinely experienced by African American women (Wingood et al., 2007). The intersection of gender, race, and disability experienced by African American women living with HIV/AIDS presents a unique paradigm.

African American Women Living With HIV/AIDS

Although the 2005 census data indicate that African American and Latina women comprise only about one fourth of all women in the United States (CDC, 2007), approximately 80% of women living with HIV/AIDS are minorities (CDC, 2007). HIV/AIDS among African American women is a “complex mix of economic, social, cultural, biological, environmental, and behavioral factors” (“Black Women and HIV/AIDS,” n.d., para. 3). African American women living with HIV/AIDS experience overlapping issues relative to disability, race, socioeconomic status, and gender (Amaro, 1995; Mulenga & Conyers, 2003; Quinn, 1993; Sigel

et al., 1998). Political scientist, Michele Berger (2004), terms this multilevel marginalization as *intersectional stigma*. These multiple and intersecting facets have presented a new outlook on the HIV/AIDS epidemic.

Heterosexual Black women are the fourth leading group of newly infected individuals, preceded only by White, Black, and Hispanic men who have sex with men (CDC, 2011b). In 2009, Black women were 12% of the United States female population; in contrast, this demographic comprised 57% of all new HIV/AIDS infections among women in the United States (CDC, 2011b; KFF, 2011). According to the Centers for Disease Control and Prevention (2012b), the HIV infection rate among Black women is currently 20 times greater for White women. In 2007, HIV infection was the fourth leading cause of death for African American women aged 25 to 34 years and the third leading cause of death for African American women aged 35 to 44 (NCIPC, 2007).

The characteristics of the mode of transmission for most Black women have significantly shifted over the last 20 years. In reported cases through 1990, 57% of Black women noted that they had been infected through intravenous drug use (Ickovics & Rodin, 1992). In contrast, in 2010, only 13% reported contracting the virus through intravenous drug use; the remaining 87% contracted HIV through heterosexual contact (CDC, 2012b). Notably, however, the literature suggests that African American women were no more likely to have unprotected sex or multiple partners than White and Latino women (Gottlieb et al., 2002; Kenney, 1996; Sly, Quadagno, Harrison, Eberstein, & Riehman, 1997; Soler et al., 2000; Tillerson, 2008). Although research has shown that the majority of newly infected African American women contract the virus through heterosexual relationships (CDC, 2012b), there is still a strong societal stigma associating HIV and AIDS with homosexual men and intravenous drug users (Herek et al.,

2005). Additionally, the stigma is experienced not only by the individual living with the disease, but also by the family members of HIV-positive women (Vetter & Donnelly, 2006). For women who have chosen not to disclose their status to their children and other family members, this situation can be particularly challenging.

Jones-DeWeever (2005) hypothesized that a consequence of the disproportionate rate of mass incarceration of African American men (as a result of the war on drugs) is that African American women have become more vulnerable to the risk of HIV infection through sexually intimate relationships with men who have been incarcerated. According to a Congressional report by the National Commission on Correctional Healthcare, approximately 20% to 26% of individuals living with HIV/AIDS have spent time in the correctional system (Hammett, Harmon, & Rhodes, 2002). The AIDS case rate among U.S. prison inmates is five times that of the general population (Hammett et al., 2002). Consequently, having a sexual partner who has spent time in prison increases one's chances of contracting HIV (Jones-DeWeever, 2005). Since women generally choose partners from members of their own racial or ethnic group (Lane, Keefe et al., 2004), the likelihood of having a sexual partner with a prison history has significantly increased the exposure of African American women to infected African American men.

Moreover, the number of incarcerated African American men has unbalanced African American male-female ratio within communities (Lane, Keefe, et al., 2004; Lane, Rubenstein, et al., 2004).

Within African American communities, an additional layer of anger has unfolded towards infected men who have sexual relationships with women while failing to disclose their prior same-sex behaviors (Jones-DeWeever, 2005). African American men who have sex with other men or with both men and women have the second highest number of new HIV infections of any listed subpopulation (CDC, 2011b). In a multi-state study with over 5,000 participants, more

African American men reported engaging in bisexual behaviors, but significantly fewer African American women reported having bisexual partners (Montgomery, Mokotoff, Gentry, & Blair, 2003). This failure of men to disclose their sexual behaviors has compounded the risk of increased exposure for African American women in sexual relationships with African American men (CDC, 2003; Montgomery et al., 2003; Tillerson, 2008).

At a time when the greatest amount of social support is needed, African American women living with HIV/AIDS have expressed concerns about disclosing their status for fear that the stigma of living with HIV/AIDS may result in social service agencies deeming them unfit or unable to parent and removing their children from the home (Mulenga & Conyers, 2003). Other African American women report being faced with the dilemma of disclosing their status in order to facilitate the receipt of much needed support, face the fear of a possible breach of confidentiality or loss of familial and romantic relationships (Peterson, 2010; Timmons & Fesko, 2004). These concerns and fears are not unwarranted, as researchers have found that multifaceted stigmatization does in fact occur, a factor that may possibly result in delays in pursuing care and significantly poorer outcomes (Black & Miles, 2002; Garcia, Cartwright, & Glenn, 1997).

HIV/AIDS Health Disparity

In discussing health differences, it is important to distinguish among *health disparities*, *health inequalities*, and *health inequities*. While these terms are sometimes used interchangeably, they have slightly different meanings. *Health inequality* refers to “an observable difference in opportunity, treatment or status” (Villarruel, 2006, p. 5). *Health inequity* also refers to similar inequalities but encompasses an additional connotation of an ethical or moral judgment about the nature of the differences (Carter-Pokras & Baquet, 2002).

Health inequality and health inequity are terms that are more commonly used outside the United States as opposed to the term *health disparity*, which is primarily used within the United States.

In 2003, the Institute of Medicine (IOM) published an extensive resource titled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, which concluded that research clearly demonstrated variations in the provision of quality healthcare by race. This was demonstrated even after controlling for access, insurance status, income, age, and the severity of the condition (Smedley, Stith, & Nelson, 2003). The operational definition of *health disparity* was subsequently credited to the Institute of Medicine, which defines it as “a racial or ethnic difference in the quality of health care that is not due to access-related factors or clinical needs, preferences and appropriateness of intervention” (Smedley et al., 2003, pp. 3-4). For the purpose of this study, the term health disparity is utilized to describe the differences in services for racial and ethnic minorities living with HIV/AIDS.

The overall rate of disability in the United States in 1991 and 1992 was 19.4%, with the highest rate of incidence among populations of Native Americans (21.9%), non-Hispanic Blacks (20%), and non-Hispanic Whites (19.7%; Bradsher, 1996). The overall rate of Americans with a severe disability was 9.6%; the highest rate was for non-Hispanic Blacks (12.2%), followed by non-Hispanic Whites (9.4%; Bradsher, 1996). This data highlights the disparities in the rates of disability between minorities and non-minorities. This disparity places an increased responsibility on the state-federal vocational rehabilitation system to be effective in addressing disabilities in people of color.

By the mid-1990s, in spite of decreasing HIV rates, it was evident that a health disparity existed with African Americans in relation to HIV/AIDS diagnoses in comparison to their White counterparts. In 1998, President Bill Clinton declared HIV/AIDS to be a national crisis among

African Americans and Hispanics and a growing crisis among other communities of color (William J. Clinton Presidential Library and Museum, 1998). In spite of acknowledgment of the health disparity among minorities, African Americans continued to be disproportionately affected by HIV/AIDS. The National HIV/AIDS Strategy, a recent domestic AIDS policy created by the Obama administration in July 2010, directs state and federal agencies to achieve three goals: (a) reduce the number of people who become infected with HIV by 25%; (b) increase access to care and optimize health outcomes for people living with HIV; and (c) reduce HIV-related health disparities (Office of National AIDS Policy, 2010). Such national directives are a response to the HIV/AIDS health disparity among people of color.

HIV-positive African Americans are more likely to die earlier after an AIDS diagnosis than HIV-positive Whites (Hall et al., 2006). According to 2008 data, African American women were over 20 times as likely to die from HIV/AIDS as their non-Hispanic White counterparts (CDC, 2008). While ethnicity and race alone are not risk factors for contracting HIV, several factors may influence the greater chances of African Americans contracting the disease, such as denial about community infection rates, poverty, stigma, limited access to health care, and mass incarceration of African American men (CDC, 2007; Jones-DeWeever, 2005). Recent trials have demonstrated that many adverse outcomes are due to late initiation of treatment, high prevalence of co-occurring conditions, lack of participation in HIV care, and differences in response rates to therapy (Smith, 2010). Additionally, access to quality healthcare and supportive services for HIV-positive people in rural areas or other medically underserved communities is particularly challenging (Black & Miles, 2002). In a survey on service utilization among a national sample of adults in the United States living with HIV, African Americans had the lowest exposure to antiretroviral combination therapies, with African American women

far from the worst of all groups in the survey (Shapiro, 1999). These findings were consistent with a separate national study employing the behavioral model for vulnerable populations to examine the extent to which predisposing, enabling, and need characteristics explain utilization of HAART treatment (Andersen et al., 2000).

African Americans Accessing the Vocational Rehabilitation System

It is standard practice for state-federal vocational rehabilitative agencies to collect data specific to race and ethnicity. In contrast, many private healthcare organizations do not collect such information due to concerns that recording patients' race and ethnicity could be regarded as offensive or even legally unacceptable (Ayanian & Williams, 2007). But because of this standard governmental vocational rehabilitation practice, it is possible to monitor the status and progress of ethnic minorities—including participation rates and outcomes—throughout the vocational rehabilitation process.

The Rehabilitation Act of 1973, as amended in 1992 cited the existence of systematic disparities within the state-federal vocational rehabilitation system. Section 21 of the Rehabilitation Act Amendments of 1992 (hereafter referred to as Section 21) contained federal legislation passed in response to these health disparities. Section 21 states in part:

Patterns of inequitable treatment of minorities have been documented in all major junctures of the vocational rehabilitation process. As compared to white Americans, a larger percentage of African-American applicants to the vocational rehabilitation system is denied acceptance. Of applicants accepted for service, a larger percentage of African-American cases are closed without being rehabilitated. Minorities are provided less training than their white counterparts.

Consistently, less money is spent on minorities than on their white counterparts.

(Rehabilitation Act of 1973, as amended in 1992, p. 26)

Despite the publication of twice as many research articles addressing cultural differences in the vocational rehabilitation process after the passage of Section 21 (Lewis, Shamburger, Head, Armstrong, & West, 2007), findings of health disparities within the state-federal vocational rehabilitation system have continued to persist (Martin, 2010). Several research studies which examined health disparities within the vocational rehabilitation system after the passage of Section 21 have reported that African Americans remain less likely to be accepted to vocational rehabilitation services, receive fewer services, and are less apt to attain successful employment outcomes (LeBlanc & Smart, 2007; Leung, Flowers, Talley, & Sanderson, 2007; Rosenthal, Ferrin, Wilson, & Frain, 2005; Wilson, Harley, McCormick, Jolivette, & Jackson, 2001). The behavioral health framework for the study of access to health care characterizes the aforementioned disparities as barriers deriving from the delivery system domain (Aday & Andersen, 1974; see Figure 1). The characteristics of the organization itself hinder all consumers from receiving fair and equitable services (Aday & Andersen, 1974).

Gender-related concerns are an added dynamic for African American women accessing the health care system. The review of the current literature provides an overview of the experiences specific to African American women living with HIV/AIDS who are attempting to access the vocational rehabilitation system.

African American Women Living With HIV/AIDS Accessing VR Services

The experiences of African American women differ from those of African American men primarily due to gender roles and expectations (Shambley-Ebron & Boyle, 2006b). Indeed, further investigation pertaining to African American women accessing the vocational

rehabilitation is both prudent and warranted. Vocational rehabilitation research studies specific to living with HIV/AIDS have focused on specific groups: all people living with HIV/AIDS (Burns, Young, & Maniss, 2006; Conyers, 2004b; Glenn, Ford, Moore, & Hollar, 2003; Hergenrather, Rhodes, & Clark, 2004; Razzano & Hamilton, 2005; McReynolds, 2003; Hunt, Jaques, Niles, & Wierzalis, 2003); Latino men (Datti & Conyers, 2010); Latino men and women (Burns et al., 2006); and women (Conyers & Datti, 2008; Mulenga & Conyers, 2003). Thus the rehabilitation literature lacks investigation into the use or lack of use of vocational rehabilitation services specific to African American women living with HIV/AIDS. The majority of relevant articles either do not include analysis by race or use only a sample with a small number of African American women. In other cases the researchers did not specify how many of the women in the study identified as African American. Below is a review of the most relevant experimental research studies in the field of rehabilitation counseling inclusive of African American.

Conyers and Datti (2008) conducted a study of 122 women living with HIV/AIDS who responded to the 2004 National Working Positive Coalition - Employment Needs Survey (NWPC-ENS), an original version of the National Working Positive Coalition - Vocational Training and Employment Survey (NWPC-VTES). Forty-eight of the participants were African American women, with 27 reporting being employed and 21 unemployed. Of the 122 participants, 74 were HIV-positive and 48 were living with AIDS. More than three-fourths of the participants reported that they had never utilized the state-federal vocational rehabilitation system (Conyers & Datti, 2008). Findings also identified significant differences between White (22%) and minority (51%) participants regarding the impact of race on the use of employment services. Minorities proportionately experienced more homelessness (46%), incarceration (29%),

substance abuse (50%), mental health issues (53%), and domestic violence (65%) according to Conyers and Datti (2008).

Conyers (2004b) directed a qualitative study evaluating the perception of vocational services and impact of employment among people living with HIV/AIDS. The study, consisting of a sample of 25 people, included 15 African Americans and 9 females. The researchers did not specify how many of the participants were African American women. Respondents reported that engaging with vocational rehabilitation services aided them in increasing confidence, motivation, and self-respect in addition to facilitating their adjustment to living with the disease (Conyers, 2004b). Individualized services that had been developed to address specific barriers and peer support were identified as positive and effective strategies of the rehabilitation process.

Conyers's (2004b) study also confirmed the theory that employment can improve and positively affect one's quality of life (Schur, 2002). Participants returning to work noted a sense of accomplishment and viewed themselves in a more positive light; they also possessed an increased sense of belonging, self-esteem, social interaction, health improvements, and ability to manage stress as well as reduced stigma (Conyers, 2004b).

A 2003 study by Glenn et al. also evaluated the employment issues of individuals living with HIV/AIDS who had either become employed within the last 3 months or expressed an interest in entering the workforce or returning to work. In a sample of 51 men and women living with HIV/AIDS, 13 of the participants were women and 23 of the participants identified as African American. The researchers did not specify how many of the participants were African American women. More than half of the participants reported having left their places of employment since being diagnosed (Glenn et al., 2003). Almost half of the participants credited this to a change in health such as AIDS-related illnesses, fatigue, stress, and side effects of

medication. Thirty-four participants indicated they had informed at least one employer of their HIV-status (Glenn et al., 2003). This willingness to disclose is contrary to other research (Holt et al., 1998; Simoni, Demas, Mason, Drossman, & Davis, 2000); however, it is important to note that approximately 75% of the study participants were male, so they may not experience the same concerns as women who fear that their children's lives may be directly or indirectly affected by their decision to disclose (Jenkins & Coons, 2002). Also, in contrast to the number of participants who had previously disclosed their status, the most commonly noted job search strategy was avoiding the disclosure of one's HIV status (Glenn et al., 2003). These study evidence that the impact of a diagnosis of HIV or AIDS can directly impact one's ability or security with gaining and maintain employment.

Another study focused on evaluating the vocational rehabilitation practices of 324 participants living with HIV or AIDS in Washington, DC (Hergenrather et al., 2004). Approximately 75% of them identified themselves as living with HIV and the other 25% met the criteria for a diagnosis of AIDS. The study consisted of 221 (68.2%) African Americans and 95 (29.3%) women. The researchers did not specify how many of the participants were African American women. Only six (2.9%) of the 324 participants reported utilizing public vocational rehabilitation services; however, approximately 89% reported having a desire to receive assistance to secure employment (Hergenrather et al., 2004). Approximately one-third of the total participants reported not working or receiving any public assistance such as Temporary Assistance for Needy Families (TANF), Social Security Income (SSI), Social Security Disability Income (SSDI), or unemployment benefits (Hergenrather et al., 2004). More than half the participants considered working as a positive change that would assist in increasing their income or enabling them to become more financially responsible (Hergenrather et al., 2004). Many

participants also referenced the importance and influence of family concerning motivation to work. As noted by the researchers, this is important to consider when providing services to this population of vocational rehabilitation consumers. If people living with HIV/AIDS perceive that a family member, friend, or physician views their decision to work as a positive one, they are more likely they to work (Hergenrather et al., 2004).

Similar to the demographics of the Glenn et al. (2003) study, Razzano and Hamilton (2005) evaluated the health-related barriers to employment of 63 participants, consisting of 16 (25%) females and 31 (49%) African Americans. The researchers did not specify how many of the participants were African American women. Participants came from the Chicago House, the first community-based organization in the Midwest to address the multifaceted needs of people living with HIV/AIDS (Razzano & Hamilton, 2005). The researchers administered the Medical Outcomes Study-HIV Health Survey (MOS-HIV), a 30-item questionnaire derived from the Medical Outcomes Survey Short Form 20 (MOS-SF20), with the addition of 10 items related to living with HIV/AIDS. The findings of the study highlight that the major barrier to employment was a definitive need for health and dental insurance (Razzano & Hamilton, 2005). Insurance was mostly granted through public assistance for those who were employed as well as those who were not. Individuals receiving insurance through public assistance are faced with the decision of losing benefits if their income exceeds established limits and finding employment that will provide adequate coverage. Those participants who reported working also displayed significantly more positive results pertaining to their overall health functioning on the MOS-HIV than did their unemployed counterparts (Razzano & Hamilton, 2005). However, no significant differences were found for overall well being between the employed and unemployed participants (Razzano & Hamilton, 2005). It is important to note that a scale evaluating self-

reports for significant depression symptoms were high for those who were employed as well as the unemployed (Razzano & Hamilton, 2005).

Characteristics of Vulnerable Populations

The behavioral model for vulnerable populations (Gelberg et al., 2000) is a framework for describing health care service utilization. This study focuses on the predisposing, enabling, and need characteristics (as mentioned above) of the vulnerable population of African American women living with HIV/AIDS. Each of these characteristics describes various factors leading to a population's utilization of health services with an emphasis on the individual as the unit of analysis (Gelberg et al., 2000). Predisposing characteristics refer to the propensity of an individual to utilize health care services. Enabling characteristics describe the resources available to an individual or that person's family. Need characteristics refer to an individual's self-perceived or professionally evaluated need for care based on that person's level of illness. The following review describes these variables, which were selected based on the most current and available literature specific to African American women living with HIV/AIDS.

Predisposing characteristics. According to the behavioral model for vulnerable populations, individuals at risk are theorized to be more prone to utilize services than others based on individual, structural, and belief characteristics. The predisposing characteristics are defined as existing prior to the individual deciding to pursue services (Gelberg et al., 2000). According to the model, these characteristics may influence an individual's disposition to use services, but the characteristics in and of themselves do not lead to the utilization of services (Gelberg et al., 2000). The following section provides a summary of this study's selected predisposing characteristics for African American women living with HIV/AIDS: age, internal and external stigma, and attitudes toward seeking professional health services.

Age. Aday and Andersen (1974) describe age as an immutable predisposing characteristic that cannot be altered by health care systems policy changes. For example, regardless of what policies or processes the vocational rehabilitation system may modify or revise, an individual's age will not change based on these revisions. African American women aged 18 to 44 are disproportionately infected with HIV (Whitmore, Satcher, & Hu, 2005). Women within this age group, who are considered to be in their childbearing years, may decide to have children regardless of a disability. This demographic also falls well within the working age range, thus representing a large population that would be expected to pursue vocational rehabilitation services in order to receive assistance in initiating or returning to work.

Older Americans are not exempt from the risk of contracting HIV/AIDS. According to 2005 data, individuals aged 50 and older accounted for 15% of all new HIV cases and 19% of new AIDS cases (CDC, 2008). Despite the rising numbers of new infections in older women, only limited studies have been conducted pertaining to this demographic. To the knowledge of this author, there are no studies specific to vocational rehabilitation and African American women over the age of 50 living with HIV/AIDS.

Children. In a study of 10 African American women living with HIV/AIDS, ranging in age from 21 to 39, who were also raising children with HIV/AIDS, participants reported their role of being a mother as one that was “critical to their existence and a reason for living” (Shambley-Ebron & Boyle, 2006b, p. 55). Motherhood was viewed as both an accomplishment and an extension of themselves (Shambley-Ebron & Boyle, 2006b).

Due to their reproductive role, women living with HIV/AIDS are often condemned and perceived as “vectors of infection” (Lekas, Siegel & Schrimshaw, 2006, p. 1173). Although a large majority of African American women living with HIV/AIDS are within childbearing years,

this demographic receives paradoxical and contradictory messages about motherhood. African American women living with HIV/AIDS have reported that social expectations of becoming a mother have come into direct conflict with communicated messages of moral and social irresponsibility for being a woman living with HIV/AIDS and wanting to have a child (Shambley-Ebron & Boyle, 2006b). While messages are communicated that motherhood should be desired, the messages drastically changed once it was clear the women are living with HIV/AIDS. Some women reported that acquaintances would inquire with judgment and disdain why they would want to bring a child into the world when they would be putting the child at risk for HIV and be dying soon themselves (Lekas et al., 2006). These conflicting messages can be an additional source of stress for African American women living with HIV/AIDS who are already mothers or have a desire to experience the socially valued role of motherhood.

Stigma. The impact of HIV stigma was previously discussed in establishing the importance of examining African American women living with HIV/AIDS. The aforementioned literature review addressed external stigma. For the purpose of this study, external stigma is operationalized as stigma imposed by another individual on an African American woman living with HIV/AIDS. The following review of the literature will examine internal stigma. In contrast to external stigma, African American women living with HIV/AIDS impose internal stigma onto themselves. Buseh and Stevens (2007) define internal stigma as the manifestation of existential despair. Examples of existential despair include being overwhelmed by feelings of shame, self-accusations, and feelings of being disregarded (Buseh & Stevens, 2007).

According to Roberts and Miller (2004), individuals living with HIV/AIDS are at risk of internalizing stigma, which can lead to a myriad of adverse emotions and increased levels of stress. Internal stigma has also been linked to lowered self-esteem, depression, anxiety,

hopelessness, and reduced self-efficacy (Lee, Kochman, & Sikkema, 2002; Treisman & Angelino, 2004). As a result of internalizing stigma, African American women living with HIV/AIDS may “become secretive, isolated, and lose social and emotional support” (Black & Miles, 2002, p. 688).

Rao, Pryor, Gaddist, and Mayer (2008) conducted a study of 224 African American and 317 White respondents living with HIV/AIDS to examine cross-cultural differences in relation to stigma, secrecy, and discrimination. Thirty-three percent of the respondents were women. The researchers did not specify how many of the respondents were African American women, therefore the findings should be viewed with caution in regards to whether they can be generalized to African American women living with HIV/AIDS. African American participants were more likely than White participants to agree with the internal stigmatizing statements such as, “I feel set apart and isolated from the rest of the world” and “Some people act as though it’s my fault I have HIV” (Rao et al., 2008). African American participants also responded in agreement with the statement, “Having HIV makes me feel like I’m a bad person” (Rao et al., 2008). Overall study findings indicated African American participants did not feel more stigmatized than White participants, but rather perceived and experienced stigmatization differently (Rao et al., 2008). The researchers opine that African American respondents may be more attuned to concepts and experiences of discrimination and racial stigma than their White counterparts (Rao et al., 2008).

Attitudes toward seeking professional services. As with age, attitudes toward utilizing vocational rehabilitation services are not necessarily identified as characteristics that can be directly changed by health care policies; however, an individual’s attitude toward seeking professional services can result in differences in willingness to utilize the services. Because of

historical abuses and medical experimentation on African Americans in the United States, many individuals in the African American community have a mistrust of the government and healthcare providers (Washington, 2006). This mistrust can mean that some African American women delay the pursuit of an accurate diagnosis, which subsequently results in receiving late treatment (Mulenga & Conyers, 2003). The concerns African Americans have expressed about medical experimentation are not unfounded and have been well documented. African Americans in the United States have been subjected to many years of unethical medical abuse and nonconsensual experimentation within the healthcare system, including such well-known cases as the Tuskegee Experiment and the exploitation of Henrietta Lacks, among others (Brandt, 1978; Jones, 1993; Skloot, 2010).

The impact of these studies on African American attitudes regarding health care services has been profound, especially in terms of treatment of HIV/AIDS. The Tuskegee syphilis experiment, officially known as the “Study of Syphilis in the Untreated Negro Male,” began in 1932; it involved 400 impoverished African American sharecroppers in Tuskegee, Alabama, who had contracted syphilis, and another 200 men who were disease-free and served as controls (Rivers, Schuman, Simpson, & Olansky, 1953). The premise of the experiment was that syphilis manifested differently in African Americans from how it did in Whites (Jones, 1993, pp. 16-29). The men living with syphilis were made to think that they were being treated for “bad blood,” a catchall phrase referring to a myriad of diseases; the incentives to participate were free physical examinations and burial stipends (Jones, 1993, pp. 73, 154; Rivers et al., 1953). The men were never informed that they were part of a longitudinal, non-therapeutic experiment to collect data on the evolution of this contagious disease on African American males or that the researchers believed the scientific findings would only be confirmed through autopsies (Brandt, 1978; Jones,

1993). The United States Public Health Service (PHS) never told the men that they were infected with syphilis nor did it provide treatment (Jones, 1993). Instead, the PHS tracked the symptoms and progress of the disease for nearly 40 years, during which time it denied treatment, even though penicillin had been identified in 1951 (20 years prior to the end of the experiment) as the standard therapy regimen for syphilis (Jones, 1993). Many of the men transmitted the disease to their sexual partners and produced children with congenital syphilis (Jones, 1993). When the men died, autopsies were conducted to determine the type and extent of damage the disease had done to their bodies (Brandt, 1978). By the end of the study in 1972, only 74 of the participants were still alive (Jones, 1993). Even years after the experiment was forced to end because it was deemed unethical, one of the leading researchers firmly stood by the decision not to provide penicillin and education to the men. In a 1976 interview, he described the men as “subjects, not patients; clinical material, not people” (Jones, 1993, p. 179).

Another example in the history of medical experimentation on African Americans without their consent is the case of Loretta Pleasant, better known as Henrietta Lacks, an impoverished African American tobacco farmer living in Baltimore, Maryland. Lacks’s cells were harvested in 1951 from a cancerous tumor as well as a healthy area of her cervix without her knowledge or consent (Skloot, 2010). Her cells were passed along to a tissue culture researcher at Johns Hopkins University who had been working for over three decades to grow malignant cells outside the body (Skloot, 2010, p. 30). Lacks’s cancer continued to spread and she died the same year; however, it was soon discovered that her cells were unique in that they could be grown at exponential rates and kept alive in a laboratory. The researcher named the cells *HeLa cells*, based on the first two letters of Lacks’s first and last names (Skloot, 2010). The cells quickly became in high demand, were produced en masse, and were sold throughout the

scientific community around the world. The cells have been used in countless scientific research studies including, but not limited to, the effects of cancer, atomic bomb testing, gene mapping, development of the polio vaccine, and treatment and various research endeavors specific to cancer, AIDS, and Ebola (Skloot, 2010). It was not until the early 1970s, when her family began to receive inquiries from researchers requesting blood samples from them, that they became aware of the infringement on their mother's body without her knowledge or consent (Skloot, 2010). As of 2010, nearly 20 tons of her cells had been produced; they were still being duplicated and sold both nationally and internationally. Until their deaths, her husband and children were impoverished and lived for extended lengths of time with chronic diseases and no health insurance coverage or money for treatment (Skloot, 2010, p. 168).

Cases such as these have led to lingering feelings of distrust and suspicion by African Americans, and have consistently affected attitudes toward health services related to HIV/AIDS. Toward the beginning of the AIDS crisis, gay communities often noted presumed similarities between the Tuskegee experiment and the AIDS epidemic (Jones, 1993). The belief that AIDS was a human-made weapon of genocide designed to exterminate homosexuals was commonly expressed in the late 1980s. One physician articulated this belief in his book, theorizing that HIV was injected via an intentionally contaminated vaccine to more than a thousand gay males in New York as a result of homophobia in the United States (Cantwell, 1988). Just as history had shown that African Americans had entrusted their healthcare to ill-intentioned White physicians, many individuals in the gay community perceived they had entrusted their healthcare to ill-intentioned heterosexual physicians (Cantwell, 1988).

As the AIDS epidemic continued to spread and to affect inner-city African Americans at disproportionate rates, many individuals within the African American community also began to

cite the dishonesty and experimentation of the Tuskegee episode as a reason for fearing or refusing treatment for HIV/AIDS (Jones, 1993). The history of the Tuskegee experiment had become well known in African American communities by then, and oral history over time has often erroneously described the experiment as “African American men being injected with syphilis” (Jones, 1993, p. 220). The history and perceptions about the study fostered the belief that the possibility of being exploited and abused in research still exists (Williams, Ekundayo, Udezulu, & Omishakin, 2003). One study that investigated the attitudes of 500 African Americans of reproductive age reported that more than half of the respondents (53%) believe there is a cure for AIDS that was being withheld from the poor, similar to the Tuskegee Experiment (Bogart & Thorburn, 2006). Nearly half (48%) of the same respondents in the same study by Bogart and Thorburn (2006) believed HIV to be a human-made virus designed by the government to eradicate or reduce the African American population. Thus the history of medical malfeasance has continued to have a long-standing effect on the trust or lack thereof of African Americans vis-à-vis available rehabilitation and healthcare services.

As the case of Henrietta Lacks became more widely known, it became a gender-specific cautionary for African American women concerned about the misuse of their bodies. This has led many African American females to experience some trepidation in accessing the health care system lest their bodies be regarded as scientific property rather than human life. This fear can also be transferred to the vocational rehabilitation system; African Americans may perceive that vocational counselors are more invested in performing their jobs than in acknowledging the humanity of their patients (Wilson, Jackson, & Doughty, 1999). This is not to say that an African American woman living with HIV/AIDS will not pursue services at all. However those

women who already have a more positive disposition toward the state-federal vocational rehabilitation system may be more prone to utilize available services.

Enabling characteristics. The behavioral model for vulnerable populations defines enabling characteristics as resources that either enable an individual to access health services or impede him or her from doing so (Gelberg et al., 2000). The resources may be personally possessed by the individual or ones that are available through family or community to assist in accessing health services. Enabling resources must be present for utilization to take place (Andersen, 1995). Examples of personal or familial enabling resources are: health insurance, transportation, and income. For the purpose of this study, the enabling characteristics are: income benefits, source of support for the participant and her children, knowledge of services, poverty status, reasonable access to services, and self-efficacy related to employment.

Income benefits. For the purpose of this study, income benefits are operationally defined as social security income (SSI) or social security disability income (SSDI). SSI is a means-tested program in which eligibility is dependent upon an individual's income and assets (United States Social Security Administration [SSA], 2012). Individuals must have less than \$2,000 in assets (\$3,000 for a couple) and an income below the poverty level to be eligible (SSA, 2012). The monthly income benefit is based on need and the maximum allowable benefit amount is determined by a federal benefit rate.

SSDI is not dependent upon an individual's income or assets. The monthly income benefit is based on the individual's lifetime record of earnings. SSDI is solely restricted to individuals with medical disabilities who have worked and paid Federal Insurance Contributions Act (FICA) taxes (SSA, 2012). To be considered eligible, a person must be unable to engage in any "substantial gainful activity" due to their disability or impairment (SSA, 2012).

African American women living with HIV/AIDS have a proportionately higher rate of unmet needs such as prolonged unemployment and financial instability (Mulenga & Conyers, 2003). While African American women living with HIV/AIDS are often eligible for social security benefits, this limited income rarely covers living expenses (Brooks & Klosinski, 1999). Such unmet needs are often offset or improved with the attainment or increase in employment through accessing the formal vocational rehabilitation system (Conyers & Datti, 2008; Mulenga & Conyers, 2003).

Source of support. The combination of social support and support for one's children is an integral enabling characteristic for African American women living with HIV/AIDS. "Social support" is operationally defined by Baumeister, Roy, and Leary (1995) as interpersonal transactions between individuals that foster positive adjustments when dealing with problems. African American women living with HIV/AIDS are commonly single, heads of households, and responsible for a parent, child, friend or extended family member who may also be infected with the disease (Owens, 2003). In a study of 30 African American women living with HIV, researchers note that because of these needs, low-income participants who choose not to use formal institutions as a source of support are often disadvantaged (Watkins-Hayes, Pittman-Gay, & Beaman, 2012).

Power imbalance between minority men and women is also an issue worth addressing in the treatment of African American women living with HIV/AIDS. African American women often maintain an African worldview that places the needs of the family above the needs of an individual member (Akbar, 1985). As a result, many women are encouraged to and believe they should suspend the urgency of their own needs for health and well-being in order to take care of other family members. This is important to note. Since the majority of African American

women with HIV are infected through heterosexual sexual contact (CDC, 2012b) they often have partners whose needs they place ahead of their own. Therefore, services that address gender empowerment, provide information specific to reproductive issues, and offer affordable childcare resources are essential in addressing the rehabilitation needs of African American women.

Owens (2003) found in her qualitative study of 18 African American women ranging in age from 31 to 49 that support can be separated into three categories: emotional, tangible, and cognitive. In Owen's study, emotional support was inclusive of love, care, reassurance, empathy, concern, compassion, availability of family assistance, and acceptance. Seventy-two percent of the sample reported receiving this type of support, indicating that it was widely valued and helpful in the reduction of fear and stress related to the disease. Concrete or tangible support was defined as activities such as providing a residence and assisting with childcare and other parental responsibilities, finances, transportation, household errands, and chores (Owens, 2003). Seventy-eight percent of the sample reported having tangible support from family members. Finally, cognitive support was described as providing information pertaining to HIV/AIDS resources or other means of coping with the disease. Only one participant reported having family members who could lend this type of support because they had training specific to HIV/AIDS (Owens, 2003). The researcher hypothesized that other participants may not receive this type of support because relatives lack of awareness that they could supply support in this way or because of denial of the disease (Owens, 2003).

An important factor affecting the provision of support is the willingness to disclose one's HIV-positive status. Because of the continued HIV/AIDS stigma, such disclosure may carry a significant risk. Negative consequences of disclosing one's HIV-positive status may include: being alienated by employers, friends, and family; possible physical violence; a breach of

confidentiality by those in the know; and estrangement from friends and family (Simoni et al., 2000; Peterson, 2010). Social support was found to be a key factor in a recent study of 45 women living with an HIV or AIDS diagnosis, 36 of whom were African American (Peterson, 2010). Many of the respondents felt that additional support around disclosing their HIV-positive status to employers and family was necessary, and expressed fear that disclosures would mean losing family as a source of support. The women described this possibility as potentially devastating, and the challenge of deciding whether they could trust others with the sensitive information as stressful (Peterson, 2010). While disclosure can be beneficial and correlates to more received support for African American women (Black & Miles, 2002), it does not lead directly to satisfaction with support and improved psychological adaptation (Simoni et al., 2000). As a result, African American women may be guarded and less likely to disclose the truth; subsequently, they may not receive much needed support from family and friends.

Many African American women living with HIV/AIDS may practice *a calculus of disclosure*, which is a “careful, reasoned evaluation of the risks and benefits for oneself and significant others when disclosing one’s diagnosis of HIV.” The goal of such evaluations is to only reveal one’s status “in situations where the risk was minimized and the benefits were maximized” (Black & Miles, 2002, p. 691). In a study comparing men and women living with HIV/AIDS, this practice of implementing a calculus of disclosure was found to be most evident in the workplace among women, who were less likely to disclose their status than their male counterparts (Fesko, 2001). However, the necessity of always appearing to be strong and in control may work to the detriment of African American women in accessing health services. Fesko (2001) concludes that the idea of displaying strength at all times can often work against African American women when they are interacting with the healthcare system. She posits that

healthcare providers may not be as sensitive to the needs of their African American female clients living with HIV/AIDS since they assume these women are able to manage their numerous life challenges with scarce resources even while being ill (Fesko, 2001).

Researchers have also found that African American women living with HIV/AIDS report a greater reliance on women-centered networks (Catz et al., 2002), but also experience less consistent support from spouses (Shambley-Ebron & Boyle, 2006a). Simoni and colleagues (2000) conducted a study with 230 HIV-positive women that included 106 non-Hispanic African American women ranging in age from 24 to 61 years. Ninety percent of the respondents reported disclosing their status to someone (Simoni et al., 2000). Disclosure was highest with steady partners, female friends, mothers, and sisters; however, it was considerably lower with fathers and other male relatives (Simoni et al., 2000). These findings were consistent with other studies which found African American women living with HIV/AIDS were more likely to disclose their illness to female relatives so they could have support with child care, transportation, and other needs (Black & Miles, 2002; Shambley-Ebron & Boyle, 2006b). The authors hypothesize that African American women find their peers less judgmental, more forgiving, and more empathetic, but they note that additional empirical research is needed to confirm this hypothesis (Simoni et al., 2000).

Knowledge of services. Possessing knowledge of available vocational services is a fundamental enabling variable. Accurate knowledge of such vocational services can potentially encourage African American women living with HIV/AIDS to utilize vocational rehabilitative services or dissuade them from doing so. While some individuals may have basic cursory knowledge of the services offered through vocational rehabilitation counseling, research has found that many individuals diagnosed with HIV/AIDS—as well as medical providers for this

population—are unaware of the breadth of available vocational rehabilitation services (Conyers, 2004a, 2004b).

Programs have been developed to address intervention strategies that prevent African American women from contracting HIV/AIDS; however, the vast majority of these programs are based on research studies specific to the reduction risky sexual behavior to prevent contracting the disease (Weiss & Vaughn, 2003; Wingood et al., 2004). There is a dearth of programs addressing the specific needs of African American women who have contracted and are living with HIV/AIDS (Sutton et al., 2009). HIV employment-specific programs have been implemented in only half of the states and the District of Columbia (National Working Positive Coalition, 2011). Many of these programs are geared to specific populations; however, none of them is specifically dedicated to improving the employment outcomes of African American women living with HIV/AIDS.

A qualitative study of 31 HIV-positive women identified lack of knowledge of services as one of several barriers to pursuing timely care after being diagnosed with HIV (Raveis, Siegel, & Gorey, 1998). A thematic analysis identified additional barriers, including: denial of status, denial of significance of being HIV-positive, fear and anxiety about having the illness, fear of being stigmatized, blunting the emotional impact of diagnosis with substance abuse, being incarcerated, and financial constraints (Raveis et al., 1998). Unlike previous research, in this study—which included 29% African American women—a lack of knowledge of services was a secondary barrier following denial and anxiety about having a positive HIV status (Raveis et al., 1998). One African American participant described accessing regular treatment for her child (who was also HIV-positive), but the physician never asked her if she was receiving

treatment herself nor was she informed of the value of receiving early medical treatment. As a result, she did not access treatment for herself for over a year and a half after her diagnosis.

For some women, the inadequate knowledge of service possibilities dissuades them from pursuing professional services. Sowell et al. (1996) conducted a study of women living with HIV to determine barriers to their healthcare-seeking behaviors. The sample of 46 women included 33 African Americans. Thirty-two of the respondents indicated a perception that the healthcare workers' knowledge of the disease or treatment of infected individuals was limited or misinformed. Another 18 respondents expressed concerns that physicians were fearful of treating individuals with HIV and that fear would negatively affect the type and quality of service. Fifteen participants reported callous, impersonal, or insensitive remarks by healthcare professionals in response to their desires or feelings (Sowell et al., 1996). The findings of another study, consisting of 36 African American women from a total sample size of 43 participants, also indicated that African American women living with HIV/AIDS believe few support services exist because of the continued stigma associated with the disease (Peterson, 2010).

For other women, their limited knowledge of services dissuades them from utilizing the available services. In a study of 36 African American women living with HIV/AIDS, participants identified one barrier to access as a mismatch in goals between their needs and the services provided (Peterson, 2010). Participants indicated that this incongruence of goals caused great distress and affected future interactions (Peterson, 2010).

Poverty status. Poverty is a social determinant that directly influences the health status of African American women living with HIV/AIDS. Research has shown that multiple sociocultural factors, including unemployment and poverty, contribute to high death rates among

women living with HIV/AIDS (Sumartojo, 2000). Compared to Whites, African Americans are more likely to live in segregated communities where poverty facilitates the spread of HIV by weakening sexual relationships and lowering the overall quality of self-care (Kim et al., 2002). These additional stressors can also adversely impact the health of African American living with HIV/AIDS.

Additional studies have shown that the unemployment rate for individuals living with HIV/AIDS is approximately 50% or higher (CDC, 2005; Dray-Spira et al., 2006). The Boston Health Study, a broad study of the health outcomes of 306 men and women living with HIV/AIDS, indicated that individuals who were both unemployed and living with HIV/AIDS were more likely to be female and non-White (Massagli, Weissman, Seage, & Epstein, 1994). A 2004 study of 101 African American women in North Carolina indicated that HIV positive women were more likely to be unemployed (with an unemployment rate of 71%) than their HIV negative counterparts (with an unemployment rate of 38%; CDC, 2005). It is important to note that employed individuals living with HIV/AIDS have reported significantly higher quality of life outcomes than their unemployed counterparts (Blalock, McDaniel, & Farber, 2002). Increased quality of life is also subsequently associated with prolonged life (Rubin, Chan, & Thomas, 2003).

Reasonable access to services. There is a strong connection between poverty and access to vocational rehabilitation services. Poverty causes a reduction in access to services, subsequently affecting an individual's overall health status and outcome (Lustig & Strauser, 2007). The United States Department of Health and Human Services (2005) reported that individuals living in poverty, whether employed or unemployed, were more likely to postpone medical care or use the emergency room as the primary means of health care.

While some African American women living with HIV/AIDS may not be aware of available vocational rehabilitation services, others may be more comfortable with an AIDS Service Organization (ASO). However, ASO counselors may not be as knowledgeable about all the available resources (Goldblum & Kohlenberg, 2005). Researchers have concluded it is not enough for African American women to have access to services; health and vocational professionals should make efforts to ensure that women are taking advantage of the available resources (Catz et al., 2002).

Self-efficacy related to employment. According to psychologist Albert Bandura, self-efficacy is an individual's belief in their ability to successfully accomplish a task (Bandura, 1986). Poor self-efficacy has been associated with impaired resilience in vocational efforts (Bandura, 1986). The theory of self-efficacy was later applied to the field of rehabilitation counseling and was defined as the self-perception of one to cope with life's urgent demands (Bandura, 1997).

There appear to be no studies that specifically address the self-efficacy of African American women living with HIV/AIDS as it relates to employment. However, it is an area worth exploring. Previous researchers have asserted an African American woman may experience "inconsistencies in environmental responses to similar performance that may make it difficult for her success experiences not to directly enhance her career-related self-efficacy" (Hackett & Byars, 1996, p. 326). Subsequently, observing the challenges or successes of their peers in seeking and maintaining employment may influence the self-efficacy of African American women living with HIV/AIDS. Seeking and maintaining employment are key tenets in the vocational rehabilitation process. As previously discussed, poverty is a social determinant that directly effects the health of African American women living with HIV/AIDS. Therefore, it

is important to explore dynamics that could impact transitioning them from impoverished conditions. As a result, it is reasonable to explore how confident African American women living with HIV/AIDS are with employment-related tasks. Exploration of this topic would fill a gap in the literature pertaining to this demographic.

Need characteristics. Illness or need characteristics describe an individual's need for care based on either the self-perceived need for care or a clinical evaluation of the person's level of illness by a healthcare professional (Andersen, 1995; Gelberg et al., 2000). According to the behavioral model for vulnerable populations, an individual's perception of health status may be influenced by the patient's level of vulnerability (Gelberg et al., 2000). Because of the episodic nature of the disease, this self-perception is particularly important for African American women living with HIV/AIDS. An African American woman living with HIV/AIDS may perceive her need for assistance differently than a clinician who evaluates her needs. The need characteristic level of the behavioral model for vulnerable populations represents the most immediate use of health services and assumes the prerequisite presence of predisposing and enabling characteristics (Andersen & Newman, 1973). Measures of perceived illness can include the number of hospitalized days, symptoms, and a general self-reporting of how one feels physically (Andersen & Newman, 1973). For African American women living with HIV/AIDS, many of these measurements are subjective and can vary over time as AIDS-related diseases develop. The need characteristics for this study are health beliefs and the need for rehabilitative services.

Health beliefs. This characteristic refers to the beliefs of African American women living with HIV/AIDS about how the disease affects their lives. In a qualitative study of 10 African American women between the ages of 18 to 45 with HIV/AIDS who had at least one child, participants repeatedly expressed a general health belief that African American woman

needed to “be strong” (Shambley-Ebron & Boyle, 2006a). Being strong was operationally defined as “possessing an extraordinary courage and ability to withstand trials of life common to black women ... often including poverty, discrimination, and raising children with meager resources as well as frequent encounters with illness and death” (Shambley-Ebron & Boyle, 2006a, p. 200). Admitting that they require support with basic needs, such as treatment of health complications, may be regarded as showing weakness. Researchers concluded that the expectation that they should always demonstrate strength may actually inhibit African American women from receiving formal and informal support.

Raveis et al. (1998) noted that one African American female participant in their qualitative study chose to delay care for a year because of her belief that treatment had nothing to offer her. She believed her health would not be adversely affected by delaying treatment. Other participants reported fears of negative responses from community members who might observe them seeking treatment at HIV-specific centers (Raveis et al., 1998). Others expressed concern that records of their treatment would not be held in confidence, and might be inadvertently reported to their employers (Raveis et al., 1998). The underlying belief was that their general health was less important than the risk of their status being disclosed or their being ostracized by friends and family.

Need for rehabilitative services. An individual’s belief about her need for rehabilitative services is also characterized by uncertainty and rapid change as a result of the non-linear progression of HIV/AIDS-related illnesses. A non-linear progression of HIV/AIDS illnesses is often related to HAART treatments unexpectedly ceasing to work as well as the impact of the side effect of drug cocktails (Rabkin, Ferrando, Lin, Sewell, & McElhiney, 2000). Women

deciding to use treatment must also determine if their need for services supersedes the risk and stigma of being identified as an individual living with HIV/AIDS.

An additional factor is the accessibility of these services. Findings from a qualitative study that included a small number of African American women living with HIV/AIDS indicated that, while they were aware of vocational rehabilitative services, the long waiting lists presented an obstacle that outweighed their perceived need for services (Timmons & Fesko, 2004). Participants indicated they were more likely to use other means of support. For instance, when confronting work-related issues, they were more prone to use personal supports before professional ones (Timmons & Fesko, 2004). Findings also suggested that support groups were helpful for supplying information and resources but were not as useful at helping to deal with employment-related concerns (Timmons & Fesko, 2004). A major limitation of this study was that the majority of the sample was White or male; therefore, the findings should be viewed with caution in regard to their generalizability to African American women living with HIV/AIDS.

Summary

A review of the literature found that the majority of articles examining the experiences of African Americans living with HIV/AIDS consisted of samples with a small number of African American women; in some cases, the researchers did not identify how many of the women in the study identified as African American. Few studies exclusively targeted African American women living with HIV/AIDS. This demographic group presents with overlapping cultural and gender-related concerns relating to various predisposing, enabling, and need characteristics. While a review of the most relevant research supported findings of health disparities for women and minorities in general, much more information needs to be gathered about the experiences of African American women.

Chapter 3: Methodology

Introduction

The purpose of this study is to identify and examine variables related to and predictive of the utilization of rehabilitative services among a volunteer sample of African American women living with HIV/AIDS in the United States. This study seeks to answer the following research questions:

RQ1: What are the descriptive characteristics of African American women living with HIV/AIDS who completed the NWPC-VDENS related to predisposing, enabling, need, and outcome variables?

Research Question 2 and the subsequent hypotheses are as follows:

RQ2: Which predisposing, enabling, and need characteristics distinguish African American women living with HIV/AIDS who completed the NWPC-VDENS and who have utilized vocational rehabilitation (VR) services from those who have not?

- H1: African American women living with HIV/AIDS within (1) the exploration and establishment stages (ages 18-43) are more likely to have used VR services than women within (2) the maintenance and decline stages (age 44 and older).
- H2: African American women living with HIV/AIDS who have children are more likely to use VR services than those who do not have children.
- H3: African American women living with HIV/AIDS who report more internal stigma are less likely to use VR services than those who do not report internal stigma.

- H4: African American women living with HIV/AIDS who report more expectations of external stigma are less likely to use VR services than those who do not report expectations of external stigma.
 - H5: African American women living with HIV/AIDS who have never received income benefits are more likely to have used VR services than those who are current or former recipients of income benefits.
- H6: African American women living with HIV/AIDS who have an identified source of support for themselves are more likely to have used VR services than those who do not have an established support system.
- H7: African American women living with HIV/AIDS who have an identified source of support for their child(ren) are more likely to have used VR services than those who do not have an established support system.
- H8: African American women living with HIV/AIDS who are not living in poverty are more likely to have used VR services than those who are living in poverty.
- H9: African American women living with HIV/AIDS who have a greater level of self-efficacy as it relates to employment (job-seeking skills, requesting accommodations, and maintaining employment) are less likely to have used VR services than those who have low levels.
 - H10: African American women living with HIV/AIDS who report having fewer beliefs about limitations of their health are more likely to have used VR services than those who have more numerous beliefs about limitations of their health.

- H11: African American women living with HIV/AIDS who report having a need for rehabilitative services are more likely to have used VR services than those who do not report having a need.

Research Question 3 is answered through an analysis of the overall data. The three accompanying hypotheses are as follows:

RQ3: Which predisposing, enabling, and need characteristics are predictive of the use of rehabilitative services among African American women living with HIV/AIDS?

- H12: Positive attitudes toward seeking professional services are predictive of the use of rehabilitative services among African American women living with HIV/AIDS.
- H13: Knowledge of vocational rehabilitation services is predictive of the use of rehabilitative services among African American women living with HIV/AIDS.
- H14: Greater access to services is predictive of the use of rehabilitative services among African American women living with HIV/AIDS.

Research Design

The design of this study is a cross-sectional, non-experimental, retrospective research project examining the utilization of vocational rehabilitation services by African American women living with HIV/AIDS. Data were previously collected from the National Working Positive Coalition - Vocational Development and Employment Needs Survey (Conyers, 2008; Appendix A). The sample is based on a non-probability technique known as convenience sampling, using a total of 313 African American female volunteer participants living with HIV/AIDS. The independent variables are the predisposing, enabling, and need characteristics of the sample population. The dependent variable is the use of vocational rehabilitative services.

Population and Sample

The total study sample consisted of 2,504 men and women. For this study, a sample of 313 females self-identifying as African American and non-Hispanic, who responded to the question of whether they had ever received state vocational rehabilitation services, volunteered to complete the survey instrument. The participants resided in 39 states.

Participants involved in HIV-related research are considered particularly vulnerable because of their disease status. As a result, privacy and confidentiality were pertinent concerns. Institutional Review Board (IRB) approval was secured through the Penn State University Internal Review Board before the onset of the study to ensure that all appropriate safeguards and possibilities of minimizing risks were addressed (Conyers, 2008). Additional IRB approval was secured through Virginia Commonwealth University for the utilization and analysis of the data.

The convenience sample for this study was recruited through multi-statewide outreach efforts to AIDS service organizations (ASOs) and national networks (e.g., Positive Women Network, National Minority AIDS Council, and The Body.com) throughout the United States. Agency staff members recruited participants individually and in groups. Staff members who administered the NWPC-VDENS were trained on recruitment, informed consent, confidentiality, instrument administration, and debriefing procedures. They were required to successfully complete an online training module developed by Penn State University's Office for Research Protections.

Staff informed participants about the study's purpose, emphasizing the need for honest responses so that the data could be as accurate as possible. All participants were informed that their participation was confidential and voluntary, and had no bearing on the services they

received. Participants knew that they could withdraw from the study at any time or choose not to answer questions without consequence.

Data for the study were gathered utilizing an implied consent process. The implied consent contained information pertaining to the nature of the research, procedures, potential benefits, and potential risks. Potential participants were informed that completing the survey would indicate their consent to participate (Conyers, 2008; Appendix B). All participants were provided with an employment resource list before taking the survey and most were paid a \$10.00 stipend. Those who did not receive a stipend had completed the survey prior to the establishment of the stipend procedure. No data were collected to identify the participants. Additionally, all responses were stored in a secure encrypted database.

Instrumentation: NWPC-VDENS

The survey used was the National Working Positive Coalition and the Vocational Development and Employment Needs Survey. Each convenience sample participant was offered the opportunity to complete the National Working Positive Coalition - Vocational Development and Employment Needs Survey (NWPC-VDENS, Conyers, 2008; Appendix A). The NWPC-VDENS was developed and administered with the purpose of assessing the vocational-related needs of people living with HIV/AIDS (Conyers, 2008). The survey is based upon a revision of a previous survey instrument, the 2004 National Working Positive Coalition - Employment Needs Survey (NWPC-ENS), which was used to survey 728 people living with HIV/AIDS (Conyers & Datti, 2008).

Since a standardized instrument did not previously exist in the literature, it was not possible to establish reliability and validity for the NWPC-VDENS (Conyers, 2008). However, during item development, researchers paid particular attention to ensuring that some of the

sources of measurement error were minimized by including the following: forward-backward translation, an extensive review of relevant research literature, focus group data, an expert panel review, and pilot testing, with several revisions based on results (Conyers, 2008). Due to the exploratory nature of the study, threats to its internal and external validity could not be controlled by using criteria generally applied to experimental designs (Polit & Beck, 2008).

The survey was available in both English and Spanish, as well as in both paper-and-pencil and internet formats. It took approximately 15 to 30 minutes to complete (Conyers, 2008). To create the Spanish version, the forward-backward translation method was utilized along with a committee of individuals with varying linguistic and cultural backgrounds who made recommendations about the questions. The English version was translated into Spanish and then back translated by a professional translator for linguistic accuracy (Conyers, 2008). The internet-based version utilized skip-pattern logic to force respondents to skip questions that were not applicable (Conyers, 2008).

The survey instrument consists of four major sections: (a) demographic information, (b) knowledge and use of vocational resources, (c) issues related to employment status, and (d) health-related subscales from the Medical Outcomes Study – HIV (Datti, 2009). The Medical Outcomes Study – Human Immunodeficiency Virus (MOS-HIV) Health Survey is a self-administered 35-item questionnaire of health-related quality of life questions, which has been used extensively in the study of HIV/AIDS (Wu, Revicki, Jacobson, & Malitz, 1997). The measure consists of one dimension of health transition and 10 dimensions of health, including general health perceptions, pain, physical functioning, role functioning, social functioning, mental health, energy/fatigue, cognitive function, health distress, and quality of life. The MOS-HIV role functioning subscale is embedded in the NWPC-VDENS (Conyers, 2008).

The role functioning subscale consists of two items used to assess the impact of an individual's health on his/her ability to perform on the job, around the house, or in school (Wu et al., 1997). The role functioning subscale of the MOS-HIV was scored as a summated rating on a 0-100 scale, with higher scores being indicative of better health (Wu et al., 1997). Data from numerous studies support the internal consistency (reliability) of the role functioning scale of the MOS-HIV (Wu et al., 1991), and the construct validity is supported via multitrait analyses (Wu et al., 1997). In initial evaluations, internal consistency for the role functioning scale was .50 and exceeded .75 in subsequent studies, suggesting adequate reliability for group comparisons (Wu et al., 1997).

Variable Measures

To adequately answer the research questions established for this study, information regarding predisposing, enabling, and need characteristics were examined. The dependent variable was the use of vocational rehabilitative services, and the independent variables were (1) predisposing, (2) enabling, and (3) need characteristics of African American women living with HIV/AIDS. A summary of the dependent variable, independent variables, definitions, and data analysis coding can be viewed in Appendix B.

Predisposing characteristics. Predisposing characteristics assist in describing the proclivity of an individual to utilize health services (Gelberg et al., 2000). The five predisposing characteristics examined were age, children, internal and external stigmas, and attitudes toward seeking professional health services.

Age. Age was categorically defined according to psychologist Donald Super's vocational developmental self-concept theory (Super, 1980). Super hypothesized that, as one's self-concept matures and becomes more stable, one's vocational behaviors and choices transition as well

(Super, 1980). Super (1980) identified the five life career stages of development as growth (birth to 14 years), exploration (15 - 24 years), establishment (25 - 43 years), maintenance (44 - 59 years), and decline (60 years and older). Based on Super's conception of vocational life stages, in response to the item, "What is your age?" the characteristic was coded as (1) being within the exploration and establishment stages (ages 18-43), or (2) within the maintenance and decline stages (age 44 and older).

Child(ren). Participants self-reported the number of children they had in response to the item, "How many children do you have?" The variable was coded as a dichotomous variable with the responses categorized as (0) has no children or (1) has at least one child.

Stigma. Two items measured internal and external stigmas. Internal stigma was defined as a continuous variable measured by responses to the item, "I sometimes feel worthless because I am HIV positive." Participants rated their response on a 5-point Likert scale, ranging from strongly agree to strongly disagree.

External stigma was defined as a continuous variable and was measured by responses to the item, "Others would think less of me if they knew I was HIV positive." Responses ranged from strongly agree to strongly disagree on a 5-point Likert scale.

Attitudes toward seeking professional health services. Attitudes toward health services were defined as a continuous variable in response to the item, "I would seek out professional help when needed." The participants rated their response on a 5-point Likert scale, ranging from strongly agree to strongly disagree.

Enabling characteristics. Enabling characteristics describe the resources at an individual's disposal to enable the utilization of health services (Gelberg et al., 2000). The nine enabling characteristics examined were: receipt of income benefits, source of support for the

participant and her child(ren), knowledge of services, poverty, reasonable access, and three measures of self-efficacy related to employment.

Receipt of income benefits. The characteristic of the receipt of income benefits was measured by self-report in response to the item, “Which income benefits have you received in the past, are currently receiving, or have never received?” Participants chose as many responses as were applicable from a list of seven choices, with the additional option of including a choice that was not listed. Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), the two largest federal programs that provide assistance to people with disabilities (SSA, 2012), were included in the list. The responses were coded as a dichotomous variable defined as (0) never received SSI or SSDI, or (1) formerly received / currently receiving SSI or SSDI.

Source of support. Source of support for the participant, a continuous variable on a 5-point Likert scale, ranged from strongly agree to strongly disagree in response to the item, “I am satisfied with the overall support I get from my friends and family.” Source of support for the participant’s child(ren), a continuous variable on a 5-point Likert scale, ranged from extremely concerned to not concerned, in response to the item, “How concerned are you about childcare related to working?”

Knowledge of services. Knowledge of services, a dichotomous variable, was defined as (0) no knowledge of vocational rehabilitative services or (1) knowledgeable of vocational rehabilitative services in response to the item, “Which of the following do you know about?” State vocational rehabilitation was one of 12 choices.

Poverty status. The poverty guidelines as defined by the United States Department of Health and Human Services were used to establish poverty for participants in this study (United

States Department of Health and Human Services, 2012). The status of poverty was measured by computing participant responses to the items, “What is your approximate yearly household (shared) income?” and “How many people live in your household under that salary?” Missing responses for the question pertaining to income were addressed by creating the category of “unknown.” Computed responses were categorized as (0) not living in poverty, or (1) living in poverty.

Reasonable access. An item that asked participants, “How many employment services that serve people with HIV have you heard of in your area”, measured reasonable access to vocational services? Possible responses ranged from 0 to 5 or more. Responses were categorized as (0) none, or (1) 1 or more.

Self-efficacy related to employment. The self-efficacy of each participant related to employment was based on three survey items. The first item was, “How confident are you in your job-seeking skills?” The second item was, “How confident are you that you could ask for job accommodations (breaks, etc.)?” The third survey item was, “How confident are you that you could hold onto a job once you had it?” This continuous variable was measured by self-report responses on a 7-point Likert scale that ranged from (1) no confidence to (7) extremely confident.

Need Characteristics. As defined by Gelberg et al. (2000), need characteristics describe an individual’s need for care based on his or her level of illness. The need characteristics for this study are health beliefs and need for rehabilitative services.

Health beliefs. The characteristic of one’s health belief was coded as a dichotomous variable with a response of yes or no to the questions, “Does your health keep you from working at a job, doing work around the house, or going to school?” and “Have you been unable to do

certain kinds or amounts of work, housework, or schoolwork because of your health?” The responses to both questions were combined and recoded into a continuous variable with a score of 0 to 100.

Need for rehabilitative services. Two items measured the need for rehabilitative services. The first item was a continuous variable on a 5-point Likert scale, ranging from strongly agree to strongly disagree, in response to the item, “It is very hard for a person with HIV to get a job.” The second item was coded as a dichotomous variable with a response of (1) yes, or (2) no to the question, “Do you need more information about employment resources and services.”

Statistical Analysis

The data analysis consisted of descriptive, bivariate, and multivariate statistical analyses. Univariate or descriptive statistics were helpful to describe the basic features of the available data. The descriptive statistics that were analyzed were the distributions and measures of central tendency including the mean and median. Percentages were also included to further describe the characteristics of the sample. A summary of the statistical analyses for all three research questions can be found in Appendix C.

A series of seven chi-square analyses and 10 independent *t* tests were utilized to answer the second research question, which compared African American women in the sample living with HIV/AIDS who had utilized rehabilitative services with those who had not. Chi-square analyses were used to compare those who had used rehabilitative services with those who had not used the services for two predisposing variables, four enabling variables, and one need variable. The two predisposing variables were age and children. The four enabling variables were receipt of income benefits, knowledge of rehabilitative services, poverty, and reasonable

access to services. The need variable was one of the two measures for need for rehabilitative services. All of the variables were either dichotomous or continuous.

Independent *t* tests were conducted for the three predisposing variables, five enabling variables, and the remaining two need variables to compare those participants who had used rehabilitation services with those who had not. The three predisposing variables were internal stigma, external stigma, and attitudes toward seeking professional health services. The five enabling variables were support services for self, support services for child(ren), and all three measures of self-efficacy. The need variables were health beliefs and the remaining measure for need for rehabilitative services. Each of the aforementioned variables was continuous.

A binary logistic regression analysis was utilized to answer the third research question, on the predictive use of rehabilitative services among African American women living with HIV/AIDS. A hierarchical approach was utilized by adding the variables into the model in three blocks. The predisposing variables were entered first, followed by enabling and then need characteristics. A hierarchical binary logistic regression analyses was appropriate, because the dependent variable was a dichotomy and the independent variables were continuous, categorical, or both (Tabachnick & Fidell, 2007). Logistic regression analyses were appropriate to analyze these data, as this form of regression was used to estimate the probability of a certain event occurring. The final analyses add to the body of literature that discusses the predictive use of rehabilitative services among African American women living with HIV/AIDS.

Summary

The methodology for this study consisted of examining previously collected data from a convenience sample of 313 African American women living with HIV/AIDS who voluntarily completed the National Working Positive Coalition - Vocational Development and Employment

Needs Survey. Descriptive statistics were compared using chi-square tests for categorical variables and independent t tests for continuous variables, to determine significant differences between those who had utilized vocational rehabilitation services and those who had not. The predisposing characteristics were age, children, internal stigma, external stigma, and attitudes toward seeking professional services. The enabling characteristics were receipt of income benefits, source of support for self, source of support for the children, knowledge of vocational rehabilitation services, poverty status, reasonable access to vocational rehabilitative services, and self-efficacy as it relates to employment. The need characteristics were health beliefs and need for rehabilitative services. A binary hierarchical logistic regression was also performed to examine the predictive use of vocational rehabilitation services. The next chapter will present and discuss the analysis for each research question and related hypothesis.

Chapter 4: Results

The purpose of this study was to identify and examine variables related to and predictive of the utilization of rehabilitative services among a sample of African American women living with HIV/AIDS in the United States who volunteered to complete the National Working Positive Coalition - Vocational Development and Employment Needs Survey (NWPC-VDENS). The first step in analyzing the data was to examine the descriptive statistics for the sample on predisposing, enabling, and need factors included in the study. This was followed by a series of bivariate analyses conducted to determine whether significant relationships existed between the predictor and outcome variables. Finally, a binary hierarchical logistic regression analysis was conducted to understand the predictive use of rehabilitative services among African American women living with HIV/AIDS. SPSS Statistics Software version 20 was used to organize and analyze the data.

Research Question 1

What are the descriptive characteristics of African American women living with HIV/AIDS who completed the NWPC-VDENS related to predisposing, enabling, need and outcome variables? All of the sample respondents (N = 313) were female, Black/African American, at least 18 years of age, and living with HIV or AIDS, who reported whether they had or had not received state vocational rehabilitation services since their diagnosis. The mean age of the respondents was 46 years, with ages ranging from 29 to 73 years. Approximately 72% of the survey participants reported living with a HIV-positive diagnosis; the remaining participants

reported living with a diagnosis of AIDS. One-fifth (20%) of the respondents reported having less than a high school education. Almost one-third (27%) of the respondents had earned a high school diploma, and 16% had earned a college degree. Approximately 26% of the participants reported being employed at the time of the survey, while 41% reported being employed when originally diagnosed. Approximately three-fourths (76%) of the respondents received services from HIV programs/organizations.

Outcome variable. Research Question 1 sought to determine the descriptive characteristics of African American women living with HIV/AIDS who had completed the NWPC-VDENS related to the outcome variable. This variable was the response of participants to whether they had or had not received state vocational rehabilitation services since being diagnosed with HIV/AIDS. The variable was dichotomous and coded 0 for never received VR services and 1 for received VR services. Data for the outcome variable are presented in Table 1. Of the 313 participants, 31% had received vocational rehabilitation services compared to 69% who had not.

Table 1

Descriptive Statistics: Outcome Variable

Variable	Frequency	Percentage
Never received VR services	216	69
Received VR services	97	31

Note. VR = vocational rehabilitation

Predictor variables. The predictor variables for this study include predisposing variables, enabling variables, and need variables.

Predisposing variables. Research Question 1 also sought to determine the descriptive characteristics of African American women living with HIV/AIDS who had completed the NWPC-VDENS related to predisposing, enabling, and need variables. The predisposing variables are age, children, internal and external stigma, and attitudes toward seeking professional services. Two of the variables, age and children, were dichotomous and the remaining three variables, children, internal stigma, external stigma, and attitudes toward seeking professional services were continuous variables. Findings for the predisposing variables are presented in Table 2.

Table 2

Descriptive Statistics: Predisposing Variables

Variable	Frequency	Percentage
Age		
Exploration and establishment (ages 18-43)	119	38.0
Maintenance and decline (ages 44+)	185	59.1
Children		
No children	51	16.3
At least one child	248	79.2
	Mean	Standard Deviation
Stigma (internal) (1-5)	3.55	1.38
Stigma (external) (1-5)	2.01	1.13
Attitudes toward seeking professional services (1-5)	1.82	0.98

Over half (59%) of the study participants were 44 years of age or older, and about 79% reported having at least one child. Three percent did not report their age and 4% did not report the number of their children. The overall mean score for internal stigma was near the upper end of the mid-range of the 5-point Likert scale ($M = 3.55$), with 1 indicating strongly agree and 5 indicating strongly disagree. These results indicated that most respondents disagreed with the

statement “I sometimes feel worthless because I am HIV positive.” The overall mean score for external stigma was near the lower end of the range of the same 5-point Likert scale ($M = 2.01$), indicating that most respondents agreed that others would think less of them if they were aware of their HIV-positive status. The overall mean score for attitudes toward seeking professional health services was also on the low end of the range of the same 5-point Likert scale ($M = 1.82$), indicating that most respondents agreed that they would seek out professional help when needed.

Enabling variables. Research Question 1 also sought to determine the descriptive characteristics of African American women living with HIV/AIDS who had completed the NWPC-VDENS related to enabling variables. These variables are income benefits, source of support for self, source of support for children, knowledge of state vocational rehabilitation services, poverty, reasonable access, and the three variables of self-efficacy related to employment. Four of the variables: receipt of income benefits, knowledge of services, poverty, and reasonable access to services, were dichotomous. The remaining four variables: source of support for self, source of support for children, and the three measures of self-efficacy were continuous variables. Findings for the enabling variables are presented in Table 3.

Three-fifths (60%) of the study participants had received or were currently receiving Social Security income benefits in the form of supplemental security income (SSI) or social security disability insurance (SSDI). Approximately 5% of the participants did not report their status regarding receiving social security income benefits. Almost 70% of the participants reported having no knowledge of state vocational rehabilitation services. Based on the United States Department of Health and Human Services (2012) poverty guidelines, slightly less than half the sample (48%) reported living in poverty. Ten percent of the participants did not report income or household size, both of which are required to calculate poverty level. Over half of the

Table 3

Descriptive Statistics: Enabling Variables

Variable	Frequency	Percentage
Income benefits		
Never received SSI/SSDI	108	34.5
Received or currently receiving SSI/SSDI	188	60.0
Knowledge of VR services		
No knowledge of services	213	68.1
Knowledge of services	84	26.8
Poverty		
Not living in poverty	133	42.5
Living in poverty	149	47.6
Reasonable access		
None	185	59.1
One or more	114	36.4
	Mean	Standard Deviation
Source of support (self) (1-5)	2.01	1.13
Source of support (children) (1-5)	4.30	1.35
Self-efficacy (job seeking skills) (1-7)	4.89	2.01
Self-efficacy (job accommodations) (1-7)	4.88	2.05
Self-efficacy (maintain job) (1-7)	5.59	1.95

Note. VR = vocational rehabilitation; SSI = supplemental security income; SSDI = social security disability insurance

respondents (59%) reported not being aware of any employment services for people living with HIV in their local area.

The mean score for satisfaction with overall source of social support for the respondents was near the lower end of the 5-point Likert scale ($M = 2.01$), with 1 indicating strongly agree and 5 indicating strongly disagree. These results indicated that most respondents were satisfied with the overall support they received from friends and family. The overall mean score for satisfaction with the overall source of support for the respondent's children was near the upper end of the same 5-point Likert scale ($M = 4.30$), indicating that most respondents were very

much concerned about childcare related to their being able to work. The overall mean score for self-efficacy specific to confidence in job-seeking skills was near the mid-range of the 7-point Likert scale ($M = 4.89$), with 1 indicating no confidence and 7 indicating extremely confident. These results indicated that most respondents were confident in their job-seeking skills. The overall mean score for self-efficacy specific to confidence in asking for job accommodations was also near the mid-range ($M = 4.88$) for the same 7-point Likert scale, indicating that most respondents were confident in asking for job accommodations. The mean score for self-efficacy specific to confidence in maintaining a job once employed was also near the upper end of the range ($M = 5.59$) for the same 7-point Likert scale, indicating that most respondents were very confident they could maintain a job once they were employed.

Need variables. Research Question 1 sought to determine the descriptive characteristics of African American women living with HIV/AIDS who had completed the NWPC-VDENS related to need variables. These variables are health beliefs and two variables of need for rehabilitative services. Health beliefs and one measure of need for rehabilitative services were continuous variables. The remaining need variable for need for rehabilitative services was a dichotomous variable. Findings for the need variables are presented in Table 4. The health beliefs variable was generated from the role functioning scale on the MOS-HIV Health Survey.

The mean score for health beliefs was 61.05, slightly above the mean of 50 for the scale of 0 to 100; this indicates their belief that the role of health impacts their daily functioning. Cronbach's alpha was computed to determine internal consistency reliability or correlations of items on the health beliefs scale. The scale had a Cronbach's alpha of 0.75, which is considered adequate internal consistency (Hulley et al., 2007), and is consistent with past studies using the

Table 4

Descriptive Statistics: Need Variables

Variable	Mean	Standard Deviation	Cronbach's Alpha
Health beliefs/role functioning scale (0-100)	61.05	43.01	.75
Need for rehabilitative services (obtain a job) (1-5)	3.51	1.27	
	Frequency	Percentage	
Need for rehabilitative services (need more information)			
Yes	166	53.0	
No	117	37.4	

role functioning scale of the MOS-HIV (Burgess, Dayer, Catalan, Hawkins, & Gazzard, 1993; Wu et al., 1991).

The overall mean score for the need for rehabilitative services specific to a person with HIV obtaining a job was near the upper end of the mid-range of the 5-point Likert scale ($M = 3.51$), with 1 indicating strongly agree and 5 indicating strongly disagree. These results indicated that most respondents were between neutral and in disagreement with the statement, "It is very hard for a person with HIV to get a job." Over half (53%) of the study participants reported a need for more information about employment resources and services. Thirty participants (9.6%) did not report whether they needed additional information or not.

Research Question 2

Which predisposing, enabling, and need characteristics distinguish African American women living with HIV/AIDS who completed the NWPC-VDENS who have utilized vocational

rehabilitation (VR) services from those who have not? To examine Research Question 2, bivariate analyses were performed analyzing the relationship between the outcome and predictor variables.

Bivariate Analyses. Chi-square analyses were carried out to compare the dichotomous variable of those who used vocational rehabilitation services with that of those who did not. Variables with a p -value of $\leq .05$ were considered to be significant for the bivariate analyses. Independent t tests were performed for continuous variables. The underlying Chi-square assumptions—namely, that all observations are independent and each frequency category contains at least five observations (Stern, 2010)—were both met. The three assumptions for the independent t tests—sampled populations were normally distributed, that the variances of the two populations being sampled were equal (homogeneity of variance), and that cases were drawn randomly and independently of each other (Stern, 2010)—were all met. To investigate normality, skewness values were examined and found to indicate normality of data for each continuous variable. To investigate homogeneity of variance, Levene’s tests were run, and each independent variable was found to have homogeneity of variance across the levels of the variables.

Predisposing variables. Table 5 displays the results of the Chi-square analyses of the outcome variable and predisposing predictor variables of age and children. The same table also displays the independent t tests of the outcome variable and predisposing predictor variables of internal stigma, external stigma, and attitudes toward seeking professional services. There was no statistical significance between those who had used vocational rehabilitation (VR) services and those who had not used VR services for any of the predisposing variables. In these cases,

Table 5

Bivariate Analyses: Predisposing Variables and Use of Vocational Rehabilitation (VR) Services

Variable	Use of VR (%)		χ^2	df	p
	Yes	No			
Age			0.00	1	.96
Exploration and establishment (ages 18-43)	31.1	68.9			
Maintenance and decline (ages 44+)	30.8	69.1			
Children			0.42	1	.52
No children	35.3	64.7			
At least one child	30.6	69.4			

	Use of VR				t	df	p
	Yes		No				
	M	SD	M	SD			
Stigma (internal) (1-5)	3.75	1.29	3.46	1.41	-1.71	294	.09
Stigma (external) (1-5)	3.24	1.43	3.09	1.41	-0.89	294	.38
Attitudes toward seeking professional services (1-5)	1.66	0.84	1.89	1.03	1.80	283	.07

the data did not support the hypotheses that a statistical difference would exist between VR users and non-VR users for the variables of age, children, internal stigma, and external stigma.

Enabling variables. Table 6 shows the results of the four Chi-square analyses of the outcome variable and enabling predictor variables of income benefits, knowledge of services, poverty, and reasonable access to services. All of the aforementioned variables were found to be significant except for poverty. Statistically significant differences were found between vocational rehabilitation users and non-vocational rehabilitation users for the variables of income benefits ($\chi^2 = 23.66, p < .001$), knowledge of services ($\chi^2 = 28.98, p < .001$), and reasonable access to services ($\chi^2 = 8.81, p < .001$). Those who had never utilized VR services were more likely to have never received income benefits such as SSI or SSDI, have no knowledge of VR services, and not be familiar with employment services in their area for people living with

Table 6

Bivariate Analyses: Enabling Variables and Use of Vocational Rehabilitation (VR) Services

Variable	Use of VR (%)		χ^2	df	p
	Yes	No			
Income benefits			23.66	1	.00
Never received SSI/SSDI	13.0	87.0			
Received or currently receiving SSI/SSDI	39.9	60.1			
Knowledge of VR Services			28.98	1	.00
No knowledge of services	21.6	78.4			
Knowledge of services	53.6	46.4			
Poverty			0.03	1	.87
Not living in poverty	29.3	70.7			
Living in poverty	30.2	69.8			
Reasonable Access			8.81	1	.00
None	24.9	75.1			
One or more	41.2	58.8			

	Use of VR				t	df	p
	Yes		No				
	M	SD	M	SD			
Source of support (self) (1-5)	1.99	1.11	2.03	1.15	0.25	291	.80
Source of support (children) (1-5)	4.31	1.36	4.30	1.36	-0.06	275	.95
Self-efficacy (job-seeking skills) (1-7)	5.14	2.01	4.78	2.01	-1.43	287	.15
Self-efficacy (job accommodations) (1-7)	4.97	2.13	4.84	2.01	-0.50	284	.62
Self-efficacy (maintain job) (1-7)	5.71	1.89	5.54	1.98	-0.71	286	.48

Note. SSI = supplemental security income; SSDI = social security disability insurance

HIV/AIDS. Table 6 also displays the five independent *t* tests of the outcome variable and enabling predictor variables; source of support for self, source of support for children, and three measures of self-efficacy. While the data indicated a statistical difference between VR users and non-VR users for the enabling variable of receiving income benefits, the hypothesis that the

participants who had never received income benefits were more likely to have used VR services than non-VR users was not supported. On the contrary, the findings suggested African American women living with HIV/AIDS who are current or former income benefit recipients are more likely to have used VR services than those who have never received income benefits. The data also did not support the hypotheses of a statistical difference between African American women living with HIV/AIDS who completed the NWPC-VDENS who utilized VR services from those who had not for the variables of source of support for self, source of support for children, poverty, and self-efficacy.

Need variables. Finally, Table 7 displays the results of the Chi-square and independent *t* test analyses of the outcome variable and the need variables. There was no statistical significance between those who had used vocational rehabilitation (VR) services and those who had not used VR services for any of the need variables. The data did not support the hypotheses that a statistical difference would exist between VR users and non-VR users for the variables of health beliefs and need for rehabilitative services.

Research Question 3

Which predisposing, enabling and need characteristics are predictive of the use of rehabilitative services among African American women living with HIV/AIDS? Data were missing on all of the predictor variables. For each variable, however, there was no association between missing values, implying that the values are missing at random. Listwise deletion was utilized as the method to address the nonignorable missing data. While several different methods have been developed to handle missing data, none of the more widely accepted methods are superior to listwise deletion (Allison, 2001). Listwise deletion involves deleting any observations that have missing data on any variables in the model, and this is followed by

Table 7

Bivariate Analyses: Need Variables and Use of Vocational Rehabilitation (VR) Services

Variable	Use of VR (%)		χ^2	df	p		
	Yes	No					
Need for rehabilitative services (need more information)			2.40	1	.63		
Yes	28.9	71.1					
No	31.6	68.4					
Variable	Use of VR				t	df	p
	Yes		No				
	M	SD	M	SD			
Health beliefs/role functioning scale (0-100)	61.77	42.64	60.73	44.08	-0.18	274	.85
Need for rehabilitative services (obtain a job) (1-5)	3.71	1.24	3.41	1.28	-1.82	281	.07

conventional methods of analysis (Allison, 2001). According to Allison (2001), listwise deletion is the most robust method to address violations of data that are missing at random among independent variables in a logistic regression analysis.

Logistic regression analysis. Three of the assumptions for logistic regression analysis—a binary dependent variable, independence of error terms, and absence of multicollinearity (Tabachnick & Fidell, 2007)—were addressed prior to conducting the analysis. The absence of multicollinearity was evaluated by conducting correlations among the independent predictor variables. In comparing predictor variables, the Pearson correlation coefficient was used to compare two continuous variables. The Phi coefficient was used to compare two dichotomous variables, and the Point Biserial correlation was used to compare one continuous variable with one dichotomous variable. The correlation coefficients among the dependent variables were less than 0.90, indicating that the assumption for lack of multicollinearity was met (Tabachnick &

Fidell, 2007). Tables 8 through 10 show correlations between the predisposing, enabling, and need variables, respectively.

Table 8

Correlations Between Predisposing Variables

Variable	1	2	3	4	5
1. Age	1.00	-	-	-	-
2. Children	.13	1.00	-	-	-
3. Stigma (internal)	.12*	-.08	1.00		
4. Stigma (external)	.04*	.01	.40**	1.00	
5. Attitudes toward seeking professional services	-.03	.01	.001	.004	1.00

* $p < .05$; ** $p < .01$

Table 9

Correlations Between Enabling Variables

Variable	1	2	3	4	5	6	7	8	9
1. Income benefits	1.00	-	-	-	-	-	-	-	-
2. Support (self)	.10	1.00	-	-	-	-	-	-	-
3. Support (children)	.09	-.05	1.00	-	-	-	-	-	-
4. Knowledge of services	.12*	-.16**	.05	1.00	-	-	-	-	-
5. Poverty	.02	-.06	-.12*	-.01	1.00	-	-	-	-
6. Reasonable access	.05	-.04	-.02	.20**	-.02	1.00	-	-	-
7. Self-efficacy (job-seeking skills)	-.07	-.11	-.003	.02	.11	.04	1.00	-	-
8. Self-efficacy (job accommodations)	-.09	-.10	.03	.09	.04	.09	.76**	1.00	-
9. Self-efficacy (maintain a job)	-.15*	-.18**	.004	.10	.11	.10	.62**	.64**	1.00

* $p < .05$; ** $p < .01$

Table 10

Correlations Between Need Variables

Variable	1	2	3
1. Health beliefs	1.00	-	-
2. Need for rehabilitative services (obtain a job)	.10	1.00	-
3. Need for rehabilitative services (need more information)	-.02	.20**	1.00

* $p < .05$; ** $p < .01$

Tables 11 through 13 show correlations between predisposing and enabling variables, predisposing and need variables, and enabling and need variables, respectively.

Table 11

Correlations Between Predisposing and Enabling Variables

Predisposing Variables	Enabling Variables						Self-Efficacy (job-seeking skills)	Self-Efficacy (job accommodations)	Self-Efficacy (maintain a job)
	Income Benefits	Support (self)	Support (children)	Knowledge of Services	Reasonable Poverty	Access			
Age	.25	.02	.34**	.02	.15	-.06	-.08	-.05	-.07
Children	.02	-.04	-.05	-.22	.16	.04	-.04	-.02	-.05
Stigma (internal)	.09	-.19**	.22**	.11	.21**	.16**	.31**	.34**	.35**
Stigma (external)	.05	-.13*	.19**	.09	-.02	.10	.19**	-.28**	.19
Attitudes toward seeking professional services	.09	.17**	.01	-.17**	-.04	-.10	-.07	-.10	-.07

* $p < .05$; ** $p < .01$

Table 12

Correlations Between Predisposing and Need Variables

Predisposing Variables	Need Variables		
	Health Beliefs	Need for Rehabilitative Services (obtain a job)	Need for Rehabilitative Services (need more information)
Age	-.06	-.02	.09
Children	-.04	.04	-.03
Stigma (internal)	.21**	.40**	.05
Stigma (external)	.16**	.32**	.03
Attitudes toward seeking professional services	.03	-.01	.08

* $p < .05$; ** $p < .01$

Table 13

Correlations Between Enabling and Need Variables

Enabling Variables	Need Variables		
	Health Beliefs	Need for Rehabilitative Services (obtain a job)	Need for Rehabilitative Services (need more information)
Income benefits	-.10	.06	.05
Support (self)	-.10	-.09	.13*
Support (children)	.13*	.08	-.004
Knowledge of services	.04	.03	-.14
Poverty	-.13	-.03	-.03
Reasonable access	.07	.07	.01
Self-efficacy (job-seeking skills)	.20**	.24**	-.05
Self-efficacy (job accommodations)	.19**	.26**	-.10
Self-efficacy (maintain a job)	.24**	.16**	-.12

* $p < .05$; ** $p < .01$

As previously mentioned in the bivariate analyses, prior to inclusion in the model, the relationship of each variable was screened with the outcome variable, rehabilitative service

usage. Due to the exploratory nature of several of the study variables, any explanatory variables with a relationship resulting in a p -value of $\leq .20$ from the bivariate analysis were considered in the logistic regression model. The significance level of the independent variables from the bivariate analyses was an a priori decision to ensure variables with a substantial association were entered into the logistic regression (Matsuoka et al., 2005; O'Neill, Risley-Curtiss, Ayon, & Williams, 2012). The variables with a p -value of less than .20 during the bivariate analyses which were included in the logistic regression were: internal stigma, attitudes toward seeking professional services, receipt of income benefits, knowledge of services, reasonable access to vocational rehabilitative services, self-efficacy related to job-seeking skills, and need for rehabilitation services (obtaining a job).

Research Question 3 sought to determine which predisposing, enabling, and need characteristics were predictive of the use of rehabilitative services among African American women living with HIV/AIDS. A binary hierarchical approach to the logistic regression analysis was conducted to answer Research Question 3. In determining the order in which the variables would be entered, the researcher chose to use the sequence that was consistent with prior research utilizing the behavioral model of health by entering the predisposing variables first, adding the enabling variables second and the need variables last (Datti & Conyers, 2010; Goodwin & Andersen, 2002; Wolinsky & Johnson, 1991).

The dependent variable was the use of vocational rehabilitation services, a dichotomous variable. Internal stigma, attitudes toward seeking professional services, receipt of income benefits, knowledge of services, reasonable access to vocational services, self-efficacy related to job seeking-skills, and need for rehabilitative services to obtain a job were the independent variables. The hierarchical logistic regression analysis was performed in three blocks in order to

determine changes in model significance with the addition of each block. The predisposing variables were entered into the model first, followed by the enabling variables, and finally the need variable. Results of these analyses are presented in Table 14.

Table 14

Logistic Regression Analysis: Use of Vocational Rehabilitation (VR) Services

	B	S.E.	Wald	df	Sig.	Exp(B)	95% C.I. for Exp(B)	
							Lower	Upper
Block 1								
Stigma (internal)	0.14	.10	1.81	1	.18	1.15	0.94	1.41
Attitudes	-0.31	.16	3.61	1	.06	0.73	0.53	1.01
Block 2								
Stigma (internal)	-0.04	.13	0.09	1	.76	0.96	0.75	1.23
Attitudes	-0.28	.17	2.43	1	.12	0.76	0.54	1.07
Income benefits	-1.44	.38	14.59	1	.00	0.24	0.11	0.50
Knowledge	-1.29	.33	14.96	1	.00	0.28	0.14	0.53
Reasonable access	-0.54	.33	2.70	1	.10	0.58	0.30	1.11
Self-efficacy (job-seeking skills)	0.10	.09	1.40	1	.24	1.11	0.94	1.31
Block 3								
Stigma (internal)	-0.07	.14	0.23	1	.63	0.94	.72	1.22
Attitudes	-0.28	.18	2.44	1	.12	0.76	.54	1.07
Income benefits	-1.45	.38	14.63	1	.00	0.24	.11	0.49
Knowledge	-1.30	.33	15.05	1	.00	0.27	.14	0.53
Reasonable access	-0.55	.33	2.78	1	.10	0.58	.30	1.10
Self-efficacy (job-seeking skills)	0.10	.09	1.30	1	.25	1.10	.93	1.31
Need for rehab (maintain a job)	0.80	.14	0.32	1	.57	1.08	.82	1.42

Model 1 of the regression model consisted of the two predisposing variables, internal stigma and attitudes toward seeking professional health services. Neither variable was statistically significant. The -2 log likelihood in the constant model was 293.04, however, it reduced to 287.19 in Model 1 (a significance in change of 5.85) indicating the model is better

than the constant model at predicting the use of rehabilitative services among African American women living with HIV/AIDS more accurately with the addition of the predisposing variables. The regression model was assessed using the Hosmer and Lemeshow Chi Square goodness-of-fit test. The Hosmer and Lemeshow statistic is more robust than the traditional goodness-of-fit statistic used in logistic regression, particularly for models with continuous covariates (Tabachnick & Fidell, 2007). The significance value for this goodness-of-fit test is determined by dividing the data into deciles based on predicted probabilities, then computing a chi-square from observed and expected frequencies (Tabachnick & Fidell, 2007). Model 1, had a good fit ($X^2 = 3.13$, $df = 8$, $p = 0.93$), with a correct classification percentage of 70.7%, showing no improvement of the classification with the inclusion of the predisposing variables. The Nagelkerke's R^2 statistic was also evaluated to quantify the proportion of variance explained by the logistic regression model (Stern, 2010). The Nagelkerke's R^2 for this model was .033, indicating a small effect size. These data did not support the hypothesis that positive attitudes toward seeking professional services would be predictive of the use of rehabilitative services among African American women living with HIV/AIDS.

Four enabling characteristics: receipt of income benefits, knowledge of vocational rehabilitation services, reasonable access to services, and self-efficacy related to job-seeking skills, were added to the logistic regression equation in Model 2. The -2 log likelihood in Model 1 was 287.19, however, it reduced to 246.34 in Model 2 (a significance in change of 40.85) indicating the model is better at predicting the use of rehabilitative services among African American women living with HIV/AIDS more accurately with the addition of the enabling variables. The Hosmer and Lemeshow goodness-of-fit test indicated Model 2, had a good fit ($X^2 = 11.62$, $df = 8$, $p = 0.17$), with a correct classification percentage of 78.5%, indicating an

improvement in the accuracy of classification with the inclusion of the enabling variables. The Nagelkerke's R^2 for Model 2 was .249, indicating a small effect size.

Consistent with Model 1, the two predisposing characteristics were not statistically significant in Model 2. Two of the enabling characteristics, receipt of income benefits ($B = -1.44, p < .001$) and knowledge of VR services ($B = -1.29, p < .001$) emerged as statistically significant variables associated with the use of vocational rehabilitation services in Model 2. For receipt of income benefits, the $Exp(B)$ value in Model 2 was .24, indicating respondents who had used VR services were more than four times more likely to have received SSI or SSDI benefits than those who had not utilized VR services. The $Exp(B)$ value for knowledge of services in Model 2 was .28, indicating African American women living with HIV/AIDS who had used VR services were approximately three and a half times more likely to have knowledge of VR services than their counterparts who had never utilized VR services. The remaining two variables, reasonable access to services and self-efficacy related to job seeking skills, were not statistically significant in the model.

One need characteristic, the need for rehabilitative services to obtain employment, was added to the logistic regression equation in Model 3. The -2 log likelihood in Model 2 was 246.34, however, it reduced slightly to 246.02 in Model 3 (a change of 0.32) indicating the model is only slightly better at predicting the use of rehabilitative services among African American women living with HIV/AIDS more accurately with the addition of the need variable. The Hosmer and Lemeshow goodness-of-fit test indicated the final block, Model 3, had a good fit ($X^2 = 12.44, df = 8, p = 0.13$), with a correct classification percentage remaining at 78.5%, indicating no improvement of the classification with the inclusion of the need variable. The Nagelkerke's R^2 for Model 3 was .251, indicating a small effect size.

In the third and final block of the model, the two predisposing characteristics continued to lack statistical significance, while two of the four enabling characteristics, income benefits and knowledge of VR services continued to remain statistically significant. The need characteristic, which was the need for rehabilitative services to obtain a job, was not statistically significant in the model. These data support the hypothesis that having knowledge of vocational rehabilitation services is predictive of the use of rehabilitative services among African American women living with HIV/AIDS. These data, however, do not support the hypothesis that greater access to services is predictive of the use of rehabilitative services among African American women living with HIV/AIDS.

For receipt of income benefits, the $Exp(B)$ value in the final model was .38, indicating respondents who had used VR services were more than two and a half times more likely to have received SSI or SSDI benefits than those who had not utilized VR services. The $Exp(B)$ value for knowledge of services in the final model was .33, indicating African American women living with HIV/AIDS who had used VR services were three times more likely to have knowledge of VR services than their counterparts who had never utilized VR services.

The overall model is significant ($X^2 = 46.88, df = 7, p < .001$). Regarding the independent variables in the model, receipt of income benefits and knowledge of vocational rehabilitative services were significant at the $p = .05$ level (see Table 14). Based on the odds ratios of statistically significant predictors, respondents are more likely to use vocational rehabilitation services if they know of vocational rehabilitation services and have received income benefits such as SSI/SSDI.

Summary

This study provided evidence of descriptive characteristics of African American women living with HIV/AIDS who had completed the NWPC-DEN Survey related to various predisposing, enabling, and need variables. Characteristics distinguishing the 69% of African American women who reported not using vocational rehabilitation services from the 31% who had used vocational rehabilitation services were also examined. Finally, the analysis indicated that, of the 17 independent variables included in the study, receiving income benefits such as SSI/SSDI and knowledge of vocational rehabilitation services were the two characteristics predictive of African American women living with HIV/AIDS using vocational rehabilitation services.

Chapter 5: Discussion

The purpose of this study was to identify and examine variables related to and predictive of the utilization of rehabilitative services among a sample of African American women living with HIV/AIDS. Chapter 5 presents a summary and important findings of the study. It also presents conclusions drawn from the responses to the study's three research questions and concludes with an exposition of the limitations of the study, implications for action, and recommendations for future research.

Descriptive Characteristics

Research Question 1 sought to identify the descriptive characteristics of the sample population related to the outcome, predisposing, enabling, and need variables. There were no hypotheses accompanying Research Question 1. The sample for this study consisted of 313 female African American women living with HIV/AIDS. Seventy-two percent of the respondents reported being HIV-positive while the remaining 28% reported having a diagnosis of AIDS.

As the prognosis and treatment of HIV/AIDS have shifted from a terminal illness to chronic illness, so have the employment service needs of individuals living with the disease. This is evidenced in the demographics of this sample relative to employment. Twenty-six percent of the participants reported being employed at the time of the survey, while 41% indicated being employed at the time of diagnosis. This higher proportion of women being unemployed after a diagnosis of HIV/AIDS is consistent with previous study findings indicating

the strength of the relationship between unemployment and living with HIV/AIDS (Dray-Spira et al., 2006) as well as the documented link between poverty and disability (Lustig & Strauser, 2007). This shift in employment status may be due in part to financial necessity since HIV/AIDS medications have helped to prolong lives (thereby requiring more financial resources) and the majority of the respondents (80%) indicated that they were supporting at least one child.

Twenty percent of the respondents reported having less education than a high school diploma, while 27% had earned a high school diploma and 16% reported earning a college degree. Studies often report a low education level as one of many barriers for African American women living with HIV/AIDS (Mulenga & Conyers, 2003). With regard to education, the descriptive data for this study are consistent with some studies exclusive to African American female participants living with HIV/AIDS in which the majority of the participants possessed a minimum of a high school diploma (Black & Miles, 2002; Shambley-Ebron & Boyle, 2006b). However, it is inconsistent with others in which the majority of the participants had not completed high school (Buseh & Stevens, 2007; Clark, Lindner, Armistead, & Austin, 2004; Weinberg & Simoni, 2004). This variety represents the growing range of diversity within subgroups of people living with HIV/AIDS.

In response to the outcome variable, 69% of the respondents reported never having used vocational rehabilitation services since being diagnosed with HIV/AIDS. These findings were consistent with those of two previous studies (Conyers & Datti, 2008; Datti & Conyers, 2010). Findings from the Conyers and Datti study (2008), which included a significant representation of women of color from research based on an earlier version of the instrument used for this study, indicated that slightly more than three-fourths of the female respondents living with HIV/AIDS had never utilized vocational rehabilitation services. Latino men were the demographic of focus

for the Datti and Conyers (2010) study which utilized participants from the larger NWPC-VDEN nationwide study, which includes the sample from which the current study was selected. Similar to the current study, the researchers in the 2010 study found that over 70% of the respondents had never used VR services (Datti & Conyers, 2010).

Predisposing characteristics are described as factors that might influence the propensity for an individual to access and utilize services (Gelberg et al., 2000). The study examined five predisposing variables: age, children, internal and external stigma, and attitudes toward seeking professional services. The respondents ranged in age from 29 to 73 years with a mean age of 46 years.

Internal stigma was defined as stigmatizing attitudes that woman living with HIV/AIDS expressed toward themselves. In regard to internal stigma, participants scored near the upper end of the mid-range of the 5-point Likert scale ($M = 3.55$), indicating that they did not experience a considerable amount of internal stigma. These findings were consistent with those of a previous study evaluating the internal stigma of African American women living with HIV/AIDS (Rao et al., 2008), which found internal rejection to be a concern for women living with HIV/AIDS, but less relevant to African American women than to White women. It is important to note that the majority of this study's participants were recruited from AIDS service organizations (ASOs). It is common for ASOs to hire individuals who are living with HIV/AIDS who can also serve as peer role models to individuals accessing services. As a result, the feelings of internalized stigma that individuals in general work environments may experience may not be as profound with this sample as they may be more accustomed to interacting with people who are both successful and open about living with HIV/AIDS (Conyers, 2004a; Roy & Cain, 2001).

External stigma was defined as stigmatizing attitudes inflicted by another individual. The mean score ($M = 2.01$) indicated that respondents agreed that others would think less of them if they were aware of their seropositive status. The current study's findings for external stigma were consistent with the experiences of African American women in previous studies (Black & Miles, 2002; Garcia et al., 1997; Peterson, 2010; Rao et al., 2008), with African American women reporting high levels of external stigma. Numerous factors may contribute toward this finding. One possible explanation for the findings related to increased experiences of external stigma may be a proliferation of other experiences by African American women dealing with racial stigma or discrimination (Rao et al., 2008). Additionally, in spite of the advancements of drug treatments that frequently extend the life expectancy of individuals living with HIV/AIDS, many Americans still perceive AIDS as a degenerative and fatal malady resulting in ongoing stigma attached to the disease (Herek, 2002). As increasing numbers of African American women are living with HIV/AIDS, increased levels of external stigma may be experienced as sweeping generalizations are made about the African American community in general and more specifically its women (Lekas et al., 2006). These sweeping generalizations may also lead to higher reported levels of external stigma resulting from the assumption of others about the cause of changes to the appearance of African American women living with HIV/AIDS as the disease progresses (Lekas et al., 2006). The data specific to external stigma is particularly important as a past study by Clark and colleagues (2004) concluded that among African American women living with HIV/AIDS, higher levels of perceived stigma were associated with lower chances of disclosing status and poorer psychological functioning.

Seventy-nine percent of the African American women living with HIV/AIDS who completed the NWPC-VDENS indicated they would seek out professional help when needed.

While this is a finding that could contribute to better health outcomes, it is not consistent with previous findings concerning the reluctance of African American women living with HIV/AIDS to seek professional help due to concerns with breaches in confidentiality (Peterson, 2010). This finding is also inconsistent with a well-established broader body of research about African Americans' mistrust of healthcare employees (Alston, 2004; Washington, 2006) and may warrant further investigation. Additionally, there may be a conflict between respondents' perceived need for professional help and when the healthcare community would deem it medically or vocationally necessary. In future quantitative research the term "when needed" may need to be operationally defined to ensure consistent interpretation or further explored for interpretation by participants in qualitative studies.

Nine enabling variables were examined in this study. The variables were: receipt of income benefits, source of support for self and children, knowledge of vocational rehabilitation services, poverty status, reasonable access to services, and three measures of self-efficacy related to employment. Sixty percent of the respondents reported either receiving SSI or SSDI at the time of the survey or having received SSI or SSDI in the past. This finding was similar to the 2008 Conyers and Datti study, which found that over 50% of the unemployed participants reported receiving SSI or SSDI. The finding was also similar to findings specific to Latino men living with HIV/AIDS (Datti & Conyers, 2010) in which 63% of the participants reported being recipients of SSI or SSDI income benefits and another study which found that 66% of the African American women living with HIV/AIDS were receiving governmental assistance (Black & Miles, 2002). African American women living with HIV/AIDS who are unemployed or underemployed while they are asymptomatic, or experiencing fluctuating symptoms and receiving public assistance benefits such as Temporary Assistance for Needy Families (TANF)

for their children may be encouraged to apply for SSI benefits as their symptoms increase or their disability is disclosed (Wamhoff & Wiseman, 2005). This finding may also be partly due to the formal relationship some state social service agencies have established with state VR agencies to review TANF client disability claims (Kaplan, 2000). When women are applying for TANF eligibility, workers are tasked with the duty of making appropriate referrals to apply for SSI and/or VR services. Additionally, some social security administration offices have adopted initiatives to refer clients to state vocational rehabilitation services after an evaluation of eligibility for SSI/SSDI (United States Social Security Administration, 1997).

The majority of participants in this study (69%) reported having no knowledge of vocational rehabilitation services. This finding is similar to findings by Datti and Conyers (2010) in which 71% of the Latino male participants were not knowledgeable of VR services. Another 60% of the participants were not aware of local employment services for people living with HIV/AIDS, which was consistent with previous study findings (Datti & Conyers, 2010). Researchers have opined that people experience a limited knowledge of VR services because there are no specialty caseloads for VR counselors working with people living with HIV/AIDS as there are for people diagnosed with other disabilities such as deaf and hard of hearing, brain injuries, developmental disabilities, end state renal disease, and epilepsy (Datti & Conyers, 2010). This finding is particularly interesting as participants for the study were recruited from ASOs. This further supports previous research indicating that the needs of individuals living with HIV/AIDS may exceed the available services and resources of ASOs in regards to employment issues (Conyers, 2004b; Timmons & Fesko, 2004). To the knowledge of this researcher, no additional studies have specifically examined the knowledge of African American women living with HIV/AIDS about VR services.

Another 60% of the participants of this study were not aware of local employment services for people living with HIV/AIDS, which was consistent with previous study findings (Datti & Conyers, 2010). Researchers have opined that people experience a limited knowledge of VR services because there are no specialty caseloads for VR counselors working with people living with HIV/AIDS as there are for people diagnosed with other disabilities such as deaf and hard of hearing, brain injuries, developmental disabilities, end state renal disease, and epilepsy (Datti & Conyers, 2010). This finding is particularly interesting as participants for the study were recruited from AIDS service organizations (ASOs). This further supports previous research indicating that the needs of individuals living with HIV/AIDS may exceed the available services and resources of ASOs in regards to employment issues (Conyers, 2004b; Timmons & Fesko, 2004). To the knowledge of this researcher, no additional studies have specifically examined the knowledge of African American women living with HIV/AIDS about VR services.

Almost half of the participants (48%) of this study were living below 200% of the federal poverty line. This finding is consistent with previous studies specific to African American women living with HIV/AIDS (Buseh & Stevens, 2007; Shambley-Ebron & Boyle, 2006b; Weinberg & Simoni, 2004) as well as another minority group, Latino men living with HIV/AIDS (Datti & Conyers, 2010). These findings are further supported by an analysis completed by the Centers for Disease Control (2010) demonstrating a strong link between poverty and HIV infection. There are higher HIV rates among low-income heterosexuals in the United States and a causal relationship between poverty and disability in general (Lustig & Strauser, 2007).

The mean score for respondents' satisfaction with the source of support received for themselves and their children was near the lower end of the 5-point Likert scale ($M = 2.01$), indicating respondents were satisfied with their level of overall support. In contrast, respondents

indicated considerable concern concerning the overall support received for their children ($M = 4.30$). Findings specific to support for the respondents and their children were consistent with a previous study of African American women living with HIV/AIDS who indicated the value of receiving emotional and tangible support from family and friends (Owens, 2003). The same study, however, indicated that only one respondent received cognitive support (Owens, 2003). The current study did not discriminate between various types of support. Future researchers may seek to specify the type of support received (such as emotional, tangible or cognitive) to discern the existence of any differences.

In regard to self-efficacy specific to confidence in job-seeking skills and requesting job accommodations, participants scored near the mid-range of the 7-point Likert scale ($M = 4.89$ and $M = 4.88$, respectively), indicating that most participants were confident with their job-seeking skills and requesting accommodations. While findings from a study by Conyers and Boomer (2005) suggest a high percentage of people with HIV/AIDS may be able to work without accommodations, further research is warranted as few of those study participants were African Americans. Respondents scored near the upper end ($M = 5.59$) of the same 7-point Likert for the measure of self-efficacy related to maintaining employment. This indicates that respondents were very confident in their ability to keep jobs once employed. Given the cross-sectional nature of the current study, it is not clear whether self-efficacy toward employment occurred as a result of having received vocational rehabilitation services or not.

Much of the research investigating self-efficacy specific to African American females has utilized a sample consisting primarily of college students (Chung, 2002) or focused on sexual behaviors rather than employment (McCree, Wingood, DiClemente, Davies, & Harrington, 2003). Regarding adults, researchers Hackett and Byars (1996) contend African American

women who have witnessed other African American women experience difficulties related to various barriers or forms of discrimination may believe they will experience similar obstacles to employment. No known studies measured the self-efficacy of African American women living with HIV/AIDS related to employment prior to this study. However, in a similar study with Latino men, findings for job-seeking skills ($M = 4.52$) and maintaining employment ($M = 5.00$) were similar to the findings of this study. African American women expressed a slightly stronger confidence in maintaining a job – perhaps because many of these respondents needed to maintain income to support their children. Future research should examine the impact of self-efficacy related to employment on African American women living with HIV/AIDS.

Health beliefs and the need for rehabilitative services were the two need variables examined for Research Question 1. The health belief variable was derived from the two questions on the role functioning scale of the MOS-HIV. The scores ranged from 0 to 100. The mean score for the study participants was 61.05, indicating a belief that their health impacted their daily functioning. This finding was similar to those in other studies examining the role of health on African American women living with HIV/AIDS which used the MOS-HIV role functioning scale (Cowdery & Pesa, 2002; McDonnell, Gielen, O'Campo & Burke, 2005).

Two questions were used to examine the need for rehabilitative services of the study participants. Only 17% of the participants agreed that it would be difficult for a person living with HIV to obtain employment. Findings from a study examining the confidence of African American women with various disabilities (Hall, 2007) found respondents were slightly less confident in their ability to find employment than the participants living with HIV/AIDS in this study. A possible explanation for the finding for this characteristic may be relative to the sample recruited for this study. Participants were recruited through ASOs, which often hire individuals

living with HIV/AIDS as employees. While no known studies solely measured the beliefs of African American women living with HIV/AIDS concerning the difficulty with obtaining employment, findings by Conyers and Datti (2008) indicated less than half of the study participants living with HIV/AIDS believed it possible to obtain employment with adequate health insurance benefits.

Fifty-three percent of the participants identified a need for more information about resources pertaining to employment. This finding is consistent with previously discussed enabling characteristics that indicate a lack of knowledge about vocational rehabilitation services as well as a study indicating a lack of knowledge of VR services or local resources for people living with HIV/AIDS (Datti & Conyers, 2010).

Summary of Key Findings

Key Findings from Research Question 2: Receipt of income benefits, knowledge of services and reasonable access to services are the characteristics which distinguish African American women living with HIV/AIDS who completed the NWPC-VDENS who have utilized vocational rehabilitation (VR) services from those who had not utilized services.

A series of bivariate analyses were run to distinguish which predisposing, enabling, and need characteristics differentiated those African American women living with HIV/AIDS who utilized vocational rehabilitation services from those who did not in order to answer Research Question 2. Eleven hypotheses accompanied Research Question 2, which suggested that significant differences would be found between those respondents who had utilized VR services and those who had not.

The three variables that were found to have statistical significance were receipt of income benefits ($p < .001$), knowledge of services ($p < .001$), and reasonable access to services

($p < .001$). While there was a statistical difference between those who had and had not received income benefits, the results did not support the hypothesis that African American women living with HIV/AIDS who had never received income benefits were more likely to have used VR services than current or former SSI/SSDI recipients. The results indicated the opposite, showing that those who were SSI/SSDI recipients were more likely to have used VR services. While this finding is consistent with that of a similar study focusing on Latino males (Datti & Conyers, 2010), the results are important since losing such income benefits has been posited as a disincentive for people living with HIV/AIDS to return to work (Conyers, 2004b; Datti & Conyers, 2010; Glenn et al., 2003). It may be that SSI/SSDI recipients are more likely to seek out VR services because of prior experience with navigating public systems in addition to the explanations mentioned above pertaining to relationships, which have been forged between some social security administration offices and state vocational rehabilitation agencies.

The remaining 10 hypotheses accompanying Research Question 2 were not supported as no statistical differences were found between VR users and non-VR users for those specific variables. The lack of statistical significance between the two groups indicates there are no real differences between the means of the two groups and variability of the variable in the population may be able to be explained by chance alone. This lack of statistical significance may also be in part due to the sample size. While the sample size was adequate for the chosen data analyses, a larger sample size may have detected more variance between the groups.

Key Findings From Research Question 3: *Receipt of income benefits and knowledge of VR services were statistically significant variables predictive of VR use among African American women living with HIV/AIDS.*

Research Question 3 sought to examine which predisposing, enabling, and need characteristics are predictive of African American women living with HIV/AIDS who utilize vocational rehabilitation services. It was hypothesized that attitudes toward seeking professional services, knowledge of vocational rehabilitation services, and access to services would be predictive variables of the use of VR services. The findings from the logistic regression analysis indicated receipt of income benefits ($p < .001$) and knowledge of VR services ($p < .001$) were predictive variables of VR use among African American women living with HIV/AIDS, thus supporting one of the hypotheses. None of the predisposing or need variables were found to be statistically significant in predicting use.

It is important to note that the findings specific to the predictive nature of the variable of receipt of income benefits are consistent with findings from a similar study (Datti & Conyers, 2010). Multiple explanations that have been discussed in terms of Research Questions 1 and 2 may explain the significance of this characteristic. They are also applicable to the explanation of their predictive value regarding the utilization of VR services among African American women living with HIV/AIDS.

Having knowledge of vocational rehabilitation services was the most predictive of VR use, as an odds ratio indicated that African American women who had knowledge of vocational rehabilitation services designed to assist people with HIV/AIDS were approximately three and a half times as likely to use these services as those who had no knowledge of VR services. The fact that knowledge of VR services was found to be a predictive characteristic is not surprising. Conventional knowledge would dictate that the use of services would be contingent upon individuals being well-informed about rehabilitative services. This finding was also consistent with previous research specific to Latino men (Datti & Conyers, 2010). The finding for this

study has merit in that it provides empirical support to the body of literature about African American women living with HIV/AIDS and their access to the formal rehabilitation system.

While conventional wisdom might suggest having an awareness of employment services in one's area would be predictive of an individual utilizing the services, these data findings suggest otherwise. Being aware of employment services serving people living with HIV in their area was not found to be a significant predictor of African American women living with HIV/AIDS who completed the NWPC-VDENS using the services. Considering the link between poverty and the use of health care services, this finding is consistent with previously reported findings indicating individuals living in poverty, whether employed or unemployed, were more likely to delay using health care resources (The United State Department of Health and Human Services, 2005). Additionally, while African American women living with HIV/AIDS may be aware of local vocational rehabilitation services, they may be more comfortable with receiving services from an AIDS Service Organization (ASO) that are not traditionally known to provide comprehensive employment and vocational services.

Relevance of Theoretical Framework

Andersen's behavioral model for vulnerable populations was utilized as the theoretical framework for this study. The revised model specific to vulnerable populations was derived as the authors purported that factors that make individuals vulnerable may also contribute to their use or lack of use of health services (Gelberg et al., 2000). The behavioral model has been one of the most utilized theoretical frameworks to explain health service utilization (Calsyn, 2003). The model provided an organized approach to guide the selection of the study's predictor variables.

Andersen (1995) posits that in examining enabling characteristics, knowing the impact of various community health care organizations is needed to expand the breadth of understanding of the model. This study adds to this base of knowledge specific to the vocational rehabilitation system, which, as defined by the American Medical Association (2011), is a segment of the larger health care system. The findings of this study provide support for the idea that the behavioral model for vulnerable populations has predictive value for explaining the utilization of vocational rehabilitation services among African American women living with HIV/AIDS. Receipt of income benefits and knowledge of VR services were significant predictors of VR use in the regression model. In this study, both of the significant predictors of the use of vocational rehabilitation were enabling characteristics. No predisposing or need variables were significantly associated with obtaining care.

The behavioral model for vulnerable populations is the latest iteration of the behavioral model in which equitable treatment was originally defined as the majority of the variance pertaining to services being attributed to predisposing and need characteristics (Andersen, 1968, 1995). In contrast, inequitable treatment was defined as enabling characteristics accounting for most of the variance in the receipt of services (Andersen, 1968, 1995). The findings from this study indicate that even with the introduction of the need characteristic, the enabling characteristics displayed the greatest impact and led to the most significant changes between the models of the logistic regression. Based upon the aforementioned theoretical perspective, the findings of this study indicate African American women living with HIV/AIDS face inequitable treatment as it relates to the utilization of vocational rehabilitation services.

Andersen (1995) suggests in order to promote changes in policies, the characteristics that are deemed as having the most importance must be mutable. Mutable characteristics are those

that are amenable to or directly influenced by public or health policies (Andersen & Newman, 1973). Mutable properties can be changed to effect the availability and consumer satisfaction with rendered services. In contrast, immutable properties are unable to be altered by policy change. Family and community enabling characteristics are considered to be highly mutable characteristics (Andersen & Newman, 1973). Andersen (1995) indicates, “policies are implied first by determining what variables explain utilization” (p. 5). As the predictive characteristics, receipt of income benefits and knowledge of vocational rehabilitative services are both mutable, results from this study could be employed to foster equitable access and implement policy changes affecting the utilization of vocational rehabilitation services by African American women living with HIV/AIDS as the findings indicate the significant and predictive variables are enabling characteristics. Policies considering the impact of losing health benefits throughout the course of the episodic condition of HIV/AIDS could influence the use of vocational services among African American women living with HIV/AIDS. Additionally, based on the predictive characteristic of the knowledge of VR services, implementing strategies targeting communities of color to increase the knowledge of services offered via vocational rehabilitation organizations should also prove to be beneficial. Both of these enabling characteristics are ones that could be increased through policy changes and targeted marketing.

Study Limitations

It is important to discuss the limitations that should be considered when interpreting the results of this study. The first limitation is the use of a convenience sample, which limits the generalizability to other African American women living with HIV/AIDS. A limitation to using a convenience sample is that the participants may be atypical of the population due to their particular interest in the study. In particular, the convenience sample participants for this study

were volunteers recruited through AIDS service organizations (ASOs) and may not capture the experiences and perceptions of African American women living with HIV/AIDS who are not affiliated to ASOs or those women who chose not to volunteer for the survey. Also, as many ASOs employ individuals living with HIV/AIDS, it is safe to assume that many of the survey respondents would be familiar with individuals living with HIV/AIDS who are working and may have a support network.

A second limitation is the use of self-reported information. The researcher acknowledges there are potential risks in utilizing self-reported data. While using the administered survey can yield information that can be quickly collected and evaluated, there is also room for bias. A common deficiency of self-reported instruments is social desirability response bias (Polit & Beck, 2008). Given the stigma that is often associated with this disease, the risk of social desirability response bias likely cannot be completely eliminated. Assuring confidentiality of responses and limiting interviewer involvement were strategies implemented to reduce the risk of social desirability.

A third limitation of the study is the use of cross-sectional data. One primary limitation of a cross-sectional study design is that exposure and outcomes are simultaneously assessed, but this means that making inferences of causality or direction of the relationships is unclear. Additionally, with cross-sectional data, alternative explanations may exist for the results.

Another limitation of the study is the use of secondary data. As this researcher was not instrumental in creating the survey instrument, the data was not specifically collected to answer these specific research questions. The primary researcher of this study was afforded the opportunity to consult with the principal investigator responsible for primary collection of the data and was able to confirm processes and accuracy related to the collection of the data.

Another limitation of the study is the use of multiple t-tests for the bivariate analyses. While the use of the bivariate analyses is an acceptable method to determine which independent variables are statistically significant to analyze in the logistic regression model, the use of separate univariate t-tests increases the chances of making a Type I error rate inflation (Kirk, 2007). An alternative is to lower the alpha level, however, this subsequently reduces the loss of power for each performed test (Kirk, 2007).

Finally, African American women living with HIV/AIDS were the primary focus for this study. As a result, the findings are not generalizable to other demographic groups such as Whites, Hispanics, Asians, men or transgender individuals. Generalizability is also not possible for other women who may identify as Black but not African American such as Black Hispanics, Black Caribbeans, and Black Africans.

Implications for Practice

The behavioral model for vulnerable populations describes predisposing, enabling and need characteristics that influence the use of the healthcare system by vulnerable populations. Predisposing and enabling characteristics exist prior to the onset of one's disability and do not have the ability to be altered by accessing the healthcare system; however, they can directly impact an individual's ability to access quality services (Gelberg et al., 2000). As Andersen (1995) describes, ensuring equitable service involves the reduction of the influence of predisposing and enabling characteristics and maximizing the impact of need characteristics on using the healthcare system. The inability of African American women living with HIV/AIDS to access rehabilitative services often leads to health disparities. In an effort to reduce health disparities within the formal vocational rehabilitation system, it is appropriate to evaluate the

characteristics that influence the utilization of services among African American women living with HIV/AIDS.

Enabling characteristics as defined by the model had strong predictive value for this study. Two enabling characteristics, receipt of income benefits and knowledge of vocational rehabilitation services were found to be predictive of the use of rehabilitative services among African American women living with HIV/AIDS. Numerous research studies (Atkins & Wright, 1980; Feist-Price, 1995; Wilson, 2002, 2005) have found that vocational rehabilitation organizations have generated below average participation among ethnic and racial groups with disabilities. This points to a need for VR systems to implement revised strategies to ensure people of color are aware of how and where to access services. In addition, there should be systems in place to deliver accurate information pertaining to what services are available. Some individuals living with HIV/AIDS may prefer receiving assistance with their disability through AIDS service organizations (ASOs) rather than general vocational rehabilitation settings. ASOs have met several needs of people living with HIV/AIDS; however, the vocational, economic and medical needs of those seeking services may exceed the availability of services through ASOs (Conyers, 2004b; Timmons & Fesko, 2004). One strategy that could combine the specialized assistance of ASOs with the expansive services of rehabilitative services would be providing vocational rehabilitation satellite services within ASOs, public health agencies, social service agencies, mental health organizations, medication adherence programs, religious institutions, or other community organizations that specifically target underserved populations.

This study provides insight about the various factors that may affect access to quality health care services for African American women living with HIV/AIDS. Kohlenberg and Watts (2003) observe that many rehabilitation counselors have limited experience in working with

people with HIV/AIDS and may not know enough about the disease to deal with its unique features. African American women living with HIV/AIDS often experience multiple layers of marginalization because of their race, gender, and disability. A failure to adequately address one of these factors alone can present challenges to the rehabilitation process; however, the intersection of these factors can be triply challenging. As Vernon (1999) posits, “the effects of being attributed several stigmatized identities are often multiplied (exacerbated) and they can be experienced simultaneously and singularly depending on the context” (p. 395). In essence, African American women living with HIV/AIDS may experience racism, sexism and disablism within the context of receiving vocational rehabilitation services from counselors who lack awareness of approaches to address these multiple issues. Moodley and Lubin (2008) contend that while there is a growing awareness of the need to provide competent counseling to members of diverse populations, few are skilled at a level to feel comfortable in providing services to those who are different than themselves in the ‘big 5’ stigmatized categories of race, gender, disability, sexual orientation and class. To maximize the potential of successful outcomes, rehabilitation counselors should be cognizant of the influence of these factors without overlooking the impact they may have on each woman during the rehabilitation process. In-service trainings focusing on the needs of people living with HIV/AIDS and specifically the needs and challenges of African American women living with HIV/AIDS may prove to be beneficial for state vocational rehabilitation counselors providing appropriate services for this population. Additionally, as further research is conducted, the implementation of evidence-based research through knowledge translation in the vocational rehabilitation system may also prove to be advantageous in accessing and receiving quality services for African American women living with HIV/AIDS.

Recommendations for Future Research

This study and its subsequent findings add to the dearth of literature specific to African American women living with HIV/AIDS accessing the vocational rehabilitation system. The study extends prior findings by applying the behavioral model for vulnerable populations to guide the selection of variables to examine utilization patterns. In addition to the findings, there are several recommendations for future research resulting from the study.

In more recent years, a developing theory has been introduced specific to vocational rehabilitation and health disparities. Within this developing theory, the term, “disability disparity” has been coined to describe a health disparity within the context of the rehabilitation system. Lewis (2009) operationally defines a disability disparity as existing:

When an underserved or ethnic minority cultural group’s goal is to receive services within the formal rehabilitation and delivery system, but there is a differential experience based primarily on cultural orientation that results in more incidence of disability and/or lower participation levels in the formal helping system and/or fewer successful individual outcomes when compared to majority culture groups. (p. 1140)

After further validation of the developing theory, future researchers may consider viewing health disparities within the vocational rehabilitation sector through this lens.

Another recommendation would be to replicate this study, but with a different target group. One suggested way of replicating the study would include targeting African American women living with HIV/AIDS who are not primarily recruited through ASOs. Suggested organizations to target participants may include community agencies, employment agencies, religious institutions, medical facilities, vocational rehabilitation agencies, and support groups.

Replication of the study would also be advantageous for other disproportionately affected groups who are underrepresented in the literature, such as African American heterosexual men, African American and Latino men having sex with men (MSMs), Latina women, and other ethnic and racial groups. Comparative studies have shown that some experiences of African American women living with HIV/AIDS differ from those of their Latina counterparts (Conyers & Datti, 2008; Lekas et al., 2006; Rao et al., 2008). Additional studies comparing the use of vocational rehabilitation services among African Americans and other ethnic and racial groups would provide insight about the differences and similarities of different demographic groups.

While this study provided initial findings specific to several variables, additional investigation would provide a better understanding of patterns of utilization. Self-efficacy related to employment was a variable examined in this study that had not been previously examined specific to African American women living with HIV/AIDS. As the findings for self-efficacy were preliminary for this population, additional exploration of this variable is needed to evaluate the consistency of the findings. Qualitative research focusing on the experiences and perceptions of African American women living with HIV/AIDS specific to social support, employment, cultural mistrust of healthcare organizations, and experiences when accessing the vocational rehabilitation system would help fill in the gap in knowledge pertaining to this demographic. Currently, a dearth of research examining the experiences of individuals over 50 years of age living with HIV/AIDS is available. Additional exploration of this age group is particularly warranted for women and African Americans. It would be valuable to evaluate both the perspectives of individuals who were diagnosed at a younger age and have lived with the disease past the age of 50 and the views of those individuals who were originally diagnosed after the age of 50.

Future studies addressing other predisposing, enabling, and need variables impacting the utilization of support services by African American women living with HIV/AIDS are needed. Examples that are worth exploring to illuminate the experiences of African American women living with HIV/AIDS include reported quality of life, resilience, impact of religion and faith, insurance, employment, comorbid disabilities, and self-esteem. The findings for this study indicated that African American women living with HIV/AIDS were inclined to seek professional help if they felt it was needed. In light of historical abuses of African Americans within the healthcare system, it would be appropriate to explore further feelings of cultural mistrust as a possible barrier to utilization of rehabilitation services.

Conclusion

The purpose of this study was to identify and examine variables related to and predictive of the utilization of vocational rehabilitation services among African American women living with HIV/AIDS. This study is one of the few studies to examine the differences between individuals living with HIV/AIDS or African Americans who have used vocational rehabilitative services and those who have not. While the few studies in vocational rehabilitation have focused on the general population of people living with HIV/AIDS, Latino men, or women in general, this is the first known study to examine the utilization patterns of vocational services by African American women living with HIV/AIDS.

Despite the identified limitations, the study has made several unique contributions to the literature and filled a gap in the current literature. The behavioral model has been one of the most utilized theoretical frameworks to explain health service utilization (Calsyn, 2003). The findings of this study provide support for the idea that the behavioral model for vulnerable populations has predictive value for explaining the utilization of vocational rehabilitation

services among African American women living with HIV/AIDS. This study further extends the service utilization literature to include vocational rehabilitation services and African American women living with HIV/AIDS. It is also the first of its kind to examine self-efficacy related to employment, beliefs concerning the difficulties of obtaining employment, and knowledge of VR services specific to African American women living with HIV/AIDS. Thus it expands professional knowledge of the characteristics that impact the lives of African American women, one the most disproportionately affected groups living with HIV/AIDS.

With this addition to the current body of literature concerning African American women living with HIV/AIDS, vocational counselors are equipped with empirical data to better serve clients who may present distinctive features, which may be analogous or dissimilar to other African American women with disabilities accessing the vocational rehabilitation system. This empirical knowledge can be used to develop and provide culturally and gender sensitive rehabilitative programs specific to African American women living with HIV/AIDS. Additionally, study findings can be utilized to address health disparities by promoting change through policy and action within the state-federal vocational rehabilitation system.

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Appendix A

Purpose, Research Questions, and Hypotheses

Purpose	Research Questions	Hypotheses
To identify and examine variables related to and predictive of the utilization of rehabilitative services among a sample of African American women living with HIV/AIDS in the United States who volunteered to complete the National Working Positive Coalition Vocational Development and Employment Needs Survey.	RQ1: What are the descriptive characteristics of African American women living with HIV/AIDS who completed the NWPC-VDENS related to predisposing, enabling, need and outcome variables?	N/A
	RQ2: Which predisposing, enabling and need characteristics distinguish African American women living with HIV/AIDS who completed the NWPC-VDENS who have utilized vocational rehabilitation (VR) services from those who have not?	H1: African American women living with HIV/AIDS within (1) the exploration and establishment stages (ages 18-43) are more likely to have used VR services than women within (2) the maintenance and decline stages (age 44 and older). (Predisposing)
		H2: African American women living with HIV/AIDS who have children are more likely to use VR services than those who do not have children. (Predisposing)
		H3: African American women living with HIV/AIDS who report more internal stigma are less likely to use VR services than those who do not report internal stigma. (Predisposing)
		H4: African American women living with HIV/AIDS who report more expectations of external stigma are less likely to use VR services than those who do not report expectations of external stigma. (Predisposing)
		H5: African American women living with HIV/AIDS who have never received income benefits are more likely to have used VR services than those who are current or former recipients of income benefits. (Enabling)

H6: African American women living with HIV/AIDS who have an identified source of support for themselves are more likely to have used VR services than those who do not have an established support system. (Enabling)

H7: African American women living with HIV/AIDS who have an identified source of support for their child(ren) are more likely to have used VR services than those who do not have an established support system. (Enabling)

H8: African American women living with HIV/AIDS who are not living in poverty are more likely to have used VR services than those who are living in poverty. (Enabling)

H9: African American women living with HIV/AIDS who have a greater level of self-efficacy as it relates to employment (job-seeking skills, requesting accommodations and maintaining employment) are less likely to have used VR services than those who have low levels. (Enabling)

H10: African American women living with HIV/AIDS who report having fewer beliefs about limitations of their health are more likely to have used VR services than those who have greater beliefs about limitations of their health. (Need)

H11: African American women living with HIV/AIDS who report having a need for rehabilitative services are more likely to have used VR services than those who do not report having a need. (Need)

RQ3: Which predisposing, enabling and need characteristics are predictive of the use of rehabilitative services among African American women living with HIV/AIDS?

H12: Positive attitudes toward seeking professional services are predictive of the use of rehabilitative services among African American women living with HIV/AIDS.

H13: Knowledge of vocational rehabilitation services is predictive of the use of rehabilitative services among African American women living with HIV/AIDS.

H14: Greater access to services is predictive of the use of rehabilitative services among African American women living with HIV/AIDS.

Appendix B
Variables, Definitions, and Coding

Independent Variables

Characteristic	Independent/ Predictor Variables	Variable type and Definition	Coding
Predisposing	Age	Dichotomous. Response to item: "What is your age?"	(1) Exploration and establishment stages (ages 18-43) (2) Maintenance and decline stages (age 44 and older)
	Children	Dichotomous. Response to item: "How many children do you have?"	(0) has no children (1) has at least one child
	Stigma (internal)	Continuous. Response to item: "I sometimes feel worthless because I am HIV positive."	Five-point Likert scale. Ranging from (1) strongly agree to (5) strongly disagree.
	Stigma (external)	Continuous. Response to item: "Others would think less of me if they knew I was HIV positive."	Five-point Likert scale. Ranging from (1) strongly agree to (5) strongly disagree.
	Attitudes toward seeking professional services	Continuous. Response to item: "I would seek out professional help when needed."	Five-point Likert scale. Ranging from (1) strongly agree to (5) strongly disagree.
Enabling	Income benefits	Dichotomous. Response to item: "Which income benefits have you received in the past, are currently receiving, or have never received – SSI/SSDI?"	(0) never received SSI/SSDI (1) has received / currently receiving SSI/SSDI
	Source of support (self)	Continuous. Response to item: "I am satisfied with the overall support I get from my friends and family."	Five-point Likert scale. Ranging from (1) strongly agree to (5) strongly disagree.

Enabling (continued)	Source of support (children)	Continuous. Response to item: “How concerned are you about the following issues related to working? – Child care”	Five-point Likert scale. Ranging from (1) strongly agree to (5) strongly disagree.
	Knowledge of services	Dichotomous. Response to item: “Which of the following do you know about?”	(0) No knowledge of VR services (1) Knowledgeable of VR services
	Poverty	Dichotomous. “What is your approximate yearly household (shared) income?” and “How many people live in your household under that salary?”	(1) Not living in poverty (2) Living in poverty
	Reasonable access	Dichotomous. Response to item: “How many employment services that serve people with HIV have you heard of in your area?”	(0) None (1) One or more
	Self- efficacy	Continuous. Response to item: “How confident are you in your job seeking skills?”	Seven-point Likert scale. Ranging from (1) no confidence to (7) extremely confident.
		Continuous. Response to item: “How confident are you that you could ask for job accommodations (breaks, etc.)?”	Seven-point Likert scale. Ranging from (1) no confidence to (7) extremely confident.
Continuous. Response to item: “How confident are you that you could hold onto a job once you had it?”		Seven-point Likert scale. Ranging from (1) no confidence to (7) extremely confident.	

Need	Health beliefs	Dichotomous. Response to item: “Does your health keep you from working at a job, doing work around the house or going to school.”	(1) Yes (2) No
	Need for rehabilitative services	Continuous. Response to item: “It is very hard for a person with HIV to get a job.”	Five-point Likert scale. Ranging from (1) strongly agree to (5) strongly disagree.
		Dichotomous. Response to item: “Do you need more information about employment resources and services?”	(1) Yes (2) No

Dependent Variable

Dependent/Outcome Variable	Definition	Coding
Use of vocational rehabilitation (VR) services	Since being diagnosed with HIV/AIDS, what services have you received in the past, are currently receiving, or have never received? – State vocational rehabilitation services	(0) Never received vocational rehabilitation (VR) services

Appendix C

Statistical Analyses per Research Question

Statistical Analyses for Research Question 1

Variables	Statistical Analysis	Question Answered
Use of VR Services	Univariate	What descriptive characteristics related to the sample of those who used VR services and those who did not?
Predisposing - Age - Children - Stigma (internal) - Stigma (external) - Attitudes toward seeking professional services	Univariate	What are the descriptive characteristics related to the sample for the predisposing variables?
Enabling - Income benefits - Source of support (self) - Source of support (children) - Knowledge of services - Poverty - Reasonable access - Self-efficacy (3 measures)	Univariate	What are the descriptive characteristics related to the sample for the enabling variables?
Need - Health beliefs - Need for rehabilitative services (2 measures)	Univariate	What are the descriptive characteristics related to the sample for the need variables?

Statistical Analyses for Research Question 2

Independent/Predictor Variables	Dependent/ Outcome Variable	Statistical Analysis	Question Answered
Predisposing - Age - Children - Stigma (internal) - Stigma (external) - Attitudes toward seeking professional services	Use of VR services	Chi Square (2 analyses) Independent T-test (3 analyses)	Which predisposing characteristics distinguish African American women living with HIV/AIDS who have utilized rehabilitative services from those who have not?
Enabling - Income benefits - Source of support (self) - Source of support (children) - Knowledge of services - Poverty - Reasonable access - Self-efficacy (3 measures)	Use of VR services	Chi Square (4 analyses) Independent T-test (5 analyses)	Which enabling characteristics distinguish African American women living with HIV/AIDS who have utilized rehabilitative services from those who have not?
Need - Health beliefs - Need for rehabilitative services (2 measures)	Use of VR services	Chi Square (1 analysis) Independent T-tests (2 analyses)	Which need characteristics distinguish African American women living with HIV/AIDS who have utilized rehabilitative services from those who have not?

Statistical Analyses for Research Question 3

Independent/Predictor Variables	Dependent/Outcome Variable	Statistical Analysis	Question Answered
Predisposing - Age - Children - Stigma (internal) - Stigma (external) - Attitudes toward seeking professional services	Use of VR services	Binary Hierarchical Logistic Regression (Block 1)	Which predisposing variables are predictive of the use of rehabilitative services among African American women living with HIV/AIDS?
Enabling - Income benefits - Source of support (self) - Source of support (children) - Knowledge of services - Poverty - Reasonable access - Self-efficacy (3 measures)	Use of VR services	Binary Hierarchical Logistic Regression (Block 2)	Which enabling variables are predictive of the use of rehabilitative services among African American women living with HIV/AIDS?
Need - Health beliefs - Need for rehabilitative services (2 measures)	Use of VR services	Binary Hierarchical Logistic Regression (Block 3)	Which need characteristic variables are predictive of the use of rehabilitative services among African American women living with HIV/AIDS?

Appendix D

National Working Positive Coalition: Vocational Training and Employment Survey Items

Measuring Variables in the Study

Age

What is your age? _____

Children

How many children do you have? _____

Stigma

(internal) I sometimes feel worthless because I am HIV positive.

Strongly Agree Neutral Disagree Strongly Disagree

(external) Others would think less of me if they knew I was HIV positive.

Strongly Agree Neutral Disagree Strongly Disagree

Attitudes toward seeking professional services

I would seek out professional help when needed.

Strongly Agree Neutral Disagree Strongly Disagree

Income benefits

Which income benefits have you received in the past, are currently receiving, or have never received? (Check all that apply).

	Received in Past	Currently Receiving	Never Received
Supplemental Security Income (SSI)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social Security Disability Insurance (SSDI)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
State disability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Private long-term disability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Housing subsidy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TANF/medical assistance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Source of support (self)

I am satisfied with the overall support I get from my friends and family.

- Strongly Agree Neutral Disagree Strongly Disagree

Source of support (child/ren)

How concerned are you about the following issues related to working – child care?

- Extremely concerned Very concerned Moderately concerned
 Somewhat concerned Not concerned

Knowledge of rehabilitative services

Which of the following do you know about?

- Workforce Investment Act (WIA) Extended Medicare
 One Stop Career Centers Trial Work Period
 Tribal Vocational Rehabilitation Health Insurance Portability and Accountability Act (HIPAA)
 State Vocational Rehabilitation Ticket to Work
 Americans with Disabilities Act (ADA) Reasonable Accommodations
 Family and Medical Leave Act (FMLA) None of these

Poverty

What is your approximate yearly household (shared) income?

- 0-10,000 25,001-30,000 50,001-55,000 100,000-200,000
 10,001-15,000 30,001-40,000 55,001-65,000 Over 200,000
 15,001-20,000 40,001-45,000 65,001-75,000
 20,001-25,000 45,001-50,000 75,001-99,999

How many people live in your household under that salary? _____

Reasonable access to services

How many employment services that serve people with HIV have you heard of in your area?

- None 1 2 3 4 5

Self-efficacy related to employment

On a scale of 1 (no confidence) to 7 (extremely confident) rate the following:

How confident are you in your job-seeking skills?

- 1 2 3 4 5 6 7

How confident are you that you could ask for job accommodations (breaks, etc.)?

- 1 2 3 4 5 6 7

How confident are you that you could hold onto a job once you had it?

- 1 2 3 4 5 6 7

Health beliefs

Does your health keep you from working at a job, doing work around the house or going to school?

- Yes No

Have you been unable to do certain kinds or amounts of work, housework, or schoolwork because of your health?

- Yes No

Need for rehabilitative services

It is very hard for a person with HIV to get a job.

- Strongly Agree Neutral Disagree Strongly disagree

Do you need more information about employment resources and services?

- Yes No

Appendix E

Additional National Working Positive Coalition: Vocational Training and Employment

Survey Items Utilized for Descriptive Survey Items

HIV status

What is your current HIV status?

- HIV Positive
- AIDS
- I do not have HIV or AIDS

Gender

What is your gender?

- Male
- Female
- Male to female transgender
- Female to male transgender

Ethnicity

Are you Latino, Hispanic, or Spanish? If yes, please specify:

- No, not Latino/Hispanic/Spanish
- Mexican, Mexican American, Chicano
- Puerto Rican
- Cuban, Cuban American
- Other Latino/Hispanic/Spanish

Race

What is your race?

- Black, Latino/Hispanic
- American Indian or Alaska Native
- Black, African American
- Native Hawaiian or Other Pacific Islander
- Black, West Indian/Caribbean
- Asian
- Black, African
- Multiracial
- White, European American, not Latino
- Other
- White, Latino/Hispanic

Employment at time of diagnosis

Were you employed at the time you first found out your HIV status?

- Yes
- No
- Don't know

Current employment

Are you currently working/employed?

- Yes
- No

Services from HIV programs

Do you receive any services from HIV programs/organizations?

- Yes
- No

Education

What was the highest level of education you have completed?

- Less than high school
- Some college
- Some high school
- Two-year college degree
- High school graduate/GED
- Four-year college degree
- Trade school
- Post-graduate

Appendix F

National Working Positive Coalition: Vocational Training and Employment Survey

Informed Consent Form

What is the study about? The purpose of this research study is to learn more about the education, training, employment and health needs of people living with HIV. The results will be used to improve access to opportunities for people with HIV.

What will I be asked to do? You will be asked to complete an online survey. Are there any risks to me? There are no known risks in taking this survey.

What are the benefits? You can share your ideas on what is needed to improve opportunities for people with HIV. Your input will help others with HIV. You will also get information on employment resources.

How much time will it take? The time to complete the survey can vary and takes about 15 to 30 minutes to complete.

Who do I ask if I have questions about the study? Please contact Dr. Liza Conyers, Ph.D. at (814) 863-6115 or lmc11@psu.edu with questions, complaints or concerns about the research. If you have questions regarding your rights as a research participant, please contact the Office for Research Protections at (814) 865-1775.

Will my information be kept private and confidential? The survey will not collect any information that can identify you. Your responses will be stored in a secure encrypted database. Your confidentiality will be kept to the degree permitted by the technology being used. No guarantees can be made regarding the interception of data sent via the Internet by any third parties. This survey uses secure sockets layer (SSL) encryption, which is the technology used for online banking sites or sites that transmit secured information. Only researchers approved for this project will have access to the data. Penn State's Office for Research Protections, the Social Science Institutional Review Board and the Office for Human Research Protections in the Department of Health and Human Services may review records related to this research study. In the event of a publication or presentation resulting from the research, no personally identifiable information will be available.

Can I change my mind if I decide that I no longer want to participate? Taking the survey is voluntary. You do not have to answer every question and you can stop at any time. Refusal to take part in or withdrawing from this study will not affect your access to services.

Is there anything else I should know? You must be 18 years of age or older and have HIV or AIDS to participate in this study. Please print off this form for your records. If you have read and understood the above statements, please click on the "Continue" button below to indicate your consent to participate in this study.

Vita

Aisha E. Shamburger-Rousseau was born in Denver, Colorado to Douglas and Estelle Shamburger. She is married to Mandle Rousseau and currently resides in Tucson, Arizona where she works as an Assistant Professor in the Department of Disability and Psychoeducational Studies at The University of Arizona. She earned her Bachelor of Arts degree with honors in psychology from Spelman College in Atlanta, Georgia in 1998 and a Master of Science degree in Rehabilitation Counseling from The Medical College of Virginia at Virginia Commonwealth University in Richmond, Virginia in 2003.

In 2008, Aisha received Virginia Commonwealth University's Department of Rehabilitation Counseling Outstanding Achievement by an Alumnus Award for her involvement in private rehabilitation in Virginia and Maryland as well as her work as the City of Richmond Public Schools' first Americans with Disabilities Act (ADA) Coordinator. Her research interests pertain to HIV/AIDS as well as the intersection of disability and multicultural issues. Aisha has also recently become intricately involved in assisting people with disabilities who are survivors of human trafficking.