Distribution Agreement

In presenting this thesis as a partial fulfillment of the requirements for an advanced degree from Emory University, I hereby grant to Emory University and its agents the non-exclusive license to archive, make accessible, and display my thesis in whole or in part in all forms of media, now or hereafter known, including display on the World Wide Web. I understand that I may select some access restrictions as part of the online submission of this thesis. I retain all ownership rights to the copyright of the thesis. I also retain the right to use in future works (such as articles or books) all or part of this thesis.

_____ _____

Loree Jackson-Mincey   Date

Identifying Barriers to Preventive Behaviors among People Living with HIV/AIDS in

Rural and Urban Georgia

By

Loree Jackson-Mincey

Degree to be awarded: M.P.H

Executive MPH

_____
Carla J. Berg, PhD, MBA, Committee Chairperson   Date

_____
Theresa Wicklin Gillespie, PhD, Committee Member   Date

_____
Juan Leon, PhD   Date
Associate Chair for Academic Affairs, Executive MPH Program

Identifying Barriers to Preventive Behaviors among People Living with HIV/AIDS in

Rural and Urban Georgia

By

Loree Jackson-Mincey

MPH, Emory University, 2018

BSHM, University of Phoenix, 2010

Thesis Committee Chair: Carla J. Berg, PhD, MBA

An abstract of

A thesis submitted to the Faculty of the

Rollins School of Public Health of Emory University

in partial fulfillment of the requirements for the degree of

Master of Public Health in Prevention Science

2018

Abstract

The development and dissemination of highly active antiretroviral therapy (HAART) have, in essence, changed HIV infection from a broadly fatal disease to a chronic condition. People living with HIV/AIDS (PLWHA) have seen a significant improvement in their morbidity, mortality, and life expectancy. As life expectancy rates among PLWHA increase, patients diagnosed with an HIV infection at an early age live into middle age with the disease, in some cases exceeding the lifespan of peers who are HIV negative. As these long-term survivors get older, they require appropriate preventative and age-appropriate early detection and cancer screenings, just as their HIV negative counterparts do. However, because of increased risk for certain conditions, PLWHA require even greater attention and interventions focused on preventing or reducing these conditions, such as cancer. The objective of this cross-sectional study was to determine this population's awareness of perceived risks for cancer, barriers to preventative behaviors, benefits of preventive behaviors and screening if they were able to overcome the identified barriers, and current compliance with existing guidelines for cancer screenings in both rural and urban areas of Georgia A total sample of 178 participants were enrolled from two of the largest infectious disease clinics in Georgia. The mean age of participants was 48.75($\pm$12.367) years; the majority was female (57%), African American (90%) and 65 % reported having a 12th grade or less education level. Data analysis showed that those seen at the rural site were significantly more likely to have received guideline-concordant screening for breast and cervical cancers compared to the urban site. Participants who pursued other types of preventive practices (e.g., flu immunization) were more likely to also pursue screening. Additionally, the data suggest that barriers to screening and preventive behaviors was associated with lack of knowledge concerning screening necessity, the cost of screenings, as well as lack of transportation to screening

appointments. These data are critical for designing and testing the feasibility, acceptability, and efficacy of interventions to promote cancer screenings and preventive behaviors among PLWHA.

Identifying Barriers to Preventive Behaviors among People Living with HIV/AIDS in

Rural and Urban Georgia

By

Loree Jackson-Mincey

MPH, Emory University, 2018

BSHM, University of Phoenix, 2010

Thesis Committee Chair: Carla J. Berg, PhD, MBA

An abstract of

A thesis submitted to the Faculty of the

Rollins School of Public Health of Emory University

in partial fulfillment of the requirements for the degree of

Master of Public Health in Prevention Science

2018

Acknowledgements

I first give honor to God from whom all blessing flow. I would like to thank my thesis advisor, Dr. Theresa W. Gillespie, whose door was constantly open whenever I ran into a trouble spot or had a question about my research or writing. Dr. Gillespie's unwavering support steered me in the right direction whenever it was needed. I would also like to acknowledge SYNERGY Grant, funded by the Woodruff Health Sciences Center of Emory University. Thank you to my colleagues and Emory University staff in the department of Epidemiology for their support and encouragement. Finally, I must express my very deepest gratitude to my husband (Rufus) and our children for their abiding support and incessant encouragement throughout my years of study and through the researching and thesis writing process. This accomplishment would not have been possible without any of them. Thank you so much.

Table of Contents

Chapter I: Introduction

Introduction and Rationale

Human Immunodeficiency Virus (HIV) is a virus that weakens the immune system and destroys cells that fight disease and infection (see Appendix for complete list of acronyms). If left untreated, HIV can lead to acquired immunodeficiency syndrome (AIDS). AIDS represents an advanced stage of HIV. An estimated 1.1 million people are currently living with HIV infection in the United States (HIV.gov, 2018). Although the annual number of HIV diagnoses has declined by 5% between 2011 and 2015, the estimated number of new HIV infections in the United States rose from 38,500 to 39,782 from 2015 to 2016. Nationally, African Americans (AA) represent the highest burden of HIV infection, with 17,528 diagnosed cases in 2016 (CDC, 2018). Particularly relevant to this study, AA represent 29% of Georgia's population; however, they account for 77% of new AIDS cases in Georgia and 63% of all existing AIDS cases in Atlanta. AA women represent 87% of all women with AIDS in Atlanta (Li, Thompson, Tai et al. 2014).

Medical advances, specifically highly active anti-retroviral therapy (HAART), have led the way for increased life expectancy among people living with HIV/AIDS (PLWHA). PLWHA lifespan has approached or even exceeds the expectancy of the general, uninfected US population. The picture of HIV/AIDS has significantly changed from the original cases diagnosed in the 1980's among primarily white gay men, now representing more African Americans, women, and those who are underserved or suffer health disparities (Becker, 1978).

Due to a variety of factors, PLWHA have an increased risk of some types of cancer compared with uninfected people of the same age. Such cancers, commonly known as AIDS-

defining cancers (ADC), include such tumors as aggressive non-Hodgkin's lymphoma, Kaposi sarcoma, and invasive cervical cancer. The success of HAART has led to a marked decrease in ADC. At the same time, non-AIDS-defining cancers (NADC) have been on the increase among PLWHA, in part due to the effect of the HIV virus and its treatment on the immune system, along with frequent co-infections with Human Papillomavirus (HPV) Hepatitis B, C, or EBV (Epstein-Barre Virus) (Shiels, Cole, Kirk, 2009). NADC include lung (representing ~20% of all NADC), anal, prostate, colorectal, breast, liver, and Hodgkin lymphoma (Shiels, Cole, Kirk, 2009). PLWHA are at increased risk of developing NADC, some of which may be detected early through screening (Sigel et al, 2011). An estimated 7,760 PLWHA in the US were diagnosed with cancer in 2010, representing approximately a 50% increase over the expected number of cancers in the general population (Robbins et.al, 2015).

Despite the increase in risk, PLWHA are less likely to participate in recommended cancer screening compared to uninfected populations (Sigel et al, 2011). Additionally, providers, who primarily focus on managing HIV and concomitant infections, often overlook the need for cancer screening in PLWHA (Wells, et al., 2014). Multiple studies have demonstrated that outcomes related to NADC among those who are HIV+ are significantly worse than among those who are HIV- (Hernández-Ramírez, et al. 2017). Underlying reasons for these findings, whether due to immune changes, barriers to earlier diagnosis or treatment, or other factors, have not been thoroughly examined. Finally, the evidence used to develop interventions to enhance compliance with cancer screening recommendations has been derived from studies including virtually no participants were PLWHA (Chiao, et al., 2006). Thus, knowledge of which cancer screening interventions may be acceptable, feasible, and effective in the PLWHA population is extremely

limited, creating a knowledge gap with critical implications for public health in view of the significant and aging population of PLWHA.

Currently, PLWHA continue to represent a population requiring wide-ranging attention, resources, and health care intervention to improve outcomes, in both urban and rural areas. Evidence-based research is needed to gain knowledge understanding and identify PLWHA views and practices concerning screening behaviors and barriers to develop comprehensive screening and preventive care guidelines targeting this population.

Problem Statement

The development and dissemination of HAART have, in essence, changed HIV infection from a broadly fatal disease to a chronic condition. The annual number of HIV diagnoses declined 5% between 2011 and 2015 but in 2016, 39,782 people received an HIV diagnosis in the United States. Currently PLWHA aged 50+ represents almost half of the infected population and have an increases risk of many cancers irrespective of HIV status. As these long-term survivors get older, they require appropriate preventative and age-appropriate screenings, because of increased risk for certain conditions, yet lack referrals for cancer screenings and early detection. Although The National Comprehensive Cancer Network has established cancer care guidelines only. PLWHA require even greater attention and interventions focused on preventing or reducing these conditions, such as cancer yet currently lack establish guidelines for cancer screening/prevention for this cohort

Theoretical Framework

The Health Belief Model was developed more than 40 years ago as a framework to help explain why individuals who were likely at risk for, or were practicing high-risk behavior (e.g., smoking) did not convert information received into behaviors to prevent or cease harmful

activities. As shown in Figure 1, an individual would need to perceive that he/she was

susceptible to certain threats (e.g., COPD, heart disease, cancer due to smoking) and that the

threats were of a severe enough nature to facilitate some change in behavior (e.g., prevention,

reduction, or cessation). Perceived benefits and barriers as well as information, education, or

interventions acted as mediators/moderators that could contribute to the desired preventive health

behaviors. The individual would have to integrate these factors that would then motivate him/her

to act on the perceived threats and benefits, overcome barriers, and change key behavior(s).

The Health Belief Model

Figure 1. Health Belief Model Becker, Radius & Rosenstock, 1978.

For this study, the Health Belief Model has been applied as shown in Figure 2. PLWHA

would need to weigh factors that favor screening and preventive behaviors, as well as factors that

are against those behaviors. Depending on their perceived risks and severity of risks, benefits,

and barriers to screening or preventive health behaviors, along with information, education, or

interventions received, PLWHA could then make a decision to pursue screening and/or

preventive behaviors. A key factor in this scenario is the perception that they are at risk, or at

increased risk, or the diseases and conditions that might benefit from prevention and screening, such as cancer.

Figure 2. Application of the HBM to Screening and Preventive Behaviors among PLWHA.

Purpose Statement

In this observational study I utilized secondary data collected from questionnaire administered to PLWHA at the Grady Memorial Hospital Ponce HIV Clinic in Atlanta and the rural Ryan White Clinic served by Albany Primary Care in Albany, GA to gauge their knowledge regarding age-specific cancer screening, to measure participation in cancer screenings, and to identify barriers to participation in such screenings. As evidence is lacking relative to effective interventions to encourage preventive behaviors and screening among PLWHA, or even to raise awareness of their risks. (Cancer.gov, 2018),direct input collected from PLWHA in this study concerning screening and prevention for diseases other than HIV can fill the gap in the literature as well as contribute to strategic interventions developments.

Research Questions

This study aimed to examine constructs from the Health Belief Model addressing individual's knowledge of perceived risk and severity of risk that factor in relation to adherence to cancer screening guidelines among PLWHA in rural and urban Georgia

Significance Statement

The burden of HIV/AIDS, particularly in the South, especially among AA residing in urban and non-urban areas of Georgia, is extremely high. Thus, it is critical to target these specific populations for development of evidence-based interventions. This study's finding could provide useful insight into the framework for interventions that promote preventive behaviors that lead to improved behavioral outcomes among this cohort.

Chapter II: Review of the Literature

Introduction

Since the initial reported cases of AIDS more than three decades ago, the close association with HIV infection and cancer malignancies have been duly noted. The goal of this chapter is to examine the literature associated with (PLWHA) and cancer malignancies, as well as cancer screening and preventive behaviors among PLWHA (CDC (a), 2018).

Historical Background

The Centers for Disease Control and Prevention's (CDC) hallmark report, on June 5, 1981, brought attention to Pneumocystis carinii pneumonia (PCP), a rare lung infection, in the context of other signs and symptoms of immunologic compromise. Subsequently, the CDC defined the condition to be AIDS, a resulting infection from HIV. HIV positive people have an elevated risk of cancer, particularly an increased risk of two malignancies, Kaposi sarcoma (KS) and non-Hodgkin lymphoma (NHL) (Engels, Biggar, Hall, et al, 2008). The CDC's initial AIDS definition identified Kaposi's sarcoma (KS) as the single malignancy in their case classification(Cooley, 2003).

HIV/AIDS in General

HIV is a virus, which attacks the immune system, rendering the immune system deficient and compromised. Consequently, HIV theoretically never disappears, although among a small cohort of patients with HIV- associated Kaposi sarcoma treated with immune inhibitors, 65% demonstrated a partial or complete remission (American Association for Cancer Research, 2018). More likely, a person infected with HIV is thought to remain HIV positive for life, requiring continued maintenance treatment with HAART. HIV hijacks immune cells known as CD4 or T-cells, replicating thousands of copies of the virus, ultimately leading towards a weaken

immune system. (CDC (b), 2018). A HIV diagnosis is no longer synonymous with a death sentence, with over a million PLWHA in the US. This population is living longer and experiencing a better quality of life than could ever have been predicted in 1981 when the epidemic began. Successful research, innovation, and technological advances in treatment and prevention of co-infections and complications have led the way for this population to stay healthy, seek medical care and begin HIV treatment as soon as diagnosed (CDC (b), 2018).

HIV/AIDS Malignancies

The evolution of the HIV/AIDS epidemic prompted revisions to CDC's case definition to include primary central nervous system lymphoma, non-Hodgkin lymphoma, and invasive cervical cancer, commonly referred to as AIDS-defining cancers (ADC), with recognition that these tumors serve as a marker for HIV infection (CDC (a), 2018). No effective cure for HIV/AIDS currently exists, but with proper medical care, HIV can be controlled as for most any other chronic disease (USNLM, 2018). Nevertheless, risks for other diseases, such as non-AIDS-defining cancers (NADC), remain high for PLWHA. The significant increased risk for non-communicable diseases (NCD), such as cancers and cardiovascular diseases, among PLWHA is indicative of the need for more cancer screening and preventive initiatives targeting this cohort to address this public health concern (Robbins et al., 2015). The increased risks for and rates of certain cancers among the HIV+ population, however, are compelling reasons to identify a framework for cancer control strategies tailored for PLWHA (Robbins, Pfeiffer, Shiels et.al, 2015).

AIDS Defining Cancers

The mid 1990's introduction of antiretroviral treatment changed the incidence and outcomes of ADC and the epidemiology of cancer malignancies. The mechanism by which

malignancies are introduced in HIV-1 infections are unknown (Angeletti, Zhang, Wood, 2008). HIV-induced immunodeficiency state has led to a variety of HIV positive cancer diagnoses. A combination of deficient CD4+ T-lymphocytes helpers and decreased normal immune cells increases the vulnerability for cancer growth in HIV-positive patients. Three neoplastic diseases have been recognized as ADC linked to HIV infection: (a) Kaposi Sarcoma (KS); (b) Non-Hodgkin Lymphoma (NHL); and (c) Cervical Carcinoma. While KS and NHL were recognized as ADC from the onset of the epidemic in 1981, cervical cancer was not classified as an ADC until 1993 (Akanmu, 2006). Compared with the general population, people infected with HIV are currently about 500 times more likely to be diagnosed with Kaposi sarcoma, 12 times more likely to be diagnosed with non-Hodgkin lymphoma, and among women, three times more likely to be diagnosed with cervical cancer (National Cancer Institute, 2018).

Kaposi sarcoma (KS) is a multicentric angio-proliferative cancer of endothelial origin typically occurring in the context of immunodeficiency, i.e. coinfection with (HIV) or transplantation (La Ferla et al., 2013). Progression in the lymph cell lining or blood vessels frequently appears as tumors on the skin mucosal surfaces and can grow as tumors in other parts of the body, such as lymph nodes, lungs, or digestive tract. *Lesions* consistent of red, purple and brown spots on the skin are primary visual on the face and extremities (Cancer. Gov, 2018). In the era of highly effective antiretroviral therapy, KS and NHL cases have decreased in the US. In 2010, KS represented 12% of cancer incidence among this population (National Comprehensive Cancer Network, 2018). However, KS continues to be the second most frequent tumor seen in HIV positive patients worldwide (World Health Organization, 2014).

A second ADC is Non-Hodgkin lymphoma, a cancer that affects the white blood cells called *lymphocytes*, a part of the body's immune system ("Cancer. Gov", 2018). Data from a

study conducted of New York State prisoners and non-prisoner intravenous drug abusers

(IVDA), to evaluate the relationship of lymphomas in this high-risk AIDS population, concluded

that non-Hodgkin lymphoma represents a frequent manifestation of AIDS among IVDA, and is

the most common malignancy seen in IVDA with AIDS (Ahmed et al., 1987). NHL represented

21% of cancer incidence among PLWHA in 2010 (National Comprehensive Cancer Network,

2018).

Additionally, cervical cancer, which affects the cell lining of the cervix, represented 1%

cancer incidence rate among this population of PLWHA (National Comprehensive Cancer

Network, 2018). The risk of cervical cancer is elevated approximately 3-5-fold in PLWHA.

Persistent infection with high-risk human papillomavirus (HPV) can also lead to cervical cancer

(National Comprehensive Cancer Network, 2018). Cervical cancer is the third most common

cancer among women worldwide, and second most frequent cause of cancer related death,

accounting for nearly 300,000 global deaths annually (USDHHS, 2018). Cervical cancer

treatment in HIV-positive and non-infected women are similar, with the inclusion of prescribed

combination antiretroviral therapy for HIV positive women. According to the National Cancer

Institute (2018), HIV positive women are 500 times more likely to be diagnosed with KS, and

twelve times more likely to be diagnosed with NHL, and three times more likely to be diagnosed

with cervical cancer. Due to lack of high-level evidence supporting alternative recommendations,

screening guidelines for HIV positive women resemble the same guidelines for the general

population, with PAP-smear and HPV screening for early detection, and HPV vaccination for

primary prevention (Grellier & Quero, 2014). The ability to detect cervical cancer early and

potentially prevent it through HPV vaccination, renders cervical cancer one of the most

successfully treatable and preventable cancers (National Cancer Institute, 2018). In 2018, the

World Health Organization, NCI, and other international agencies set forth a goal of eradication of cervical cancer globally (WHO, 2018), a goal that would be particularly impactful for PLWHA.

Non-AIDS Defining Cancers

Due to the effectiveness of HAART, leading to prolonged survival of HIV-infected people in the US, cancers not previously associated with HIV/AIDS appear to be increasing in incidence. NADC's, include; liver, lung, anus, kidney, and Hodgkin lymphoma (Deeken et al., 2012). The increased risk for NADC among this cohort typically develops in later stages of life and has been associated with aging, similarly to the HIV-negative population. In this aging population, increased exposure to carcinogens (e.g. tobacco, alcohol), co-infections, as well as the effects of aging on the immune system, has led to an increased incidence of NADC. HIV/AIDS Cancer Match linkages between US cancer and HIV registries in multiple states have reported increases in NADC over a 15-year period (1991-2005). Increases in the population of those who are HIV+, along with the aging of PLWHA, suggest the need for targeting cancer prevention and treatment strategies to address the growing burden of cancer in PLWHA (Shiels et al., 2011).

Furthermore, colorectal cancer (CRC), (National Comprehensive Cancer Network, 2018) in 2010, represented 5% cancer incidence cases among this population. CRC malignancies are primary malignant tumors located in the colon or rectum. CRC is the third leading cause of cancer deaths of both males and females in the US, and second leading cause of cancer mortality among men 40-59 years of age. Currently, 10-15% of HIV positive patients are over 50 years of age (Ford et al., 2008), suggesting that PLWHA are also at increased risk for CRC and need to participate in screening for this cancer as well.

The prolonged survival rates among HIV-positive women has also led to increased risks of breast cancer among this cohort, representing about 2% of the breast cancer incidence cases (National Comprehensive Cancer Network, 2018). In a cross-sectional population-based study of breast cancer screening among HIV-positive women in Ontario, Canada, HIV-positive women underwent breast cancer mammography screening less than HIV negative women. However, HIV infection may impact the natural history and treatment of breast cancer; thus, participating in screening activities may be even more important among PLWHA than for women who are HIV-negative (El-Rayes, Berenji, Schuman, & Philip, 2002).

Shiels, et al. (2010) reported that prostate carcinoma among men with AIDS had decreased 50% compared to the general population when associated with early stage PSA screening. As the life expectancy of men with HIV infection increases, prostate cancer screening will become increasingly important in this population (Crum, Spencer, & Amling, 2004). However, special guidelines for PSA screening among HIV+ men have not been developed.

Overall, although mortality rates from HIV/AIDS have significantly decreased over the past several decades, PLWHA remain at high risk for deaths from other causes. In a population-based Canadian cohort study of changes in mortality rates among PLWHA from 1996 to 2012, mortality rates from HIV/AIDS reasons decreased by 94% over that time period. Yet, PLWHA showed consistently higher mortality rates compared to HIV-negative individuals (Eyawo, et.al, 2017).   In this study, NADC's were the main non-HIV/AIDS-related cause of death in both HIV+ and HIV-negative subjects in the cohort.

HIV/AIDS Statistics

United States

In 2016, there was an estimated 39,782 new cases of HIV diagnosed; gay and bisexual men accounted for 67% of all cases. In the US, HIV diagnoses are not evenly distributed ethnically. African Americans represents 12% of the US population but had 44% of all new HIV diagnoses in 2016. Additionally, Hispanic/Latino represents 18% of the US population but accounted for 25% of all new HIV diagnoses. In the same year, individuals infected through heterosexual sex made up 24% of all HIV diagnoses. Southern states accounted for more than half of new HIV diagnoses in 2016, while making up 38% of the national population. The vast majority of HIV positive individuals are now concentrated in urban areas in the South, with 23% of cases existing in smaller metro and rural areas.

Urban and Rural Georgia

Georgia heads the list of rates of new HIV diagnoses nationwide (see Figure 3), with 31.8 cases diagnosed per 100,000 people (HIV surveillance report, 2017). In 2015, there were 32,818 PLWHA in Georgia: 80% were men, 20% were women, and 70% were Black, 7% Hispanic/Latino, and 19% White. Georgia HIV mortality rate in 2015 was 373 per 100,000 (AIDSVU, 2015).

Figure 3. CDC. Diagnoses of HIV infection in the United States and dependent areas, 2016. HIV Surveillance Report 2017, Volume 28.

Outcomes among HIV+ Malignancies

African American men have the highest incidence of prostate cancer among all racial groups, with the highest racial disparity in younger men. According to systematic review of the literature of HIV and prostate carcinoma (PCa), true incidence was unknown, though few studies have shown increased frequency malignancy among this population. Due to improved survival and antiretroviral therapies, prostate cancer cases are increasing among HIV+ men (Silberstein, 2008). A 2010 prospective cohort study of prostate cancer risk in 2,800 HIV-infected and uninfected men who had sex with men (MSM) aged 40-70 years (22% African American), examined associations between race and HIV-infection status and prostate cancer risk. Among MSM, both HIV-positive and HIV-negative African American men aged 40-55 years showed increased risk of young-onset prostate cancer (Dutta, Uno, Holman, Lorenz, & Gabuzda, 2017). There are well established disparities between Caucasian and African American men diagnosed with PCa , although these disparities are complex, involving socioeconomic and cultural factors as well as biological determinants according to (Pietro, et.al, 2017.

Screening Guidelines for Non-AIDS Defining Cancers in HIV+ Individuals

Comprehensive cancer screening guidelines directed specifically towards PLWHA have not yet been developed or issued by relevant agencies. The National Comprehensive Cancer Network has developed guidelines for cancer care for PLWHA, but not for screening. The NCCN (2018) estimates for PLWHA a 25-to-35-fold increased likelihood of being diagnosed with anal cancer, a 2-5 times higher risk of non-small cell lung cancer, and 5 to 14 times increase in likelihood to be diagnosed with Hodgkin lymphoma. Instead, guidelines for HIV-negative populations may be accompanied by the caveat that those at increased risk for a particular cancer may need to be screened at more frequent intervals or may start screening at an

earlier age (Mani & Aboulafia). The Veterans Health Affairs states that US Preventive Services Task Force (USPSTF) for cancer screening recommendations may be applied to HIV-infected patients with CD4 counts of >350 cells/µL or completely suppressed HIV RNA (Veterans Affairs). For patients with lower CD4 counts, screening should be discussed in relation to a patient's prognosis, preferences, and goals.

To date, no formal national recommendations have been established for cancer screening in either HIV-infected men or women. An attempt to define the optimal cancer screening recommendations for PLWHA was published by Mani & Aboulafia. Evidence from the USPSTF provides recommendations for lung, breast, colorectal, anal, and cervical cancers. Insufficient evidence currently exists to support prostate cancer screening that differs from USPSTF recommendations in PLWHA (NY State Dept. of AIDS). A conceptual model from Sigel et al. addresses the gap in cancer screening recommendations by weighing the risks and benefits for individual patients. In general, the recommendations by Mani & Aboulafia were used to assess guideline concordance for cancer screening among PLWHA.

Review of Literature Related to the Health Belief Model Theoretical Frame work

The increased risk of cancer among this aging population is noted throughout the literature. The utilizing of the construct of the HBM perceived susceptibility component to examine preventative practices resulted in obtaining vital insight regarding an individual's perceived risk and severity for NCD screening such as cancer. Perceived severity refers to how severe an individual's views their vulnerability and increased risk of developing cancer. Additionally, the likely hood of incorporating preventive behavior practices is often motivated by factors associated with known risk awareness. Participants consistently acknowledge that they would get the required screenings if their health care provider informed and initiated the process.

In a study conducted by Hennig and Knowles (1990) utilized the HBM to predict Pap test

intentions of a cohort of 144 women age 40 years old.

Chapter III: Methodology

Introduction

Included in this chapter is a descriptive outline of study procedures conducted to gain

knowledge of attitudes regarding the perceived risk of cancer and barriers to cancer screening

participation practices among PLWHA in rural and urban settings. Information presented in this

chapter includes the following: study design, sample characteristics, data collection composition

and data analysis methodology.

Study Design

This research study integrated an observational, cross-sectional design approach, utilizing

survey instrument (Study of Health Behavior and Disease Prevention). The questionnaire

included categorical responses and responses consistent with Likert scale metrics concerning

questions that gauge individual's perception of their risk assessment, healthy behaviors and early

screening practices. In addition, all participants completed an on study data form that collected

demographics, education, income, health literacy, numeracy, and co-morbidity information.

Sample Characteristics

This study collected data prospectively from HIV+ patients at two the Grady Ponce HIV

Clinic, Atlanta, GA (urban) and the Ryan White Clinic in Albany, Ga (rural) sites to explore

more about perceived barriers and facilitators to preventive behaviors among PLWHA. Both

rural and urban sites serve individuals with lower socioeconomic status who are predominantly

AA. A convenience sample of 180 participants were enrolled during a six month recruitment

phase, of those, N=178 met the single (HIV+) eligibility criteria, provided written informed

consent to be in the study, and each completed a survey inquiring about individual views toward

perceived cancer risk, participation in screening, acceptability of evidence-based interventions to promote cancer screening, and barriers to screening.

Data Collection Procedures

The study was approved by Emory University Institutional Review Board (IRB), as a minimal risk study (see appendix). The study also received approval by the Grady Research Oversight Committee, and additional review and approval by a subcommittee for research conducted with patients in the Grady Infectious Disease Clinic. Participants received a $25 incentive for completing the questionnaire. The survey instrument was derived from a CDC-validated tool used as A Framework for Patient-Centered Health Risk Assessments (https://www.cdc.gov/policy/hst/hra/frameworkforhra.pdf) with modifications based on the target population of HIV+ individuals. The tool was then built into Survey Gizmo software. Questionnaire responses were manually entered into Survey Gizmo by clinical research personnel. Subsequently, survey response data was exported into IBM SPSS 23.0 for data analyses. Data collected from the questionnaire was cleaned and transformed into specific numerical value responses for further analysis. The questionnaire (see appendix) included questions about perception of risk assessment and practices of healthy behaviors and screening. In addition, all participants completed an on-study data form that collected demographics, education, income, health literacy, numeracy, and co-morbidity data.

Data Analysis

Analyses were performed utilizing both IBM SPSS Statistics Client 23.0 software and SAS. Descriptive statistics were used to define the characteristics of the sample, which included mean and standard deviation value of respondents. Additionally, inferential statistics was used to illustrate perceived barriers to preventative screenings. Univariate analyses were conducted

inclusive of all variables to identify significance. Univariate analysis (UVA) of all listed risk factors for cancer types was screened based on UVA with $P < 0.1$, and then the backward elimination in MVA with criteria of $p < 0.1$ were put into a regression model.

Chapter IV: Results

Introduction

In this chapter the data analysis is distributed into three sections: descriptive statistics of sample demographics and individual questions, inferential statistics of research questions, and predictors of uptake of cancer screening behaviors by type (see Table 1).

Key Findings

Table 1. Descriptive Statistic Baseline Covariates - All participants

Variable	Level	N (%) = 178
Age	Mean ± SD	47.20 (±14.18)
Study site	Ponce	118 (66.3)
	Albany	60 (33.7)
Breast cancer screening	Screened	116 (65.2)
	Not screened	62 (34.8)
Prostate cancer screening	Screened	138 (77.5)
	Not screened	40 (22.5)
Cervical cancer screening	Screened	120 (67.4)
	Not Screened	58 (32.6)
Colon cancer screening	Screened	120 (67.4)
	Not screened	58 (32.6)
Insurance	Uninsured	53 (29.8)
	Government + Suppl.	104 (58.4)
	Private	21 (11.8)
Race	White	10 (5.6)
	Black	161 (90.4)
	Other	7 (3.9)
Income	0-$19,999/yearly	149 (87.1)
	$20,0000+/yearly	15 (8.4)
Gender	Male	
		77 (43.3)
	Female	101 (56.7)
Education level	≤ 12 years	118 (66.3)
	>12 years	60 (33.7)
Comfortable with medical form	Never-sometimes	23 (13.2)
	Often-always	151 (86.8)
	Missing	4

Variable	Level	N (%) = 178
Comfortable with numbers	Never-sometimes	24 (13.8)
	Often-always	150 (86.2)
	Missing	4
Previous cancer diagnosis	No	171 (96.1)
	Yes	7 (3.9)
At least one co-morbidity	No	152 (85.4)
	Yes	26 (14.6)
Perspective of risk - heart disease	Low/no risk perspective	106 (59.6)
	High/med risk perspective	35 (19.7)
	Had previous diagnosis	37 (20.8)
Perspective of risk - stroke	Low/no risk perspective	110 (61.8)
	High/med risk perspective	36 (20.2)
	Had previous diagnosis	32 (18.0)
Perspective of risk - Hbp	Low/no risk perspective	82 (46.1)
	High/med risk perspective	44 (24.7)
	Had previous diagnosis	52 (29.2)
Perspective of risk - diabetes	Low/no risk perspective	115 (64.6)
	High/med risk perspective	29 (16.3)
	Had previous diagnosis	34 (19.1)
Perspective of risk - cancer	Low/no risk perspective	139 (78.1)
	High/med risk perspective	28 (15.7)
	Had previous diagnosis	11 (6.2)
Screening for any non-communicable disease	No	10 (5.6)
	Yes	168 (94.4)
Recommended by doctors: screening for any non-communicable disease	No	69 (38.8)
	Yes	109 (61.2)
Received any vaccines?	No	10 (5.6)
	Yes	168 (94.4)

Variable	Level	N (%) = 178
See a dentist	No	56 (31.5)
	Yes	122 (68.5)
Cholesterol check	No	70 (39.3)
	Yes	108 (60.7)
Visit health fairs	No	124 (69.7)
	Yes	54 (30.3)
Track weight	No	42 (23.6)
	Yes	136 (76.4)
Participate in cancer screening	No	112 (62.9)
	Yes	66 (37.1)
Check blood pressure regularly	No	92 (51.7)
	Yes	86 (48.3)
Stopped smoking	No	87 (48.9)
	Yes	91 (51.1)
Do not use chewing tobacco	No	78 (43.8)
	Yes	100 (56.2)
Do not use or abuse drugs	No	64 (36.0)
	Yes	114 (64.0)
Do not use alcohol excessively	No	60 (33.7)
	Yes	118 (66.3)
Do eat healthy foods	No	47 (26.4)
	Yes	131 (73.6)
Do exercise regularly	No	80 (44.9)
	Yes	98 (55.1)
Other describe what preventive health behaviors you participate in	No	158 (88.8)
	Yes	20 (11.2)
No my healthcare provider/doctor has never discussed screenings	No	163 (91.6)
	Yes	15 (8.4)
Yes my healthcare provider/doctor advised me to stop smoking	No	66 (37.1)
	Yes	112 (62.9)
Yes my healthcare provider/doctor advised me to get more regular exercise	No	42 (23.6)
	Yes	136 (76.4)
Yes my healthcare provider/doctor advised me to eat more healthy	No	50 (28.1)
	Yes	128 (71.9)
Yes my healthcare provider/doctor advised me to try to maintain a normal weight	No	68 (38.2)
	Yes	110 (61.8)

Variable	Level	N (%) = 178
Yes my healthcare provider/doctor advised me to reduce my stress level	No Yes	66 (37.1) 112 (62.9)
Yes my healthcare provider/doctor advised me to avoid excess sunshine	No Yes	128 (71.9) 50 (28.1)
Yes my healthcare provider/doctor advised me to practice safe sex	No Yes	46 (25.8) 132 (74.2)
Yes my healthcare provider/doctor advised me to avoid getting an infection	No Yes	77 (43.3) 101 (56.7)
Hbp screening	No Yes	29 (16.3) 149 (83.7)
High/bad cholesterol screening	No Yes	72 (40.4) 106 (59.6)
Diabetes screening	No Yes	79 (44.4) 99 (55.6)
Heart disease screening	No Yes	105 (59.0) 73 (41.0)
Mental health screening	No Yes	73 (41.0) 105 (59.0)
Dementia Alzheimer screening	No Yes	150 (84.3) 28 (15.7)
No one has ever previously recommended I get screened for any chronic diseases	No Yes	116 (65.2) 62 (34.8)
Yes it was recommended and I got all screenings	No Yes	74 (41.6) 104 (58.4)
Yes it was recommended but I didn't understand the importance	No Yes	167 (93.8) 11 (6.2)
Yes it was recommended but I didn't know where to go to get screened	No Yes	167 (93.8) 11 (6.2)
Yes it was recommended but I didn't have insurance to cover screening	No Yes	166 (93.3) 12 (6.7)
Yes It was recommended but I couldn't pay for the screening	No Yes	162 (91.0) 16 (9.0)

Variable	Level	N (%) = 178
Yes it was recommended but it didn't seem to apply to me	No	167 (93.8)
	Yes	11 (6.2)
Yes it was recommended and I got the screening but didn't know how often	No	165 (92.7)
	Yes	13 (7.3)
Tetanus vaccine	No	113 (63.5)
	Yes	65 (36.5)
Pertussis/whooping cough vaccine	No	150 (84.3)
	Yes	28 (15.7)
HPV vaccine	No	118 (66.3)
	Yes	60 (33.7)
Hepatitis vaccine	No	129 (72.5)
	Yes	49 (27.5)
Herpes zoster vaccine	No	104 (58.4)
	Yes	74 (41.6)
Influenza (flu)	No	75 (42.1)
	Yes	103 (57.9)
Hepatitis A virus vaccine	No	121 (68.0)
	Yes	57 (32.0)
Hepatitis B virus vaccine	No	125 (70.2)
	Yes	53 (29.8)
Meningococcal vaccine	No	160 (89.9)
	Yes	18 (10.1)
Hiv are at a higher risk for chronic diseases	Disagree/neutral	75 (42.1)
	Strong/moderately agree	103 (57.9)
HIV are at a lower risk for chronic diseases	Disagree/neutral	128 (71.9)
	Strong/moderately agree	50 (28.1)
What do you do to stay health? (number of items checked)	Mean	2.71
	Median	3.00
	Minimum	0.00
	Maximum	6.00
	Std dev	1.47
	Missing	0.00

Variable	Level	N (%) = 178
Preventive behavior (number of items checked)	Mean	3.78
	Median	4.00
	Minimum	0.00
	Maximum	7.00
	Std dev	1.82
	Missing	0.00
Doctors discussion with you (number of yes items checked)	Mean	5.04
	Median	5.00
	Minimum	0.00
	Maximum	9.00
	Std dev	2.28
	Missing	0.00

Demographics. A total of 178 participants were enrolled in this study, with over 65% of participants recruited from Grady Ponce Clinic (urban) in Atlanta, Georgia (Table 1). The mean participant age was 48.26 years (±12.367). The gender distribution was primarily female (57%), and male (43%). The ethnic breakdown included over 90 % were African American, 6% Caucasian, and 4% other. More than 85% of participants reported earning ≤ $19,000 a year. Almost 60% of this cohort received some form of government and/or government + supplement assistance. The reported education level among this cohort was 66% having ≤ 12 years of education.

Univariate comparison analysis of rural & urban sites among age appropriate eligible individuals for cancer screening types (see Table 2). Breast cancer screening among women aged 50 and older who were eligible but not screened was significantly higher among urban site (44.9%) in comparison to rural site. Cervical cancer screening among women aged 21 and older who were eligible but not screened was also significantly higher among urban site (89.13%) in comparison to rural site (10.87%). Colon cancer screening among men and women ≥ age 50 who were eligible but not screened showed no significant difference as compared by site. Prostate cancer screening among men ≥ age 50 who were eligible but not screened showed no significant difference by site comparison.

Covariate	Level	Urban N (%)	Rural N (%)	P-value*
Breast ca screening[1]	Elig, not screened	22 (44.9)	0 (0)	**0.009**
	Screened	27 (55.1)	10 (100)	
Cervical ca screening[2]	Elig, not screened	41 (89.13)	5 (10.87)	**0.003**
	Screened	32 (62.75)	19 (37.25)	
Colon ca screening[3]	Elig, not screened	39 (76.47)	12 (23.53)	0.319
	Screened	31 (67.39)	15 (32.61)	
Prostate ca screening[4]	Elig, not screened	9 (56.25)	7 (43.75)	0.917
	Screened	12 (54.55)	10 (45.45)	

Table 2. Comparison of Cancer Screening Uptake for Subjects Eligible for Screening Who Were or Were Not Screened, by Study Site

Univariate analysis for perceived barriers to preventative behaviors among PLWHA, several perceived barriers were identified among this population utilizing a Likert scale response. When asked, "What factors might promote or block health behaviors or participation in screening tests", more than 37% of participants stated uncertainty about what screening tests are needed, cost and lack of transportation (36.5%), and 32% were afraid of what might be found on a screening test.

Graphs 1-3. Univariate analysis for perceived barriers to preventative behaviors

Predictors of uptake of cancer screening behaviors (Table 3). Breast cancer screening among women 50 years and older (age appropriate) who received a flu vaccine, increased the odds of also receiving a mammogram.

Table 3. Multivariable Logistic Regression Model for Breast Cancer Screening

Covariate	Level	N	Odds Ratio (95% CI)	OR P-Value
Recommended by Doctor Screening for any non-communicable disease	No Yes	23 36	0.29 (0.07-1.15)	0.078
Participated in cholesterol screenings	No Yes	20 39	0.30 (0.08-1.15)	0.080
Participated in diabetic screenings	No Yes	29 30	0.25 (0.06-1.01)	0.052
Received Influenza (Flu) vaccine	No Yes	19 40	0.20 (0.05-0.83	**0.026**

*Number of observations in the original data set = 38. Number of observations used = 38.
** Backward selection with an alpha level of removal of 0.1 was used. The following variables were removed from the model: var_Yesmyhealthcareproviderdoctoradvisedmetotrytomaintainanormal, var_Yesmyhealthcareproviderdoctoradvisedmetoavoidexcesssunshinea, var_HIVareataHIGHERriskforchronicdiseases, education, Perspective of Risk - Heart Disease, Perspective of Risk - Diabetes, and Perspective of Risk - Stroke.

Women 21 years of age and older participating in health screening such as diabetes and receiving a Hep B vaccine were significant predictors for cervical cancer screening.

Table 4. Multivariable Logistic Regression Model for Cervical Cancer Screening

Covariate	Level	N	Odds Ratio (95% CI)	OR P-Value
Study site	Ponce Albany	73 24	0.34 (0.10-1.20)	0.093
At least one co-morbidity	No Yes	86 11	0.13 (0.01-1.34)	0.087
Visit the dentist	No Yes	24 73	0.34 (0.11-1.06	0.063
Participated in diabetic screenings	No Yes	45 52	0.25 (0.06-1.01)	**0.007**

| Received Hepatitis B virus vaccine | No | 66 | 0.26 (0.09-0.75 | **0.013** |
| | Yes | 31 | | |

* Number of observations in the original data set = 97. Number of observations used = 97.
** Backward selection with an alpha level of removal of 0.1 was used. The following variables were removed from the model: high/bad cholesterol screening, diabetes screening, heart disease screening, var_Yes it was recommended, and I got all, var Hepatitis A virus vaccine, and gender.

Having at least one co-morbidity was a significant predictor for colorectal cancer

screening among men and women age 50 years of age and older.

Table 5. Multivariable Logistic Regression Model for Colorectal Cancer

Covariate	Level	N	Odds Ratio (95% CI)	OR P-Value
At least one co-morbidity	No	80	0.22 (0.07-0.76)	**0.017**
	Yes	11		
Recommended by Doctor: Screening for any non-communicable disease	No	31	0.14 (0.16-1.04)	0.061
	Yes	66		

Number of observations in the original data set = 97. Number of observations used = 97.
** Backward selection with an alpha level of removal of 0.1 was used. The following variables were removed from the model: high/bad cholesterol screening, diabetes screening, heart disease screening, var _Yes it was recommended and I got all, var Hepatitis A virus vaccine, and gender.

Receiving a Hepatitis A vaccine was a significant predictor for prostate cancer screening

among men age 50 years and older.

Table 6. Multivariable Logistic Regression Model for Prostate Cancer

Covariate	Level	N	Odds Ratio (95% CI)	OR P-Value
Participated in heart disease screening	No	19	0.27(0.06-1.25)	0.093
	Yes	19		
Received Hepatitis A virus vaccine	No	23	0.10 (0.02-0.59)	**0.011**
	Yes	15		

Number of observations in the original data set = 38. Number of observations used = 38.
** Backward selection with an alpha level of removal of 0.1 was used. The following variables were removed from the model: var_Yesmyhealthcareproviderdoctoradvisedmetotrytomaintainanormal, var_Yesmyhealthcareproviderdoctoradvisedmetoavoidexcesssunshinea, var_HIVareataHIGHERriskforchronicdiseases, education, Perspective of Risk - Heart Disease, Perspective of Risk - Diabetes, and Perspective of Risk - Stroke.

Chapter V: Conclusion, Implications, Limitations, Recommendations

Conclusion

This chapter provides a summary of key findings on preventative screening behaviors among PLWHA. The implications of these research finding, in the context of its limitations, were examined. The conclusions suggest recommendations for future research studies.

Results Summary

Study site was a consistent predictor of findings, including the primary endpoint of receipt of guideline concordant cancer screening participation. The rural site has implemented a systematic approach to preventive care, including reminders for screenings for non-communicable diseases (cancer and others), vaccines due (flu), and follow-up care, that is integrated into the EMR. The urban Grady clinic utilizes no such systematic approach to preventive care, particularly if not related to HIV care, as nearly all the care provided is focused solely on HIV-related issues and problems. Identifiable perceived barriers to preventive screenings among PLWHA respondents in both rural and urban Georgia suggest that cost, necessary screenings, transportation, and fear of findings are key barriers to preventative screenings among this population. The main reason why PLWHA received screening or other preventive care was if the screening was recommended by the healthcare provider, or not. In the case of Grady patients, such recommendations rarely or never occurred in our sample.

Implications

Relevance to Disparities

The population of PLWHA is growing and aging over time, but little research has been directed towards this group that experiences worse outcomes when diagnosed with NADC compared to HIV- populations. The reasons to explain these worse outcomes, including cancer

survival, are not known. But it is possible that PLWHA are not referred to screening and preventive activities, so they do not participate even when eligible for screening based on HIV-negative guidelines. So an underlying explanation for the worse outcomes compared to HIV-negative populations may be lack of screening and early detection. Consequently, PLWHA continue to experience worse cancer survival in NADC's compared to HIV-negative individuals.

Health Policy needs

Although PLWHA are known to be at higher risk for both AIDS-defining and NADC, in the absence of evidence-based guidelines related to cancer screening, PLWHA and their providers are left to develop their own approaches to cancer and other NCD screenings. Thus, recommendations for screening and prevention can vary significantly by patient, provider, and site. A real need exists to generate the needed evidence in order to develop guidelines for cancer screening frequency and age at onset that are specific to PLWHA and the unique problems presented by HIV infection, aging, and co-morbidities.

Educational needs

PLWHA and their providers both demonstrate gaps in their knowledge and awareness of the increased risk for cancer among PLWHA and the need to pursue cancer and NCD screening. The qualitative data will further inform gaps in comprehension of cancer risk and screening recommendations that may apply to this population.

Limitations

This study was funded as a pilot project with the intent to gather preliminary data leading to a larger, extramural grant in the future. As a result, the study was conducted with minimal resources and a relatively small sample size that may affect the generalizability of the findings as compared to a larger population. . Additionally, site selection bias may also be a consideration

among respondents. Beyond being classified as rural versus urban settings, each clinical site was administratively run very differently, including the rural site having reminders for screening and prevention built into the EMR. The data collected was not unlimited and some key variables, such as religion, which might affect certain preventive behaviors, were not collected. Although qualitative data were collected as part of the overall study, those findings were not reported here and may well help elucidate the quantitative results since the study design included mixed methods. Selection bias may also be present in the sample overall, since participants were given incentives to take part in the study, and that may have attracted certain individuals in the clinic and the result may be a sample that was not entirely representative of the clinic population or the HIV-positive population at-large.

Conclusions and Recommendations

As over 200 variables were collected as part of this study, as well as data collected from four different focus groups, the next steps would be to complete both qualitative and quantitative analysis of data collected from this study. The mixed methods findings would then serve to help inform the study overall.

Some of the data collected related to participants' preferences and interest in different approaches to promote and encourage screening and preventive behaviors. To date, none of the evidence-based approaches to promote cancer screening have included PLWHA, so whether these approaches will work, and how well they might work, among an HIV-positive population is not known. Those data will be used to design either new approaches or to modify existing approaches, and then test their use in a population of PLWHA to see how well received such methods might be to these special populations. Ultimately, a randomized study to evaluate the use of established screening promotion approaches compared to new or modified approaches

derived from this study, should be pursued. Additionally, integrating recommendations provided from healthcare providers/patient regarding preferred strategies and prospective will enhance development of targeted interventions to promote cancer screening and compliance. Predictive factors identified through this study, in terms of which factors were associated with receipt of guideline-concordant care, need to be evaluated as a way to either highlight those patients most at risk for not receiving guideline-concordant care, and to identify those patients who are more likely to receive guideline-concordant care and ensure those same methods are applied and tested to see if similar results are obtained in a bigger sample.

PLWHA, as a result of the effectiveness of HAART over several decades, are now living longer and no longer succumbing to HIV/AIDS as a cause of death. While this is a remarkable accomplishment, it also means that PLWHA are now at greater risk for diseases and conditions frequently associated with older age and an aging immune system, including cancers, especially non-AIDS-defining cancers. The need to find new and better ways to promote screening and prevention, and to generate the evidence vital to developing screening guidelines specific to PLWHA is essential in order to impact and reduce the disparities currently existing for PLWHA and their risk for worse cancer outcomes compared to HIV-negative populations.

References

Angeletti PC, Zhang L, Wood C. 2008. The viral etiology of AIDS-associated malignancies. Adv
Pharmacol 2008; 56:509-557. Retrieved from:
https://www.ncbi.nlm.nih.gov/pubmed/18086422

Becker, M.H., Radius, S.M., & Rosenstock, I.M. (1978). Compliance with a medical regimen for
asthma: a test of the health belief model, *Public Health Reports, 93,* 268-77

Cancer.Gov. (2018). Cancer Screening and Early Detection, Retrieved from:
https://www.cancer.gov/research/areas/screening

Centers for Disease Control and Prevention. HIV Surveillance Report, 2016; vol. 28.
http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html. Published November 2017.
Accessed 7/2/2018.

Centers for Disease Control and Prevention. 2018. www.cdc.gov HIV/AIDS Statistics Center.
HIV and AIDS in the United States by Geographic Distribution.

Chiao EY, Giordano TP, Palefsky JM, Tyring S, El Serag H. Screening HIV-infected individuals
for anal cancer precursor lesions: a systematic review. *Clinical Infectious Diseases.* 2006;
43(2):223-233.

Coghill, A. E., Engels, E. A., Schymura, M. J., Mahale, P., & Shiels, M. S. (2018). Risk of
Breast, Prostate, and Colorectal Cancer Diagnoses among HIV-Infected Individuals in the
United States. *J Natl Cancer Inst*. doi:10.1093/jnci/djy010

Cooley, T. P. (2003). Non-AIDS-defining cancer in HIV-infected people. *Hematol Oncol Clin
North Am, 17*(3), 889-899

Deepthi Mani, David M Aboulafia. Screening guidelines for non-AIDS defining cancers in HIV-

    infected individuals. *Curr Opin Oncol*. 2013 Sep; 25(5): 518–

    525.doi: 10.1097/CCO.0b013e328363e04a

Eyawo, O., Franco-Villalobos, C., Hull, M. W., Nohpal, A., Samji, H., Sereda, P., Hogg, R. S.

    (2017). Changes in mortality rates and causes of death in a population-based cohort of

    persons living with and without HIV from 1996 to 2012. *BMC Infectious Diseases, 17*(1),

    174. doi:10.1186/s12879-017-2254-7

Galanina, N. 2018. Immunotherapy may be efficacious in patients with HIV-associated Kaposi's

    sarcoma. American Association for Cancer Research. Retrieved from; http:

    https://medicalxpress.com/news/2018-09-immunotherapy-efficacious-patients-hiv-

    associated-kaposi.html

Hennig, P. and Knowles, A. (1990) Factors influencing women over 40 years to take precautions

    against cervical cancer, Journal of Applied Social Psychology, 20: 1612-21.

Hernández-Ramírez RU, Shiels MS, Dubrow R, Engels EA. Cancer risk in HIV-infected **people**

    in the USA from 1996 to 2012: a population-based, registry-linkage study. Lancet HIV.

    Nov; 4(11):e49 (2017)

HIV.Gov. 2018. HIV Basics. Retrieved from: https://www.hiv.gov/hiv-basics/overview/about-

    hiv-and-aids/what-are-hiv-and-aids

Kendall, C. E., Walmsley, S., Lau, C., Jembere, N., Burchell, A. N., Loutfy, M., Antoniou, T.

    (2017). A cross-sectional population-based study of breast cancer screening among

    women with HIV in Ontario, Canada. *CMAJ Open*, *5*(3), E673–E681.

    http://doi.org/10.9778/cmajo.20170038

Li J, Thompson TD, Tai E, Zhao G, Oster AM. Testing for Human Immunodeficiency Virus

    Among Cancer Survivors Under Age 65 in the United States. *Prev Chronic Dis* 2014;

    11:140274. DOI: http://dx.doi.org/10.5888/pcd11.140274

Mani, D., & Aboulafia, D. M. (2013). Screening guidelines for non-AIDS defining cancers in

    HIV-infected individuals. *Curr Opin Oncol, 25*(5), 518-525.

    doi:10.1097/CCO.0b013e328363e04a

National Cancer Institute. 2018. HIV Infection and Cancer Risk. National Institute of Health.

    Retrieved from: https://www.cancer.gov/about-cancer/causes-prevention/risk/infectious-

    agents/hiv-fact-sheet

National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, CDC, Selected

    national HIV prevention and care outcomes, 2015.

National Comprehensive Cancer Network. 2018. NCCN Guidelines Version 1.2018 Cancer in

    People Living with HIV.

National Institute of Health.2018, HIV Prevention. Retrieved

    from:https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/20/50/preventing-

    mother-to-child-transmission-of-hiv

National Institute of Health. 2018. Dictionaries. Retrieved from:

    https://www.cancer.gov/publications/dictionaries/cancer-terms/def/highly-active-

    antiretroviral-therapy

New York State Department of Health AIDS Institute. *Neoplastic complications of HIV*

    infection. Available

    at: http://www.hivguidelines.org/wpcontent/uploads/2009/05/NEOPLACOMPLIC.pdf

Pietro, G. D., Chornokur, G., Kumar, N. B., Davis, C., & Park, J. Y. (2016). Racial Differences in the Diagnosis and Treatment of Prostate Cancer. *International Neurourology Journal*, *20*(Suppl 2), S112–119. http://doi.org/10.5213/inj.1632722.361

Shiels, M. S., Goedert, J. J., Moore, R. D., Platz, E. A., & Engels, E. A. (2010). Reduced Risk of Prostate Cancer in U.S. Men with AIDS. *Cancer Epidemiology, Biomarkers & Prevention : A Publication of the American Association for Cancer Research, Cosponsored by the American Society of Preventive Oncology*, *19*(11), 2910–2915. http://doi.org/10.1158/1055-9965.EPI-10-0741

Robbins, H. A., Pfeiffer, R. M., Shiels, M. S., Li, J., Hall, H. I., & Engels, E. A. (2015). Excess cancers among HIV-infected people in the United States. *J Natl Cancer Inst, 107*(4). doi:10.1093/jnci/dju503

Shiels M, Cole S, Kirk G, Poole C. A Meta-Analysis of the Incidence of Non-AIDS Cancers in HIV-Infected Individuals. *JAIDS Journal of Acquired Immune Deficiency Syndromes.* 2009;52(5):611-622

Sigel, K., Dubrow, R., Silverberg, M., Crothers, K., Braithwaite, S., & Justice, A. (2011). Cancer screening in patients infected with HIV. *Current HIV/AIDS Reports, 8*(3), 142-152. doi:http://dx.doi.org/10.1007/s11904-011-0085-5

Silberstein, J., Downs, T., Lakin, C., & Kane, C. J. (2008). HIV and prostate cancer: a systematic review of the literature. *Prostate Cancer And Prostatic Diseases, 12*, 6. doi:10.1038/pcan.2008.44

Tanaka, L. F., Latorre, M., Gutierrez, E. B., Heumann, C., Herbinger, K. H., & Froeschl, G. (2017). Trends in the incidence of AIDS-defining and non-AIDS-defining cancers in

people living with AIDS: a population-based study from Sao Paulo, Brazil. *Int J STD AIDS, 28*(12), 1190-1198. doi:10.1177/0956462417692924

United States Department of Health & Human Services.2018.NIH Research Portfolio Online Reporting Tools RePORT. Retrieved from:

https://report.nih.gov/nihfactsheets/viewfactsheet.aspx?csid=76

United States. HIV. Gov; 2017. Retrieved from: //www.hiv.gov/hiv-basics/overview/data-and-trends/statistics

U.S. Department of Veterans Affairs. *Primary Care of Patients with HIV; Cancer Screening* http://www.hiv.va.gov/provider/manual-primary-care/cancer-screening.asp#S2X. Accessed 5/13/16.

Wells JS, Holstad MM, Thomas T, Bruner DW. An Integrative Review of Guidelines for Anal Cancer Screening in HIV-Infected Persons. *AIDS patient care and STDs.* 2014;28(7):350-357.

World Health Organization.2018. Sexual and Reproductive Health. Retrieved from:

http://www.who.int/reproductivehealth/call-to-action-elimination-cervical-cancer/en/

Appendages

Appendix A

<u>Institutional Review Board Approval Letter</u>

EMORY
UNIVERSITY

Institutional Review Board

TO: Theresa Gillespie, Ph.D., MA, BSN

      Principal Investigator

      SOM: Medicine RAS

DATE: May 04, 2017

RE: Expedited Approval
            11000095399
            Advancing Screening and Preventive Behaviors Among People Living with HIV/AIDS (PLWHA)

Thank you for submitting a new application for this protocol. This research is eligible for expedited review under 45 CFR.46.110 and/or 21 CFR 56.110 because it poses minimal risk and fits the regulatory' categories F [(5), (7)] as set forth in the Federal Register. The Emory IRB reviewed it by expedited process on 05/04/2017 and granted approval effective from 05/04/2017 through 05/03/2018. Thereafter, continuation of human subjects' research activities requires the submission of a renewal application, which must be reviewed and approved by the IRB prior to the expiration date noted above. Please note carefully the following items with respect to this approval:

- Synergy grant-funded (04/02/2017) - Protocol
- Clinician Questionnaire (04/02/2017)
- Moderator Guide - Pt. Focus Group (04/02/2017)
- On study form (04/02/2017)
- Patient Questionnaires (04/02/2017)
- Clinician Consent Form (04/02/2017)
- Grady Clinician Consent (04/12/2017)
- Grady pt consent (04/12/2017)
- Patient Consent Form (04/02/2017)
- A partial waiver of HIPAA authorization has been approved by the IRB for the purpose of identifying potential subjects for this protocol. As subjects are contacted, you are required to obtain their HIPAA authorization.

Any reportable events (e.g., unanticipated problems involving risk to subjects or others, noncompliance, breaches of confidentiality, HIPAA violations, protocol deviations) must be reported to the IRB according to our Policies & Procedures at www.irb.emor.y.edu,

immediately, promptly, or periodically. Be sure to check the reporting guidance and contact us if you have questions. Terms and conditions of sponsors, if any, also apply to reporting.
https://eresearch.emow.edu/Em0ty/Doc/O/JT4VJFGATDOK9917HRS7315E62/fromString

Before implementing any change to this protocol (including but not limited to sample size, informed consent, study design, you must submit an amendment request and secure IRB approval.

In future correspondence about this matter, please refer to the IRB file ID, name of the Principal Investigator, and study title. Thank you

Will smith, MPH

IRB Research Protocol Analyst

This letter has been digitally signed

CC:	Mincey	Loree	*SPH: Epidemiology
	Chawla	Saurabh	SOM: Medicine: Digestive Dis
	Lipscomb	Joseph	*SPH: Health Policy and Mgmt.
	Liu	Yuan	*SPH: Biostatistics
	Nguyen	Minhly	SOM: Medicine: Infectious Dis
	Wells	Jessica	Surg Serv. Admin

Appendix B

Definition of Terms

HIV Infections: HIV stands for human immunodeficiency virus. It is the virus that can lead to acquired immunodeficiency syndrome, or AIDS, if not treated (HIV, Gov, 2018).

AIDS: Acquired Immune Deficiency Syndrome, is an advanced stage of HIV disease.

Highly Active Antiretroviral Therapy: Treatment that uses a combination of three or more drugs to treat HIV infection. Highly active antiretroviral therapy stops the virus from making copies of itself in the body. This may lessen the damage to the immune system caused by HIV and may slow down the development of AIDS. It may also help prevent transmission of HIV to others, including from mother to child during birth (National Institute of Health, 2018)

Incidence: The number of new cases of a disease diagnosed in a specific population each year (National Institute of Health, 2018).

AIDS Defining Cancers: A type of cancer that a person infected with human immunodeficiency virus (HIV) is at high risk of developing. For an individual with an HIV diagnosis, the presence of one of these cancers has been used to generate a diagnosis of AIDS. AIDS-defining cancers

include Kaposi sarcoma, certain types of non-Hodgkin lymphoma, and cervical cancer (National Institute of Health, 2018).

Non-AIDS Defining Cancers: Non-AIDS defining cancers can occur among PLWHA and those who are HIV-negative, but NADC may occur at higher rates among PLWHA. Non-AIDS-defining cancers include Hodgkin lymphoma and cancers of the mouth, throat, liver, lung, and anus (National Institute of Health, 2018).

Cancer Screening: Examination for cancers when there are no clinical signs the disease is present. Since screening may find diseases at an early stage, there may be a better chance of curing the disease. Examples of cancer screening tests are the mammogram (for breast cancer), colonoscopy (for colon cancer), spiral CT for lung cancer screening, oral examination for oral cancers, and the Pap test and HPV tests (for cervical cancer) (National Institute of Health, 2018).

Appendix C

Study Questionnaire

Study of Health Behaviors and Disease Prevention - PATIENT Synergy Grant

Study ID: _____

Study Site: ☐ 1.Ponce Clinic
☐ 2. Albany Clinic

Date Completed: _____

The purpose of this questionnaire is to learn more about your health habits and behaviors that may prevent disease or certain conditions, or find health problems early. This will take about 15 minutes to complete.

Please answer the following questions. Check all that apply for each question or add additional items in the blanks for "Other". Thank you!!

General Health Habits

>   **A.   What do you do to stay health generally? Check all that apply.**
☐ 1. I go see the dentist for checkups
☐ 2. I have my cholesterol or sugar level checked regularly

☐ 3. I visit health fairs to monitor my health

☐ 4. I keep track of my weight or watch what I eat regularly

☐ 5. I participate in cancer screening

☐ 6. I get my blood pressure checked regularly

☐ 7. OTHER – describe _____

B. **What <u>PREVENTIVE</u> health behaviors do you participate in? This means activities that help stop a disease or condition from starting, or help to control the disease or condition from getting worse. Check all that apply.**

☐ 1. I stopped smoking or never used cigarettes

☐ 2. I do not use chewing tobacco or snuff

☐ 3. I do not use or abuse drugs or other substances

☐ 4. I do not use alcohol excessively

☐ 5. I do eat healthy foods and maintain good nutrition

☐ 6. I do exercise regularly

☐ 7. OTHER – describe other preventive behaviors you do: _____

_____

C. **How important do you see disease <u>PREVENTION</u> as a priority for your health? Mark the place on the line below that shows how important this is to you.**

Not important at all	Somewhat important	Neutral	Moderately important	Very Important
1	2	3	4	5

D. **Have you ever had a doctor/healthcare provider discuss with you or advised specific things you can do to <u>prevent</u> diseases? Check all that apply.**

☐ 1. No, my healthcare provider/doctor has never discussed things I can do to prevent diseases.

☐ 2. Yes, my healthcare provider/doctor advised me to stop smoking

☐ 3. Yes, my healthcare provider/doctor advised me to get more regular exercise

☐ 4. Yes, my healthcare provider/doctor advised me to eat a more healthy diet

☐ 5. Yes, my healthcare provider/doctor advised me to try to maintain a normal weight

☐ 6. Yes, my healthcare provider/doctor advised me to reduce my stress level

☐ 7. Yes, my healthcare provider/doctor advised me to avoid excess sunshine and use sunscreen

☐ 8. Yes, my healthcare provider/doctor advised me to practice safe sex

☐ 9. Yes, my healthcare provider/doctor advised me to avoid getting an infection

☐ 10. OTHER – describe _____

General Health Screening

A. **The following section allows you to rate your level of risk for several diseases. If you have already been diagnosed with one or more of these diseases, please write "Yes" in the first box. Then rate your level of risk for being diagnosed with the remaining diseases by checking the appropriate box underneath the risk categories**.

Disease/Condition	Already have diagnosis?	I believe my risk for being diagnosed with this disease is:			
	Yes/No	High Risk	Med Risk	Low Risk	No Risk at all
Heart Disease					
Stroke					
High blood pressure					
Diabetes/high sugar					
Cancer – in general					
Specific Cancers:					
Skin cancer					
Breast cancer (females)					
Prostate cancer (males)					
Lung cancer					
Cervical cancer (female)					
Colon cancer					
Rectal cancer					
Anal cancer					
Liver cancer					
Pancreatic cancer					
Cancer of the mouth					
Cancer of the lymph nodes (lymphoma)					
Leukemia					

B. **How important do you see disease SCREENING or FINDING DISEASE EARLY as a priority for your health? Mark the place on the line below that shows how important this is to you.**

Not important at all	Somewhat important	Neutral	Moderately important	Very Important
1	2	3	4	5

C.   Have you ever been <u>screened</u> (NOT diagnosed) for the following diseases?
Check all that apply and complete the blank if you check "Other".
☐ 1. High blood pressure
☐ 2. High or "bad" cholesterol
☐ 3. Diabetes (high blood sugar)
☐ 4. Heart disease
☐ 5. Mental health disorders
☐ 6. Dementia, Alzheimer's disease, or memory loss
☐ 7. OTHER – describe _____

D.   If you have NOT been previously screened for any of the diseases above, e.g. cancer, heart disease, why not? Check all that apply.
☐ 1. Never recommended by my healthcare provider
☐ 2. Recommended by my provider but I never followed up
☐ 3. Didn't believe that I was at risk for those diseases
☐ 4. I have enough to focus on right now with my current health or other issues
☐ 5. OTHER – describe _____

E.   Have you ever been screened for other kinds of diseases, e.g. cancer and viral diseases? ☐ 1. Breast cancer (females only)
☐ 2. Prostate cancer (males only)
☐ 3. Cervical cancer (females only)
☐ 4. Colon cancer
☐ 5. Lung cancer (if smoker/ex-smoker and at high risk)
☐ 6. Anal cancer
☐ 7. Hepatitis C virus (HCV)
☐ 8. Human papilloma virus (HPV)
☐ 9. OTHER – describe _____

F.   Have you ever been recommended by a doctor to be screened for chronic diseases such as cholesterol, blood sugar, cancer, etc.? Check all that apply.
☐ 1. No, no one has ever previously recommended I get screened for any chronic diseases

☐ 2. Yes, it was recommended and I got all the recommended screenings

☐ 3. Yes, it was recommended but I didn't understand the importance

☐ 4. Yes, it was recommended but I didn't know where to go to get screened

☐ 5. Yes, it was recommended but I didn't have insurance to cover screening

☐ 6. Yes, it was recommended but I couldn't pay for the screening

☐ 7. Yes, it was recommended but it didn't seem to apply to me

☐ 8. Yes, it was recommended and I got the screening but didn't know how often to follow-up

☐ 9. OTHER – describe _____

G.   Have you received any of the following vaccines, regardless of how long ago you received? Check all that apply.

☐ 1. Tetanus vaccine

☐ 2. Pertussis (whooping cough) vaccine

☐ 3. HPV vaccine (human papilloma virus)

☐ 4. Hepatitis C vaccine (HCV)

☐ 5. Herpes Zoster Vaccine (HZV)

☐ 6. Influenza (Flu) vaccine

☐ 7. Hepatitis A virus vaccine (HepA)

☐ 8. Hepatitis B virus vaccine (HepB)

☐ 9. Meningococcal vaccine (against meningitis)

☐ 10. OTHER – describe _____

H.   What things do you consider when making the decision whether or not to be screened for a disease or condition? Check all that apply.

☐ 1. If my healthcare provider/doctor recommended being screened

☐ 2. If my current disease is controlled or not

☐3. If I consider the disease I'm being screened for is serious or not

☐ 4. If I have a family history of the disease or not

☐ 5. If I believe I am at increased risk of the disease or condition being screened for or not

☐ 6. If I have a friend or colleague that has been diagnosed with the disease or condition

☐ 7. If the screening recommended will cost me money

☐ 8. If the screening recommended will take much of my time

☐ 9. If the screening results would be considered to be accurate

☐ 10. OTHER – describe _____

HIV and Chronic Disease Risk

How much do you agree with the following statements?
Mark the place on the line below that shows how much you agree with each statement.

A.   In terms of risk or health outcomes, there is a relationship between HIV and chronic diseases such as heart disease or diabetes (sugar).

Strongly Disagree	Somewhat Disagree	Neutral	Moderately Agree	Strongly Agree
1	2	3	4	5

B.   Individuals with HIV or AIDS are at <u>HIGHER</u> risk for other chronic diseases, e.g. cancer

Strongly Disagree	Somewhat Disagree	Neutral	Moderately Agree	Strongly Agree
1	2	3	4	5

C.   Individuals with HIV or AIDS are at <u>LOWER</u> risk for other chronic diseases, e.g. cancer

Strongly Disagree	Somewhat Disagree	Neutral	Moderately Agree	Strongly Agree
2	2	3	4	5

D.   Individuals with HIV are at a <u>HIGHER </u>risk for chronic diseases like

Strongly Disagree	Somewhat Disagree	Neutral	Moderately Agree	Strongly Agree
1	2	3	4	5

heart disease, diabetes (sugar), high blood pressure.

E.   Individuals with HIV are at a <u>LOWER</u> risk for chronic diseases like heart disease, diabetes (sugar), high blood pressure.

Strongly Disagree	Somewhat Disagree	Neutral	Moderately Agree	Strongly Agree
1	2	3	4	5

Ideas about How to Promote Preventive and Screening Behaviors

A. There are many different ways to encourage healthy behaviors, including those that prevent disease and those that help find diseases early when they are more easily treated. Some of those ways are listed below. Read each of the examples listed and <u>mark in the appropriate</u> <u>column to tell us how helpful each example might be in helping you practice healthy behaviors</u>.

Ways to help promote healthy behaviors	How helpful do you think each way listed might be for you to practice more healthy behaviors?

	Very helpful	Somewhat helpful	Neutral	Somewhat unhelpful	Very unhelpful
Reminders sent to me in regular mail, like a postcard					
Reminders sent to me as an email					
Reminders sent to me as a text on my phone					
Reminders sent to my DOCTOR or HEALTHCARE PROVIDER to recommend preventive or healthy behaviors for me					
Receiving counseling from healthcare providers about my need for preventive and healthy behaviors					
Attending a class in the clinic about my preventive and healthy behaviors					
Attending a class in the community about my preventive and healthy behaviors					
Finding out more about my own specific risk for certain diseases and conditions					
Finding out more about how HIV affects risk for getting other diseases and conditions					
Receiving a schedule of preventive and healthy behaviors for me to follow					
Completing an online learning tool about my preventive behaviors and risks for diseases like diabetes or cancers					
Watching a video about preventive behaviors and my risks for diseases like diabetes or cancers					
Hearing from others with similar diseases and conditions as mine about their own experiences related to preventive behaviors					
My own ideas:					

Things that might block health behaviors or participation in screening tests	How important do you think each of these things might be as an obstacle for you to practice more healthy behaviors or participate in screening?

	Very important	Somewhat important	Neutral	Somewhat unimportant	Very unimportant
How much it costs me					
Difficulties accessing my care					
Lack of transportation for me					
Family issues, including my child care or elder care					
My own uncertainty about behaviors I need to follow					
My own uncertainty about what screening tests I need to have					
How busy I already am with my current health issues					
My own fear of what might be found on a screening test					
My concern that preventive or screening activities would not improve my health overall					
My concern that prevention or screening takes too much time					
My own preference not to deal with these issues about my health					
My unwillingness to do other prevention or screening because I am happy with my own behavior, habits & health					
Lack of a recommendation from my doctor or healthcare provider					
My concern that prevention or screening will not impact my **long-term** health					
My concern that prevention or screening will not impact my **current** health					
My concern that it is too hard for me to make changes in prevention or screening behaviors					

B. How important do you think the following things are TO YOU regarding participating in healthy behaviors or recommended screening tests?

Mark in each column to indicate how important you believe each thing might be as an obstacle for YOU to practice better preventive and screening behaviors.

Mark the place on the line below each statement that shows how much you agree or disagree with each statement.

A. **I would likely get screened for a chronic disease, like heart disease, diabetes, or cancer if my doctor or health care provider recommended it to me.**

Strongly Disagree	Somewhat Disagree	Neutral	Moderately Agree	Strongly Agree
1	2	3	4	5

B. **Having a diagnosis of HIV would affect my decision regarding being screened for chronic diseases.**

Strongly Disagree	Somewhat Disagree	Neutral	Moderately Agree	Strongly Agree
1	2	3	4	5

C. **I would likely follow preventive behaviors, like stopping smoking or eating more healthy foods, if my doctor or health care provider recommended them to me.**

Strongly Disagree	Somewhat Disagree	Neutral	Moderately Agree	Strongly Agree
1	2	3	4	5

D. **Having a diagnosis of HIV infection would affect my decision to engage in more preventive behaviors.**

Strongly Disagree	Somewhat Disagree	Neutral	Moderately Agree	Strongly Agree
1	2	3	4	5

E. **Practicing preventive behaviors is even more important for someone with a diagnosis of HIV.**

Strongly Disagree	Somewhat Disagree	Neutral	Moderately Agree	Strongly Agree
1	2	3	4	5

F. **Getting screened for other chronic diseases, like heart disease, diabetes, or cancer, is even more important for someone with a diagnosis of HIV.**

Strongly Disagree	Somewhat Disagree	Neutral	Moderately Agree	Strongly Agree
1	2	3	4	5

Concerns about How Your Disease or Condition Might Affect You, or Others in your Family or Community

A. How likely do you think each of the following things might be regarding how you might deal with a particular disease or condition, or how others might deal with you if you had a specific diagnosis?

Mark in each column to indicate how likely those things listed might affect how you behave or others might deal with you based on a specific diagnosis.

IF you had a diagnosis of HIV or AIDS	How likely do you think you or others might do the following?				
	Very likely	**Somewhat likely**	**Neutral**	**Somewhat unlikely**	**Very unlikely**
I would be willing to share my diagnosis with neighbors and co-workers					
I would believe that my disease could be spread through person to person contact					
I think others would be willing to eat meals with me					
I would believe that my disease was caused by my past actions or wrong-doing					

Thank you for completing this questionnaire and helping us understand others' views about practicing healthy behaviors and participating in screening for chronic diseases!

Please return this form to the Study Coordinator.

List of Tables

Figures