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Adherence Barriers to Healthcare for African Americans with HIV/AIDS on Antiretroviral Medications

Angela Bumphus Corbin Walden University

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Walden University

College of Health Sciences

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Angela Bumphus-Corbin

has been found to be complete and satisfactory in all respects, and that any and all revisions required by the review committee have been made.

Review Committee

Dr. Raymond Panas, Committee Chairperson, Public Health Faculty Dr. LaToya Johnson, Committee Member, Public Health Faculty Dr. Patrick Tschida, University Reviewer, Public Health Faculty

Chief Academic Officer Eric Riedel, Ph.D.

Walden University 2017

Abstract

Adherence Barriers to Healthcare for African Americans with HIV/AIDS on Antiretroviral Medications

by

Angela Bumphus Corbin

MPH, Walden University, 2010 BS, Western Kentucky University, 1999

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Public Health

Walden University

May 2017

Abstract

The purpose of this mixed methods research study was to examine the role of adherence barriers to healthcare and the impact that such barriers have on highly active antiretroviral therapy (HAART) compliance for African Americans living with HIV/AIDS. HAART helps reduce HIV/AIDS morbidity and mortality. Of the 49% of study participants who had been out of medical care for more than 12 months, financial concerns were listed as the most common barrier (22.8%). Not having the support from family and friends (17.5%), being tired of going to doctor appointments (15.8%), health challenges (12.3%), lack of transportation (12.3%), and incarceration (12.3%) were also barriers in medical care that had a direct influence on noncompliance. The overall model of the linear regression analysis was significant, $R^2 = .469$, adjusted $R^2 = .458$, F(1, 49) =43.24, p < .001. Being in medical care on a regular basis accounted for 46.9% of the total variance in attending primary care visits. The outcome of this analysis confirms the hypotheses (H_A1) that attending 2 primary care visits within 6 months of being linked to care increased the rate of compliance for African Americans on HAART living with HIV/AIDS. The overall model of the linear regression analysis was significant, $R^2 = .469$, adjusted $R^2 = .458$, F(1, 49) = 7.206, p < .001. Being in medical care on a regular basis accounted for 46.9% of the total variance in attending primary care visits. The outcome of this analysis empasizes the importance of HAART compliance. These findings can lead to positive social changes by improving quality of life and health, which impacts gainful employment, sustains positive relationships, improves finances, and increases self-sufficiency.

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Dedication

This project is dedicated to all persons living with HIV/AIDS who are taking it one day at a time to live their best life. Continue to live with fervent happiness in your hearts.

Acknowledgments

I want to first thank God for His grace, mercy and favor. It is true that "God never gives us more than we can bear." When I started this journey, I had no idea of the unforeseen challenges, sacrifices and duration this would take in order to come into fruition. My faith has played a vital role in helping me to complete this journey. Not only was I praying for myself, but I know my family and friends were interceding on my behalf. So many people have supported me through this process, and I am forever grateful. Your words of encouragement provided motivation when I felt I could not reach my goal.

I would especially like to thank my amazing husband, Clyde, for being my number one fan and motivator. I know this journey was not in our plans after I received my Master's degree, but you have been so understanding through this process and have sacrificed so very much; more than I am sure you ever imagined. The gratitude and love that I have for you is beyond measure. As we welcomed our son, Elias, into our family, you displayed the epitome of what a great father is. Thank you for always being there. Elias is awesome and I am so happy that God chose us to be his parents!

Elias James, thank you for being such an amazing son. There were many times that I would be studying and you would bring one of your books to read and study too. Your random kisses and hearing you say "I love you" or "good job mommy!" are priceless moments I will always cherish. You are my greatest accomplishment. Being your mother is truly an answered prayer. I love you more than anything.

To my mom and dad, I would not be where I am had it not been for your love and support. You have always instilled the confidence in me to know I could accomplish my

dreams and take on challenges knowing that I am equipped with what it takes to be successful. Thanks for always being there. To my siblings, Timmy, Brenda, Darlena, and Tarsha being the youngest has had many advantages over the years. You have been there from the beginning and never shied away from letting me know how proud you were of my achievements. Thank you for the late night and early morning phone calls just to check on me. These conversations were refreshing as they resulted in laughs, prayers, encouragement and wisdom. To my in-loves (in-laws), thank you so much for your support, understanding, prayers and words of encouragement. They helped more than you know.

To my friends, thank you for understanding the change in my life that this journey caused. I know I have missed vacations, birthday parties, dinners, brunches, mixers and did not always respond to text messages, emails or phone calls promptly. Thank you for not taking it personal and supporting me along the way. To my brilliant friends and fellow advocates in this fight against HIV/AIDS — Anthony, Shanta, Genetha, and Yolanda — thank you for always going that extra mile. The dedication that each of you have when it comes to saving lives is definitely commendable. I am grateful to have such spectacular advocates to help tackle the fight against HIV/AIDS. We help make the world better one life at a time.

Finally, I would like to thank my committee members for all of their guidance and support during this journey. Dr. Raymond Panas and Dr. Latoya Johnson, thank you both for serving on my committee and helping to ensure that this dissertation was a success. I appreciate you very much and could not have done this without you.

To God be the glory! Ashe!

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Highly Active Antiretroviral Therapy (HAART). This is a form of prescription	
therapy used to prevent HIV replication and advancement (AIDS Info,	
2005)	8
MSM. This is the acronym for men who have sex with men (Young & Meyer,	
2005)	8
MSMW. This is the acronym for men who have sex with men and women	
(Young & Meyer, 2005).	8
Seroconversion. Transition from HIV infection to being able to detect HIV	
antibodies in the blood (AIDS Info, 2005).	8
WSW. This is the acronym for women who have sex with women (Young &	
Meyer, 2005)	8
WSWM. This is the acronym for women who have sex with men and women	
(Young & Meyer 2005)	8

Young and Meyer (2005) noted these terms are politically correct terms used in
public health dialogue because not all MSM, WSW, MSMW, and WSWM
identify as being gay, homosexual, bisexual or lesbians. Instead of using
these terms as labels, the acronyms are used as a way of focusing on
behaviors instead8
Human Immunodeficiency Virus (HIV). This term is used interchangeably for
the HIV virus and the infection it causes. According to AIDS Info (2013),
the HIV virus composed of the following five components:9
HIV Envelope. This is the outer surface of HIV9
HIV RNA. This is the genetic material of HIV9
HIV Capsid. This is a bullet-shaped core that contains the RNA of HIV9
HIV Enzymes. These are proteins that carry out the steps in the life cycle of HIV9
HIV Glycoproteins. These are protein "spikes" that are embedded in the envelope
of HIV9
Protease. This enzyme is defined by AIDS info (2013) as a protein that breaks up
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The impact of HAART adherence reaches beyond the scope of medical care.
HAART compliance influences social change and social position, personal
and professional relationships, financial stability, and quality of life.

Having the ability to identify, reduce or eliminate barriers of HAART
adherence is definitely a positive attribute. Knowing that successful
HAART impacts clinical progression and, in most cases, extends the
longevity of life for persons living with HIV/AIDS on HAART, it is
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Summary
As previously discussed in this chapter, Population Reference Bureau (2013)
highlighted that more African Americans are living with HIV or have
already died from AIDS in the United States than any other racial or
ethnic group. Minorities, especially African Americans, are underserved
by the AIDS Drug Assistance Program (ADAP) (Horneffer & Yang,
2013), and continue to experience significant imbalances in medical care,
linkage to care, and HAART implementation (Stone et al., 2009). The
current themes in the literature pertaining to African Americans and
HAART compliance resonate with the commonalities of barriers being
access to care, financial concerns, comorbidities, and poor behavior
choices that increase the risk of HAART success due to other lifestyle
issues such as drugs, or homelessness
Recent procedures such as testing and treating early on when a person is
diagnosed with HIV, focusing on linkage to care, retention of medical
care, and prevention hold great promise for women and minorities with
HIV in the U.S. (Stone, 2011). Although these forms of intervention are

promising, Morin et al. (2011) communicated that implementing

multilevel interventions and evaluation of the HIV/AIDS epidemic impact

poses challenges to traditional research paradigms because they do not

consider evaluation and efficiency of studies that respond to	
implementation challenges (Morin et al., 2011). This study filled the gap	
in terms of implementation challenges that may be thwarting multilevel	
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AID Atlanta, Inc. and Fulton County Health and Wellness are the two	
nonprofit agencies that will be essential in conducting this research.	
Servicing persons living with HIV/AIDS since its inception in 1982,	
AID Atlanta, Inc. continues to prove itself as a leader in the battle	
against HIV/AIDS in metropolitan Atlanta and is the Southeast's	
oldest, largest, and most comprehensive AIDS Service Organization	
(ASO) (AID Atlanta, Inc., 2014). The mission of AID Atlanta, Inc. is	
to reduce new HIV infections and improve the quality of life of its	
members and the community by breaking barriers and building	
community by providing primary healthcare services, AIDS Drug	
Assistance Program (ADAP) assistance, case management, a linkage	
and retention to care program, and educational programs (AID Atlanta	
Inc., 2014).	.41

Fulton County Health and Wellness HIV/AIDS Primary Care Clinic is a Ryan
White funded public health center that offers services for persons
living with HIV (Fulton County Georgia, 2011). Services at the clinic
range from primary medical care services, dental services, case
management, ADAP assistance, educational and behavioral health
services, Tuberculosis screening and treatment, STD medical care
screening and treatment, and linkage and retention services (Fulton
County Georgia, 2011). At present their primary care clinic has more
than 1,100 active clients who receive services
Surveys were given to study participants at ADAP appointments and medical
visits. I escorted study participants to a private exam room or clinician
office to complete their surveys. All surveys were collected by me
daily42
Research Design and Rationale
By using mixed methods, I was able to collect data from surveys that
participants completed, and was able to analyze data inclusive of
multilevel perspectives. I collected quantitative and qualitative data
concurrently; I used the convergent mixed-method design. I chose this
type because I analyzed the two data sets separately and then merged
the results during interpretation

Overall, I chose this method to capture multidimensional intelligence that
produced a well-defined understanding of HAART compliance
through data on behaviors, emotions and existing barriers. My study
benefited from both of these methods, which is why I selected the
mixed methods route using primarily qualitative methods42
Research Questions and Hypotheses
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Quantitative Research Questions
Concept of Study 44
Role of the Researcher
I served as the investigator in this research study. As the investigator, I had a
direct encounter with clients by asking them to complete surveys and
by collecting the surveys when participants completed them each day.
When a study participant agreed to participate in the research study, I
escorted them to a private office and gave them the consent form to
read and study survey to complete. If desired, study participants kept a
copy of the consent form. My relationship with the clients remained
professional at all times
As a manager working at the Fulton County Health and Wellness HIV/AIDS
Primary Care Clinic, part of my duties was to manage the day to day

operations in the clinic. This included working closely with

The criteria for participant selection were that a person must be infected with HIV/AIDS. In order to be a patient at the Ryan White clinic or AID Atlanta, Inc. a person had to be infected with HIV or have an AIDS diagnosis. Clients also had to be (a) receiving medical care for their HIV infection, (b) 18 years of age or older, and (c) be HAART experienced. With the new recommendations of the implementation of HAART almost all of the clients at these two clinics had HAART experience. The relationship between saturation and sample size was not a major concern. Saturation happened due to the nature of the

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Case managers and ADAP coordinators had daily appointments scheduled	
with clients living with HIV/AIDS. At these appointments, AID	
Atlanta, Inc. case managers and ADAP coordinators assisted in	
passing out flyers for the research study. These flyers had my contact	
information and information about the study on it. Each participant	
completed a consent form acknowledging their willingness to	
participate in this study by completing the survey. When a study	
participant agreed to participate in the research study, I placed them in	
a private office and gave them the consent form to read and study	
survey to complete. If desired, study participants kept a copy of the	
consent form. The consent form was the cover page for the survey. I	

was always available to discuss the study and collect data onsite for all
study participants
I will keep all raw data and completed surveys in a locked file cabinet in my home
office for five years. No follow up contact is needed with the study
participants. All of the data was collected and put into SPSS and analyzed
I collected both quantitative and qualitative data concurrently (parallel
form)
Threats to Validity49
SEATEC had previously tested the original survey for reliability and validity. The
only possible threat of validity in this research study may be clients not
completing every question of the survey. The importance of this will be
stressed at the beginning of the survey and again, after the clients finishes
the survey. They will be asked to ensure each question has been answered.
Talbert (2007) noted that research studies steered to assess behaviors are
most effective for quantitative analysis of descriptive data49
Furthermore, threats to internal validity will be eliminated because there will be
no design contamination with the survey. Compensatory rivalry will not
be an issue because there will be no goods or services exchanged for study
participation, and selection criteria will not change. Threats to external
validity will be reduced because there will be no selection bias,
experimental treatment, or physical performance experiments conducted49

Ethical Procedures	49
Ethical procedures of this research study were to ensure that each survey	
completed was anonymous and that no identifying information was	
captured as part of the survey. Laws and policies were in place to help	
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AID Atlanta, Inc. and Fulton County Health & Wellness are the two nonprofit	
agencies that were essential in conducting this research. Servicing	
persons living with HIV/AIDS since its inception in 1982, AID	
Atlanta, Inc. continues to prove itself as a leader in the battle against	

HIV/AIDS in metropolitan Atlanta and is the Southeast's oldest,
largest, and most comprehensive AIDS Service Organization (ASO)
(AID Atlanta, Inc., 2014). The mission of AID Atlanta, Inc. is to
reduce new HIV infections and improve the quality of life of its
members and the community by breaking barriers and building
community by providing primary healthcare services, AIDS Drug
Assistance Program (ADAP) assistance, case management, a linkage
and retention to care program, and educational programs (AID Atlanta
Inc., 2014)
Fulton County Health and Wellness HIV/AIDS Primary Care Clinic is a Ryan
White funded public health center that offers services for persons
living with HIV (Fulton County Georgia, 2011). Services at the clinic
range from primary medical care services, HAART, dental services,
case management, ADAP assistance, educational and behavioral
health services, Tuberculosis screening and treatment, STD medical
care screening and treatment, and linkage and retention services
(Fulton County Georgia, 2011)57
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Case managers and ADAP coordinators had daily appointments scheduled
with clients living with HIV/AIDS. At these appointments, AID
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participate they were given an anonymous survey to complete. Once
the survey. Once the study participants gave their consent to
a copy of the consent form. This consent form was the cover page for
agreement to participant in the study. If desired, study participants kept
information. The participant consent form acknowledged their
being in the study, lack of payment compensation, privacy, and contact
sample questions, volunteer nature of the study, risks and benefits of
for participants, the purpose of the study, procedures and duration,
and were given a consent form to read that explained the qualifications
to participate in the research study, they were placed in a private office
When a study participant spoke to me face to face, or contacted me and agreed
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Stressful situations in life can help to tear down a person's beliefs, health status,
faith and relationships with others. Increasing awareness and helping to
provide a clear understanding of what causes such stressors and barriers,
gives facts that can produce a clear avenue of what needs to happen in an
effort to address them. HAART compliance influences social change,
social position, personal and professional relationships, financial stability,
and quality of life. Having the ability to identify, reduce or eliminate
barriers of HAART adherence is definitely a positive attribute82
As shared in Chapter 2, when a parent is infected with HIV/AIDS, the quality of
their health may have a direct impact on the dynamics of their family.
These dynamics may result in an increased responsibility load for others,
including children, in the home. When a person is HAART compliant and

Family connections are a huge part of the African American community.

Knowing that a lack of support from family and friends was identified as a barrier to HAART compliance, processes to improve the dynamics of relationships with loves ones is critical. This social change is multileveled. It is a positive social change within marriages, parent to child relationships, caregiver relationships, sibling relationships, friendships and social relationships. Having the capacity to be an asset and productive citizen in their community has a ripple effect. When family, friends or coworkers see this behavior that led to a positive economic impact, it may perhaps influence them to encourage their loved ones to continue with these behaviors and work collectively to ensure it becomes habitual.

As a result of this research project, results can directly impact positive social change. Results can lead to positive social changes by allowing African Americans living with HIV/AIDS to have an advanced quality of life and extended longevity leading to positive behavior changes by being able to improve their health. Increasing self-accountability and self-confidence

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researchers' findings are worthy of interest being given (Elo et al., 2014).

Analysis strategies should aspire to support trustworthiness by reporting

The intention of trustworthiness is to authenticate the argument that the

the process of content analysis accurately (Schreier, 2012). There were no major limitations in completing my research study. The only limitation presented was the ability to ensure that all honest and accurate information was captured and that each survey was completely filled out by the study participants in higher HAART rates. Creswell (2009) noted validity is whether one can draw meaningful and useful inferences from scores on the instruments (Creswell, 2009). Frankfort-Nachmias and Nachmias (2008) shared validity wants to ensure that what is being measured is

actually the intended target of measurement. The concept of validity for	
measurement deals with (a) content validity, (b) empirical validity, and (c)	
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Retention in HIV care is an essential measure for achieving long-term survival	
while living with HIV/AIDS (Thompson et al., 2012). When medical care	
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increase and the potential for declining in health may occur as a result of	
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In Georgia, HIV/AIDS diagnosis cases are legally required to be reported to the	
HIV/AIDS Epidemiology Section (HAES) (Georgia Department of Public	
Health, n.d.). The Georgia Department of Public Health (DPH) (n.d.)	
noted Georgia has a dual reporting system that legally requires both health	
care providers and laboratories to report cases of HIV/AIDS. This is	
supposed to be completed within 7 days of diagnosis. Cases are reported	
using a case report form that is sent to the HIV/AIDS surveillance	

HAART compliance or noncompliance data can be also qualitative for the reason that it allows individuals to express their beliefs, behaviors, and rational for actions. This could provide additional clarity surrounding the results of the quantitative data. HIV/AIDS infection can be very difficult in terms of coping with the diagnosis, and medical care and

HAART compliance may not be a priority to infected persons if other	
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behavioral health issues exist9) 3
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AID/ATLANTA

Letter of Cooperation from a Research Partner

LaTonya M. Wilkerson AID Atlanta Latonya.wilkerson@aidatlanta.org (404) 870-7780

June 23, 2016

Sincerely.

Dear Angela Corbin,

Based on my review of your research proposal, I give permission for you to recruit from AID Atlanta case managed patients for the study entitled Adherence Barriers to Healthcare for Minorities with HIV/AIDS on Antiretroviral Medications. As part of this study, I authorize you to recruit clients at their case management visits and conduct a survey to assess barriers and healthcare views clients living with HIV/AIDS. These surveys will be anonymous and no follow up contact will be needed from any clients that participate. Individuals' participation will be voluntary and at their own discretion.

We understand that you will work with the site to provide confidential space whereas clients can complete the research survey in private, adhering to Health Insurance Portability and Accountability Act (HIPAA). No supervision will be required to administer surveys to clients. I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the student's supervising faculty/staff without permission from the Walden University IRB.

LaTonya M. Wilkerson
Director of Quality and Compliance
AID Atlanta, Inc.

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Chapter 1: Introduction to the Study

Introduction

Piot, Kazatchkine, Dybul, and Lob-Levyt (2009) noted that the emergence of the human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) began around the 1980s. The global effect that the virus and its related disease was underestimated. Tens of millions of individuals in the world would become infected within a few decades (Piot et al., 2009). The disease continues to leave communities devastated on a global level. Unfortunately, not all persons who are diagnosed as being infected with HIV (also referred to as being HIV positive) or develop AIDS have access to the necessary healthcare and medication. As such, HIV/AIDS is now a global health issue, major public health concern, and human rights issue.

Identified as a global pandemic, more than 34 million people now live with HIV/AIDS worldwide (World Health Organization [WHO], 2013). HIV is spread through the exchange of bodily fluids (blood, vaginal fluids, semen, preseminal fluid, rectal fluids, and breast milk) from a person infected with HIV through high risk behaviors such as oral, vaginal, anal sex, and sharing needles or syringes (Centers for Disease Control and Prevention [CDC], 2014). Mother to child transmission of the virus is another form of transmission that can occur during pregnancy; however, if a pregnant woman does not breastfeed, has an undetectable viral load, and is on prescribed medication, the risk of transmission is reduced to 1% (CDC, 2014). While numerous scientific accomplishments resulted in treating this disease and determining its etiology, there is no cure, and millions

of people continue to become infected with HIV or die from complications associated with AIDS annually (Schneiderman, 2001).

Clinical trials have been unsuccessful in the development of a vaccination to prevent the occurrence of HIV/AIDS (Virgin & Walker, 2010). Therefore, methods of prevention include safe sex practices and health education. Unfortunately, safer sex methods are not always practiced (Nkansah-Amankra et al., 2011). This increases risk as persons who become infected with herpes, gonorrhea, or syphilis also increase their chances of becoming infected with HIV (CDC, 2015c). Additionally, education, at times, may not suffice to induce healthy behavior modification practices as it relates to the prevention of diseases (Nkansah-Amankra, et al., 2011). Fortunately, in terms of treatment options, one advance, highly active antiretroviral therapy (HAART), has resulted in the reduction of HIV/AIDS transmission, morbidity, and mortality (Montaner et al., 2014). Recent studies showed an estimated 8 million people living with HIV/AIDS are receiving HAART, with an estimated 7 million eligible people waiting to enroll in treatment for HAART (Granich, 2010). As such, ensuring that comprehensive care happens as soon as possible should be a priority for persons living with HIV/AIDS, because HAART has shown success in reducing incurred costs and improving clinical outcomes (Pollini, Blanco, Crump, & Zuniga, 2011).

Interestingly, despite the availability and success of HAART, Kalichman et al. (2011) noted that individuals who engage in high risk behaviors for HIV infection are less likely to be adherent to HAART, which is a critical factor in the quality of life. Issues such as co-morbidities, increase in viral load and decrease of CD4 count are some of the

reasons that a person living with HIV/AIDS may decide to start HAART. Nutritional requirements, transportation, finances, stigma, and demographic location can also present as barriers to appropriate medical care. If an individual lacks food, shelter, or other medical or behavioral health care, adherence may not be a priority to them. This is of particular concern in African American communities as health disparities are often prevalent in this community, especially in the case of HIV/AIDS, and these barriers may be affecting their decisions regarding health care (Colasanti, Nguyen, Kiem, Deeb, & Jayaweera, 2012).

Reducing behaviors that could increase fatalities, health issues, and the spread of disease are important. The potential findings of this research project would lead to positive social changes by allowing African Americans living with HIV/AIDS to have life longevity leading to positive behavior changes. This would present opportunities for gainful employment, sustaining positive relationships, and improving financial stability.

Background

Primary, secondary, and tertiary intervention strategies have been implemented globally to reduce the spread of HIV/AIDS. For behavioral interventions to succeed in reducing infections across a population, they need to reach a broader sector of the population, be of sufficient intensity and reach the proper individuals (Cohen et al., 2007). Major milestones have been made over the past decade in behavioral research on how to help persons avoid contracting HIV (primary prevention) and how to reduce or alleviate adverse consequences among persons who are living with HIV disease (secondary prevention).

Within the primary prevention areas, research has shown the effectiveness of risk-reduction interventions undertaken with individuals, couples, small groups, communities, and at a social policy/structural level. Advances in HIV medical care have also created important new challenges and roles for behavioral scientists in the area of HIV secondary prevention (Kelly & Kalichman, 2002). Tertiary prevention, in this case, would be more like slowing or stopping the progression of the diseases, and would rely on treatment with medication and practicing healthy behaviors.

Montaner et al. (2014) noted that HAART has influenced a profound population-level decrease in HIV transmission, mortality and morbidity rates, but adherence to HAART has been a critical concern for the past decade (Konkle-Parker, Erlen, & Dubbert, 2007). To date, not much is known about adherence barriers and facilitators such as being able to accept an HIV/AIDS diagnosis, spirituality and prayer, support systems from loved ones and the implications of poor medication adherence (Konkle-Parker et al., 2007). In order to make a positive social change there should be an understanding of what treatment barriers are and why they exist.

Problem Statement

HAART has been successful in prolonging life expectancy and decreasing the viral load of HIV in the human body (Cahill & Valadez, 2013). Population Reference Bureau (2013) highlights that, of all racial or ethnic groups, more African Americans are living with HIV or already dead from AIDS in the United States than any other ethnic group. While there has been a decrease in HIV/AIDS cases; the number of African Americans diagnosed with HIV/AIDS has not (Kaiser Family Foundation, 2014).

Furthermore, when compared to other minorities, African Americans were more underserved by the AIDS Drug Assistance Program (ADAP) (Horneffer & Yang, 2013) and were 2.40 times more likely to be noncompliant with HAART than whites (Osborn, Paasche-Orlow, Davis, & Wolf, 2007). This study focused on the present gap in literature, which are the adherence barriers to healthcare for African Americans with HIV/AIDS on antiretroviral medications.

Purpose of the Study

Capable of generating a major social change, this study was a mixed methods paradigm. The potential findings of this research project will lead to positive social changes by allowing African Americans living with HIV/AIDS to have an advanced quality of life and lead to positive change by being able to improve their health. This presents opportunities for these individuals to gain employment, sustain positive relationships, to improve financial stability, present for follow up medical visits and to even volunteer with local public health agencies that are centered on HIV/AIDS patients as consumers. Individually and collectively these indicators impact social change in a progressive manner.

Research Questions and Hypotheses

Qualitative Research Questions

RQ 1. What are the barriers causing African Americans living who with HIV/AIDS to have lower adherence rates with HAART than persons of other ethnic groups?

RQ 2. How can barriers for medical treatment of African Americans living with HIV/AIDS be eliminated?

Quantitative Research Questions

RQ 3. Will attending two primary care visits within six months of being linked to care increase the rate of compliance for African Americans on HAART living with HIV/AIDS?

 H_01 : Attending two primary care visits within six months of being linked to care will not increase the rate of compliance for African Americans on HAART living with HIV/AIDS.

 $H_{\rm A}1$: Attending two primary care visits within six months of being linked to care will increase the rate of compliance for African Americans on HAART living with HIV/AIDS.

RQ 4. Will African Americans living with HIV/AIDS who have been out of care for 12 or more months have a low linkage to care rate?

 H_02 : African Americans that have been out of care for 12 or more months while living with HIV/AIDS will not have a low linkage to care rate.

 H_A 2: African Americans that have been out of care for 12 or more months while living with HIV/AIDS will have a low linkage to care rate.

Framework

The Health Belief Model (HBM) theoretical framework was applicable to this study because an individual's perceptions and/or beliefs had a direct impact on strategies that can decrease disease occurrence (Glanz, Rimer, & Lewis, 2002). These perceptions

included seriousness, benefits, barriers, and susceptibility (Glanz et al., 2002). The aforementioned perceptions have a positive or negative influence on a person's health. As previously mentioned, individuals who are living with HIV/AIDS, who are on HAART looked at this part of their medical care as beneficial, but they also viewed it as harmful, due to some of the possible side effects. Therefore, negative perceptions reduced compliance with HAART.

Nature of Study

A mixed methods approach, primarily qualitative, was used to address the questions that were proposed in this study that helped prevent bias. The qualitative information helped to bridge the gap of knowledge or data collected from the quantitative data collection tools. The qualitative data consisted of results that identified barriers of care for study participants. Quantitative data consisted of statistics that showed a direct correlation of HAART noncompliance and HAART availability. Addressing linkage care rates resulted in options that are more successful in order for medical and HAART compliance to occur. Data from the surveys represented an accurate account of barriers and positive behaviors that affected HAART compliance rates.

Definitions

There are certain acronyms/terms/definitions used in the field of HIV/AIDS that may not be known to others who are not familiar with these infections or specialty.

Treatment failure. This term is interchangeable with the phrase "drug resistance", and is used when a bacterial component, viral agent, or microorganism

becoming insensitive to a drug that was previously effective, but is no longer effective (insensitive) (AIDS Info, 2011).

Highly Active Antiretroviral Therapy (HAART). This is a form of prescription therapy used to prevent HIV replication and advancement (AIDS Info, 2005).

MSM. This is the acronym for men who have sex with men (Young & Meyer, 2005).

MSMW. This is the acronym for men who have sex with men and women (Young & Meyer, 2005).

Seroconversion. Transition from HIV infection to being able to detect HIV antibodies in the blood (AIDS Info, 2005).

WSW. This is the acronym for women who have sex with women (Young & Meyer, 2005).

WSWM. This is the acronym for women who have sex with men and women (Young & Meyer, 2005).

Young and Meyer (2005) noted these terms are politically correct terms used in public health dialogue because not all MSM, WSW, MSMW, and WSWM identify as being gay, homosexual, bisexual or lesbians. Instead of using these terms as labels, the acronyms are used as a way of focusing on behaviors instead.

Socioeconomic status (SES). At times, this term is used interchangeably with "social position." Socioeconomic status, as noted by the National Center for Health Statistics (2012), is a "multidimensional concept comprising measures of resources such as income, wealth, and educational credentials, and the access to goods, services, and

knowledge that these resources afford those who have them. It is most commonly measured using educational attainment, income or poverty status, and, when available, wealth, employment, and occupational status" (p. 24).

Social position. This term is similar to and is often interchanged with SES, but it encompasses a look at the level of education achieved, financial stability and income, and occupational level (Strenze, 2007). An individual's social position at any given time is identified as attained social position (Strenze, 2007).

Human Immunodeficiency Virus (HIV). This term is used interchangeably for the HIV virus and the infection it causes. According to AIDS Info (2013), the HIV virus composed of the following five components:

HIV Envelope. This is the outer surface of HIV.

HIV RNA. This is the genetic material of HIV.

HIV Capsid. This is a bullet-shaped core that contains the RNA of HIV.

HIV Enzymes. These are proteins that carry out the steps in the life cycle of HIV.

HIV Glycoproteins. These are protein "spikes" that are embedded in the envelope of HIV.

Protease. This enzyme is defined by AIDS info (2013) as a protein that breaks up the long protein chains that form the underdeveloped HIV.

CD4 cells. Also, known as helper T cells or CD4 lymphocytes, these are white blood cells that work to fight infections in the body (AIDS Info, 2005). A persons CD4 cell count has a direct impact on their immune system (AIDS Info, 2005). A normal/healthy CD4 count ranges from 500 to 1,400 cells (AIDS Info, 2005). Whenever

a person infected with HIV has a CD4 cell count at or below 200, they are diagnosed as having AIDS (AIDS Info, 2005).

Viral load. The amount of HIV in a sample of blood is known as a viral load (AIDS Info, 2005). The viral load is the quantity of HIV copies per ml of blood (AIDS Info, 2005). As CD4 counts have a range, viral loads have a range as well. Viral load counts range from undetectable or as high as 750,000 (AIDS Info, 2005). Viral loads are used to determine the best options for HAART (AIDS Info, 2005).

Post-exposure prophylaxis (PEP). This term describes a medication treatment involving antiretroviral medications no later than 3 days of a possible exposure to HIV (CDC, 2015a). This helps to reduce the possibility of becoming infected with HIV. PEP can also be used after sexual assaults and for healthcare workers that have been exposed to HIV through infected fluids or needle sticks (CDC, 2015a).

Pre-exposure prophylaxis (PrEP). This term describes a medication treatment that involves taking antiretroviral medications on a daily basis to prevent HIV infection (CDC, 2015a).

HIV progression/clinical progression. Both terms refer to measurements that are observable and diagnosable relating to signs and symptoms, such as CD4 counts and viral loads (AIDS Info, 2011).

Treatment Regimen. This term is interchangeably used with recommended regimen and treatment therapy to describe a structured a treatment plan focused on improving or maintain health and often requires prescription therapy with a combination of HAART from at least two drug classes as a component (AIDS Info, 2011).

Person-years. This is a measurement combining the number of persons and their time contribution in a research study. It is the sum of individual units of time that the persons in the study population have been exposed or at risk to the conditions of interest. It is not the same as persons per year.

The Life Cycle of HIV+

To understand the HIV life cycle, it helps to first understand what HIV looks like.

As noted and illustrated in Figure 1, there are five components that make up the HIV cell.

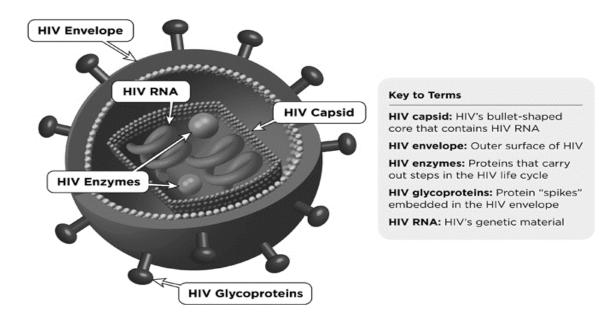


Figure 1. The components of the HIV virus. This figure is an illustration of the major component of the HIV virus and their functions (AIDS Info, 2013).

In order for HIV to spread it must attack and infect CD4 cells as a means of completing its life cycle. AIDS info (2015) and The Body (2013) noted several stages in the life cycle of HIV (Figure 2).

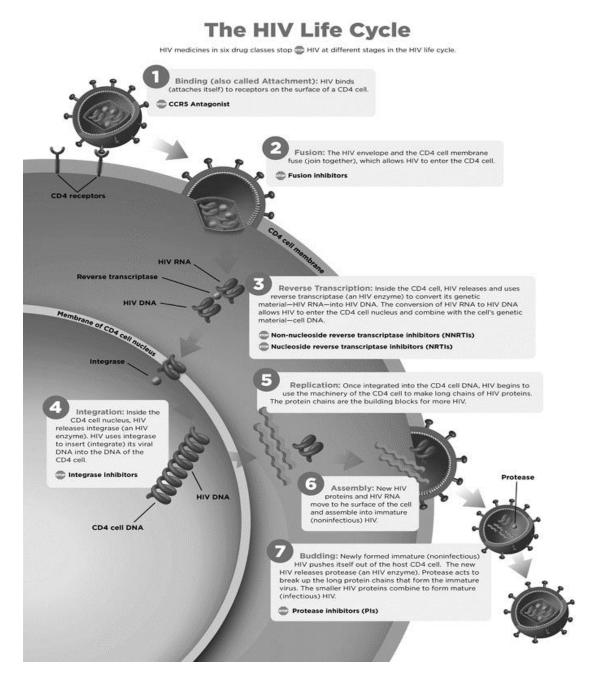


Figure 2. The Life Cycle of HIV. This is an illustration of the seven phases of the life cycle of HIV, a description of what happens during each phase, and the types of medications that block each phase (The Body, 2013).

Assumptions, Scope, Delimitations and Limitations

Assumptions

An assumption that all study participants will honestly answer and complete all of the survey questions is valid since the survey will be administered anonymously.

Although they survey is anonymous, some clients may prefer to answer survey questions in a private setting allowing them the ease and will to answer questions in a more honest manner.

Scope and Delimitations

This study was geared towards male, female, and transgendered African

Americans living with HIV/AIDS who were or are presently taking HAART. They are
receiving some form of medical care for their HIV/AIDS infection, even if it is not

HAART. This study took place in Atlanta, Georgia.

Limitations

Capturing honest and accurate information was a limitation. As previously stated, a mixed methods approach, primarily qualitative, was used for the nature of the research study. Due to the content of the research questions and information that were collected, this approach was most sufficient. This helped to prevent bias.

Qualitative information helped to bridge the gap of knowledge or data collected from the Quantitative data collection tools. Quantitative data consisted of statistics that showed a direct correlation of HAART noncompliance and HAART availability. Data from the survey represented an accurate account of barriers and positive behaviors that resulted in higher HAART rates.

Significance of Study

Adherence is defined as the "active, voluntary, and collaborative involvement of the patient in a mutually acceptable course of behavior to produce a therapeutic result" (Ho, Bryson, & Rumsfield, 2009, p. 3028). The contribution that this study made in filling the gap for data and literature on adherence barriers to HAART is one that allows the use of data from the study to highlight areas of improvement. This was utilized to give insight on methods that reduced barriers for HAART and healthcare of African Americans living with HIV/AIDS. This research impacts professional practice by identifying what barriers exist so that behavior changes were addressed. Furthermore, resources may be implemented to help those persons dealing with this issue to have the knowledge and means to have compliance with their regimen of HAART. Additionally, for the past decade, HIV prevention programs have started to emerge in the public health sector as a means to decrease the spread of HIV infection (Fisher & Fisher, 2006).

Possible causes for medication noncompliance included reasons for medication non-adherence inclusive to the individual being treated, socioeconomic status, type of therapy, condition, and health system—related factors (Osterberg & Blaschke, 2005; Ho et al., 2009). The findings of this research project can lead to positive social changes by allowing African Americans living with HIV/AIDS to have an advanced quality of life and lead to positive change by being able to improve their health. This presented opportunity for these individuals to gain employment, sustain positive relationships, to improve financial stability, present for follow up medical visits, and to even volunteer with local public health agencies that are centered on HIV/AIDS as consumers.

Summary

The impact of HAART adherence reaches beyond the scope of medical care. HAART compliance influences social change and social position, personal and professional relationships, financial stability, and quality of life. Having the ability to identify, reduce or eliminate barriers of HAART adherence is definitely a positive attribute. Knowing that successful HAART impacts clinical progression and, in most cases, extends the longevity of life for persons living with HIV/AIDS on HAART, it is critical that persons needing HAART have access to it and are able to have the tools and resources to be successful while on it.

Chapter 2: Literature Review

Introduction

Granted the pandemic of HIV/AIDS has existed over 30 years, challenges in medical care continue to be cumbersome. This, in part, is due to the fact that health problems vary by race and even by geographic areas. There is a decrease in the overall number of HIV/AIDS cases; unfortunately, the number of African Americans diagnosed with HIV/AIDS has not declined. In fact, Population Reference Bureau (2013) highlighted that more African Americans are living with HIV or have already died from AIDS in the United States than any other racial or ethnic group. While minorities in general are underserved by the AIDS Drug Assistance Program (ADAP), of those minorities; a majority are African American (Horneffer & Yang, 2013).

Highly active anti-retroviral therapy (HAART) has been successful in prolonging life expectancy and decreasing the viral load of HIV in the human body (Cahill & Valadez, 2013), but the use of HAART in the prevention of spreading HIV relies on patient adherence and eliminating co-occurring sexually transmitted infections (Kalichman et al., 2011). Primary care programs that put emphasis on HAART and prevention requires persons to pay close attention to adherence, and sexually transmitted co-infections (Kalichman et al., 2011). African Americans were 2.40 times more likely to be noncompliant with HAART than Whites (Osborn, Paasche-Orlow, Davis, & Wolf, 2007).

The focus of this mixed-methods research was to determine what adherence barriers exist to healthcare for African Americans infected with HIV/AIDS who were on

HAART. This study helped to determine manners in which these barriers are reduced or eliminated, resulting in improved compliance and HAART results.

Literature Search Strategy

Various types of resources were used to obtain information to construct this literature review. Primarily peer-reviewed articles were obtained from databases and search engines: Google Scholar, Academic Search Complete, PubMed, MEDLINE with full text, Health & Medical Complete, Science Direct, ProQuest Central, and the Web of Science. Key search terms individually and/or combinations such as HAART compliance, HAART availability, access to healthcare for persons living with HIV/AIDS and other opportunistic infections, HAART and comorbidities, HIV/AIDS in minorities, the existence of ADAP, the quality of life of persons on HAART, AIDS Drug Assistance Program (ADAP), HAART concerns, HAART cost, HAART financial assistance, HIV/AIDS medical care, infectious disease medical treatment therapy, viral load, and CD4 counts were used for these searches.

Literature Review

Impact of Socioeconomic Status and HAART Compliance

It was important to examine the health status of racial and ethnic subgroups because different social groups, whether defined by marriage, gender, race or ethnicity (Adler & Newman, 2002; Cohen et al., 2007); and even income, education, or region, experience dramatically different levels of health (Cohen et al., 2007). It was important to note that socioeconomic status (SES) is comprised of level of education completed, occupation, financial stability, and income level (Friss & Sellers, 2004), and it is the most

important predictor of health because all of these factors tend to be strongly associated with each other (Schneider, 2006). For example, if children have parents or guardians that are not financially stable, the children are directly impacted because they may lack proper healthcare, housing, and nutrition. Therefore, it is important to make every effort possible to make healthcare not only affordable, but also accessible.

Patient Assistance Programs/AIDS Drug Assistance Program

Although there is no cure for HIV/AIDS, treatments for HIV infection have been successful in extending the lives of persons infected with HIV (Schneiderman, 2001). Medications are not as harsh as they were when they were first introduced. As scientists gained a better understanding of the virus, they were able to develop drugs that would target the various stages of the replication process. Unfortunately, these medications are very costly and the average person may not be able to afford them. However, programs exist that assist people with paying for or getting their medication for little to no costs known as *Patient Assistance Programs* (PAPs).

PAPs are pharmaceutical company plans that provide free medications to low-income, uninsured, and underinsured people who need them. Persons who are eligible to participate in PAPs must qualify. Each program is somewhat different for its specific eligibility criteria. The following are general guidelines for most PAPs: (a) be a U.S. citizen or legal resident; (b) have a doctor or other healthcare provider who can write prescriptions and provide medical care for them; (c) cannot have any health insurance that provides prescription coverage; (d) cannot be eligible for Medicaid, Medi-Cal (in California), AIDS Drug Assistance Program (ADAP), or any other drug assistance

program; and (e) must meet the annual income limits of the specific program (The Body, 2004).

Horneffer and Yang (2013) revealed that due to the expensive nature of HAART medications, ADAPs were created to help offset the high costs of these medications especially for low-income patients. In addition to funding sources such as pharmaceutical vouchers and rebate programs, general revenue by states are needed for the continuation of ADAPs because funds from the federal government no longer propel the program's budgetary growth (Kaiser Family Foundation, 2009). Regrettably, financial support for ADAP has tapered over the past few years resulting in a waitlist for program enrollment, formulary reductions for various medications and reduced coverage for HAART (Horneffer & Yang, 2013). To further complicate issues, ADAPs were being inundated by persons who needed financial assistance, and there was a rapid increase of persons on the ADAP waiting list between the months of January 2010 through May 2011 (Figure 3). The number of persons on this list jumps from 361 to almost 7900 in less than 18 months (Knowledge Ecology International, 2011).

Number of HIV+ persons on ADAP waiting list

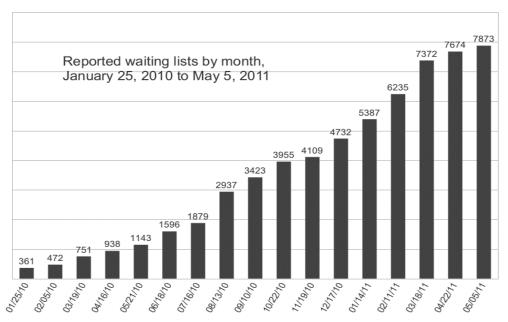


Figure 3. ADAP waiting list enrollment between January 2010 and May 2011. This graphs illustrates the increase in the number of HIV+ patients enrolled on the waiting lists for ADAP (Knowledge Economy International, 2011 Dramatic increase in waiting lists for AIDS Drug Assistance Programs, January 2010 to May 2011. Retrieved from http://keionline.org/node/1128).

As could be expected with a decrease in funding, the length of the waitlist also varies by states, and some states have cost containments measures that limit the amount of funds that are available for ADAPs (Figure 4).

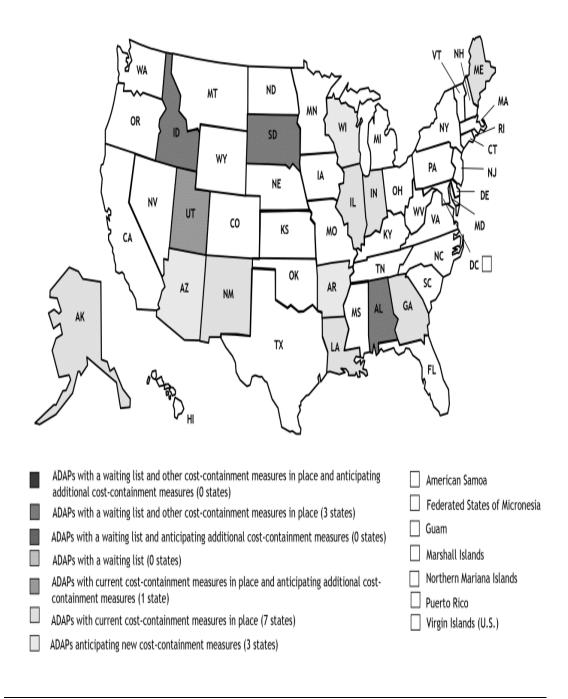


Figure 4. ADAPs by state. This graph illustrates differences by state in ADAPs with waiting lists and/or cost-containment measures (NASTAD, 2013).

With the growth of the ADAP waiting list, there was also a growing differentiation of race/ethnicities who were on the ADAP waiting list as of June 2013, (The National Association of State and Territorial Apprenticeship Directors [NASTAD], 2013) (Figure 5). Approximately 64% of persons on the ADAP waiting list as of June 2013, were African Americans (NASTAD, 2013). This aligned with the excessive prevalence of HIV/AIDS infections amongst African Americans who need HAART. Typically, the higher incidences of HIV infections result in an increased need for persons living with HIV/AIDS who are looking to prolong their life with HAART.

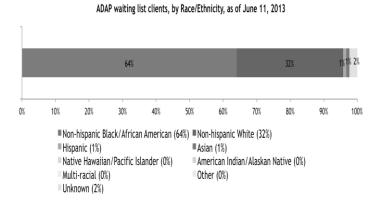


Figure 5. ADAP client waiting list by race/ethnicity as of June 2013. The graph illustrates the percentage of HIV+ patients on ADAP waiting lists by race/ethnicity (NASTAD, 2013).

Numerous academics and policy makers emphasize that those traditionally underserved by ADAP, yet most affected by the HIV/AIDS epidemic, are minorities of African American ethnicity (Horneffer & Yang, 2013). Not having access to ADAP programs can hinder the inception or continued compliance of HAART. Underserved by ADAPs and less likely to have insurance or medical coverage than Caucasians, African

Americans typically receive coverage through Medicaid and may not consider other means to receive HAART (Kahn, 2009).

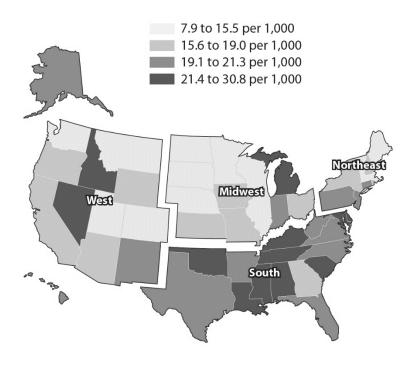
Geographic Factors and HIV/AIDS Infection

Statistics show that ethnic minorities in the United States have significantly higher mortality rates from most diseases than whites (Schneider, 2006). Trending an estimated seven years, diagnosed HIV cases in the south have steadily increased in heterosexual African American women and African American men who have sex with men (MSM) (CDC, 2009; 2011). Despite the implementation of education and prevention programs, HIV/AIDS cases to continue to progressively rise in the South.

Overall, states in the South have a higher mortality rate associated with HIV (Figure 6). With data collected from the National Vital Statistics System and the National HIV/AIDS reporting system, Hanna, Selik, Tang, and Gange (2012) completed a cross-sectional analysis looking at mortality rates of persons infected with HIV living in 37 states between 2001 and 2007 and determined that nine of the ten states with the highest mortality rates were located in the South (Hanna et al., 2012).

Furthermore, age-adjusted rates varied from 9.6 (95% CI 6.8–12.4) in Idaho to 32.9 (95% CI 29.8–36.0) in Mississippi, therefore demonstrating substantial disparities across states, even after adjusting for race/ethnicity (p<0.0001) (Hanna et al., 2012). These interstate differences in rates suggest differentiation in secondary and tertiary prevention of HIV-related mortality among individuals living with HIV and imply that state-specific contextual barriers to care may have a negative impact in quality and disparities of health-care without targeted interventions (Hanna et al., 2012).

Death Rate among People with Diagnosed HIV by State, 2012



Source: Centers for Disease Control and Prevention

Figure 6. Fatality rate per 1,000 persons in 2012. This figure is an illustration of HIV mortality rates by state (Centers for Disease Control and Prevention, 2016).

Another study identified the Southeastern region of the United States as the core of HIV/AIDS infections with HIV infection cases increasing faster than any other national region (Hixson, Omer, del Rio, & Frew, 2011). It is, therefore, important to understand why diseases are more prevalent in certain groups of people in different geographic regions as a means of catering education and behavior modification programs that effectively impact behavior change and could decrease disease infection rates.

Interestingly, Fowler-Brown, Ashkin, Corbie-Smith, Thaker, and Pathman (2006) shared

that minorities living with HIV/AIDS in the Southern region of the United States have higher incidences of isolation and stigmatization. This may cause poor primary care adherence if these persons do not seek treatment because of these emotions and fear of disclosure.

Gender Variances

Gender is a construct that individually and in conjunction with other social factors creates social norms that affect the behavior of men and women, provide various protections and risks related to health, and shape institutional policies and practices that privilege on gender over another (Cohen et al., 2007). Gender norms and values give rise to gender inequalities, or differences between men and women that systematically empower one group to the detriment of the other. Gender roles vary cross-culturally, although the cultures produce particular systems of gender relations that affect life cycles, roles, choices, and often inequalities in health (Lane & Cibula, 1999; WHO, 2014).

In 2010, one in four people infected with HIV in the United States were women (CDC, 2014). Only 50% of women diagnosed were receiving medical care, with 40% having the virus under control (CDC, 2014). Women are more likely to become infected with HIV than men due to (a) a history of previous sexually transmitted infections which increases the likelihood of HIV infection, (b) fear of partner abandonment if she insists on condom use, (c) lack of knowledge about what their partners' HIV infection high risk behaviors are (such as injection drug use or having sex with other men) while engaging in unprotected sex, (d) the risk being higher when engaging in anal sex than vaginal sex

without a condom, and (e) having multiple partners and abusive partners who refuse to use condoms during sex for those who have a prior history of sexual abuse (CDC, 2014).

Previous studies highlight the gender disparities seen in HIV infections rates of white, black, and Hispanic/Latino men and women according to their sexual preference and injectable drug use (IDU) (Figure 7), with white and black MSM had higher infections rates than any other population (CDC, 2010). Oster et al. (2014) notes although the MSM community is at the highest risk of HIV infection; large fringe and central metropolitan areas experienced an elevated HIV rate in the MSM community.

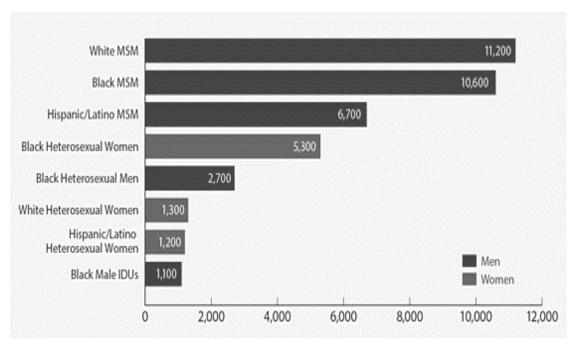


Figure 7. Estimated HIV Infections in the United States for the Most-Affected Subpopulations in 2010. This graph illustrates data obtained from the CDC in 2010 regarding estimated new HIV infections for the most-affected subpopulations (CDC, 2010). Abbreviations: MSM, men who have sex with men; IDU, injection drug user.

A prospective, longitudinal study completed by Heffron et al. (2011) evaluating 3,790 heterosexual HIV-1-*serodiscordant* couples (where one partner is HIV negative and the other is HIV positive) and compared for HIV-1 acquisition by women and HIV-1

transmission from women to men to analyze the implication contraceptive use on HIV-1 risk. The female participants either used condoms, oral and injectable contraceptives or were not using any form of contraception. Rates of HIV acquisition were 6.61 per 100 person-years in women who used hormonal contraception and 3.78 per 100 person-years in those who did not use any form of hormonal contraception in cases where the female was negative for HIV (adjusted hazard ratio 1.98, 95% CI 1.06 -3.68, p = 0.03) (Heffron et al., 2011). Conversely, rates of HIV transmission from women to men were 2.61 per 100 person-years in couples in which women used hormonal contraception and 1.51 per 100 person-years in couples in which women did not use hormonal contraception (adjusted hazard ratio 1.97, 95% CI 1.12—3.45, p = 0.02) (Heffron et al., 2011). The results of this study indicated that behaviors associated with contraceptive use may be a factor in the rate of HIV and STI transmission (Heffron et al., 2011).

Meditz et al. (2011) collected and analyzed data from individuals that were primarily North American cohort of HIV-1 *Seroconverters* (HIV-infected persons who have had a negative antibody test within 3 years of their first antibody positive test). Although women were more advantageous in clinical parameters than men, women experienced more critical outcomes than male seroconverters. Blatant morbidity was supplemental with being nonwhite and residing in the southern United States (Meditz et al., 2011).

When gender is addressed in the HIV/AIDS community, the transgender population is also impacted by the HIV/AIDS pandemic. The term transgender pertains to the gender, not the sexual orientation with which a person identities; transgendered

people can be gay or lesbian, heterosexual, or bisexual (MacKenzie, 1994). There is no national surveillance data currently available on the incidence or prevalence of HIV/AIDS within the U.S. transgender population; however, data collected by local jurisdictions suggest disproportionately high rates of HIV infection among transgender persons.

In 2002, the State of California began recording male-to-female (MTF) and female-to-male (FTM) as gender reporting options in publicly-funded HIV counseling and testing sites. Despite accounting for a small proportion of the population, data collected in 2003 revealed that self-identified transgender clients had a much higher rate of HIV diagnoses (6.3%) than other risk categories, including men who have sex with men (MSM; 4.2%) or partners of people living with HIV (4.8%) (Herbst et al., 2008). This data also revealed that MTF African American transgender clients had a substantially higher rate of HIV diagnoses than all other racial or ethnic groups (Herbst et al., 2008).

A transgendered person's risk for HIV/AIDS from IV drug use is also a concern; however, the extent to which IV drug use is a factor in the transmission of HIV in the transgender community is not clear. HIV infection might be the result of a combination of IV drug use and sexual activity. It is very likely that alcohol and drugs are being used to decrease one's inhibition to engage in high-risk sexual activity (Kenagy, 2002). Lack of AIDS knowledge may also be a risk factor for HIV infection among transgendered people. The amount of information available is limited, but research seems to suggest that MTF transgendered people have lower levels of AIDS knowledge than other non-

transgendered groups (Kok et al., 1990). CDC (2015b) reports grander rates of newly diagnosed HIV infections were among black/African American transgender women (56.3%) versus white (16.7%) or Latina (16.1%) transgender women.

Those identifying as transgender often experiment with their own sexual orientations and attractions. In addition, many are involved in money for sex in an effort to support substance addictions or to make money for the purchase of necessary hormonal therapy. Some reuse or share needles to inject their hormones because of the insurance industry's unwillingness to cover hormonal therapy. Like any population, these sexual behaviors and sharing of needles increase HIV transmission risk (Cichocki, 2007).

HIV prevention efforts must take into consideration the complexity of their sexual orientation. Sexual orientation of transgendered persons is not well documented in the literature and at times seems to be confused with gender identity. Because of disclosure fears and risks, identifying and finding the transgender community is difficult. This in turn makes it difficult to target prevention messages to the transgender community. In addition, prevention messages are often biased according to gender. If one does not identify as that gender, the prevention message may not be received at all (Cichocki, 2007). Public health officials must be able to understand the special needs of this population and make certain that education and prevention efforts are implemented to meet the needs of this particular group.

Disproportionately afflicting minorities, HIV continues to present as a formidable challenge altering the social geography of families across generations (Colasanti, Nguyen, Kiem, Deeb, & Jayaweera, 2012). When a parent is infected with HIV/AIDS,

the quality of their health may have a direct impact on the dynamics of their family.

These dynamics may result in an increased responsibility load for children in the home.

Similarly, children living with HIV/AIDS may have unique barriers of their own.

Children and HAART

To date, few studies have been conducted relating to children and HAART and not much is known about specific barriers or successes for HAART among children. Buchanan et al. (2012) completed a longitudinal sub-study of a multicenter cohort study between 2000 and 2007 in the Unites States that tracked HIV-infected and uninfected, perinatally HIV-exposed children between the ages of 8 years and 19 years old and focused on the perceptions of caregivers and barriers associated with HAART adherence for the HIV positive youth and children they are caring for (Buchanan et al., 2012). The researchers noted anytime nonadherence ensues after an HIV/AIDS diagnosis and the start of HAART, there was a high probability of treatment failure and even resistance. Because children depend on someone else to assist with their HAART, they experience different barriers (Figure 8) than many adults (Figure 9), with logistic issues being the most common barrier reported by both (Buchanan et al., 2012). This early experience with nonadherence is a concern as it opens the door for swift disease progression and other possible health issues (Buchanan et al., 2012). Limitations with this study were that the surveys completed did not specifically mention HIV/AIDS medications or HIV/AIDS status, so it is a possibility that children included non-HAART medications in answering their questions (Buchanan et al., 2012).

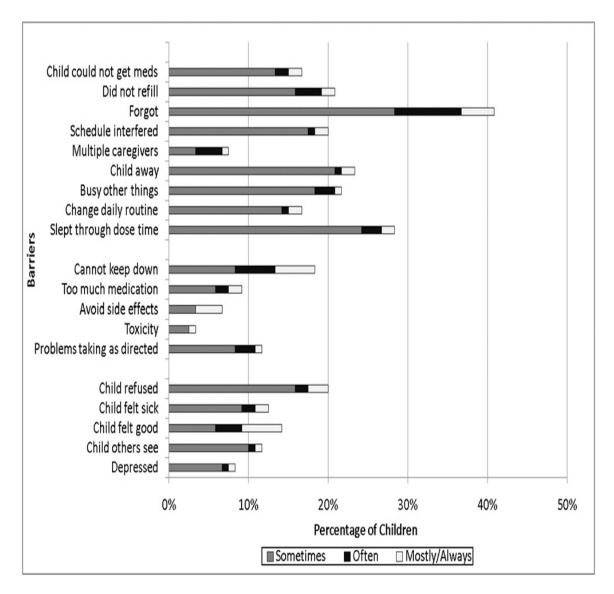


Figure 8. Child-reported barriers to adherence. This graph is an illustration of the types of barriers reported by children and their relative frequency (in percentage). Most children forgot to take their medication, with the second most common barrier being oversleeping (Buchanan et al., 2012).

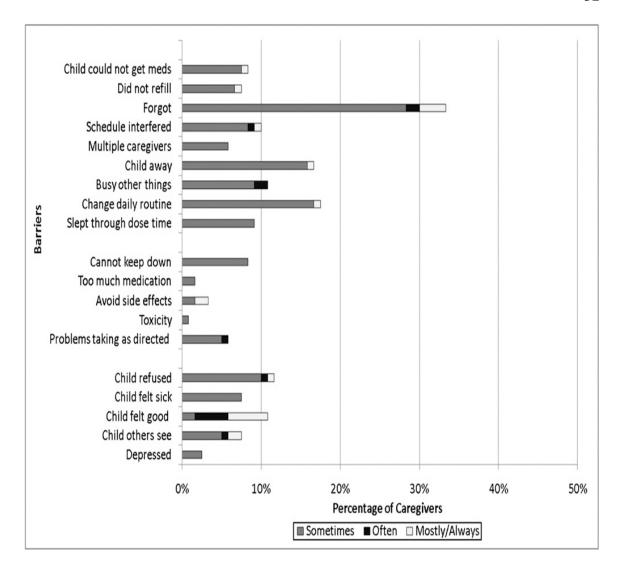


Figure 9. Caregiver-reported barriers to adherence. This graph is an illustration of the types of barriers reported by adults and their relative frequency (in percentage). Most adults forgot to give their children medication, with the second most common barrier being a change in the daily routine (Buchanan et al., 2012).

Guidelines for Implementing HAART

In general, persons living with HIV/AIDS are either treatment-naïve or treatment-experienced. *Treatment-naïve* refers to a person living with HIV/AIDS that has never been on HAART, while *treatment-experienced* refers to a person living with HIV/AIDS that has been on, or is currently taking HAART (AIDS Info, 2011). It has been shown

that early treatment with HAART is very effective in treating persons living with HIV/AIDS (Gulick, 2010). In fact, since the introduction of HAART, there has been a significant decrease in the number of persons dying from AIDS-related deaths (Figure 10).

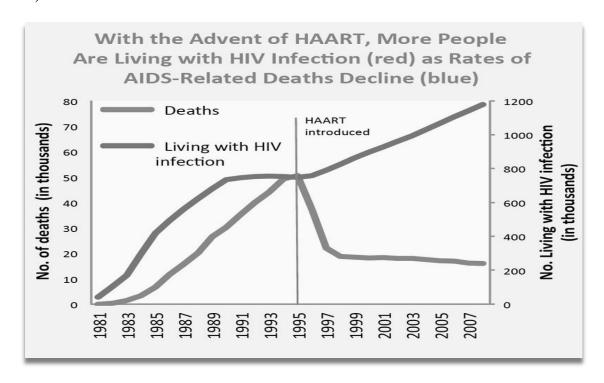


Figure 10. Number of HIV related deaths and number of persons living with HIV, 1981-2007. This figure illustrates the impact of HAART treatment on HIV infection and AIDS-related deaths (National Institute of Drug Abuse, 2012).

Modified clinical guidelines for initiating HAART earlier in the course of HIV infection have shown benefits relating to improved health and decrease of illness occurrences (Department of Health and Human Services [DHHS], 2011). These modified guidelines, which were implemented in 2013, encourage an earlier start on HAART and directly impacted the number of persons eligible for HAART to increase to 9.2 million (AVERting HIV and AIDS [AVERT], 2014). Morin et al. (2011) emphasized guidelines

for initiating HAART have also shifted toward commencing prescription therapy at higher CD4 cell counts, with the goal of total HIV viral suppression, also known as an undetectable viral load.

As of lately, many clinicians agreed HAART should be recommended for all HIV-infected individuals, irrespective of their clinical status, at the time of diagnosis in order to improve long-term health outcomes (DHHS, 2011).

Mills et al. (2006) stated the following:

Adherence to antiretroviral therapy is a powerful predictor of survival for individuals living with human immunodeficiency virus (HIV) and AIDS. HAART adherence of 95% is a target goal; however, HAART adherence is much lower....

Concerns about incomplete adherence among patients living in poverty have been an important consideration in expanding the access to antiretroviral therapy. (p. 679)

Unfortunately, while clinicians and researchers are aware of the importance of early medical care and HAART, not all HIV infected persons share those feelings and place emphasis on the disadvantages of HAART (Beer et al., 2012). Therefore, it is imperative that clinicians providing medical care to persons on HAART discuss any issues with mistrust of the medical system and religious beliefs that may impact compliance (Gaston & Alleyne-Green, 2012). Another possible reason for noncompliance is complexity of treatment. Stone et al. (2001) noted there is a greater rate of self-reported adherence among persons whose HAART is less complicated than other prescription therapy. The more complex a person's HAART is, the less likely they are to

grasp details of all of the components of HAART. The HIV Causal Collaboration (2011) documented that persons who are compliant with their prescription regimen experience a higher rate of healthy living and lower healthcare expenses during their lifetime since they are less likely to access medical care than those persons who are less compliant with their prescription regimen (Fleishman et al., 2010). Likewise, Kelly and Kalichman (2002) acknowledged HAART nonadherence destabilizes the possibility of reduction in HIV transmission.

Comorbidities & HIV/AIDS Infection

Persons living with HIV/AIDS, who are co-infected with other communicable diseases, have a higher probability of a decline in their CD4 cells. Kelly and Kalichman (2002) highlighted that secondary preventive efforts are focused on preventing any occurrence of opportunistic infections and adverse events for persons living with HIV/AIDS. Taye and Lakew (2013) demonstrated that co-infection with Hepatitis C (HCV) resulted in a rapid decrease of a person's CD4 and CD8 cells; higher CD4 and CD8 counts typically mean that a person is healthier and less likely to be as sick. Adherence to HAART decreases the likelihood of lower CD4 and CD8 counts (Taye & Lakew, 2013).

Theoretical Foundation

For this study, the health belief model (HBM) was the theoretical framework.

This model was applicable because an individual's perceptions and/ or beliefs had a direct impact on strategies that may decrease disease occurrence (Glanz et al., 2002).

These perceptions included seriousness, benefits, barriers and susceptibility (Glanz et al.,

2002). The aforementioned perceptions had a positive or negative influence on a person's health. Individuals who are living with HIV/AIDS who were on HAART may have looked at this part of their medical care as either beneficial or harmful, due to some of the possible side effects of the medication. Any negative perceptions reduced compliance with HAART.

The HBM was developed in the 1950s as a method to describe why medical screening programs offered by the U.S. Public Health Service were having poor success rates (Hochbaum, 1958). The HBM is the most utilized theory in health education and health promotion (Glanz et al., 2002; National Cancer Institute [NCI], 2003). eMedOnline (2012) incorporated theoretical models that define health beliefs and behaviors associated to adherence, which is defined as compliance plus persistency, to create a telehealth platform involving medication and disease presentation; illness representation; individual difference; medication adherence; cognitive function; and external cues (Figure 11).

The platform focused on the perception of threats posed by the disease; belief that adherence ameliorated the risk; complexity, interval, safety, efficacy, accessibility and financial impact of medication; and patient-doctor relationship, and it highlights concerns of a patient's sense of participation in being empowered about decisions impacting their

therapy (EMedonline, 2012).

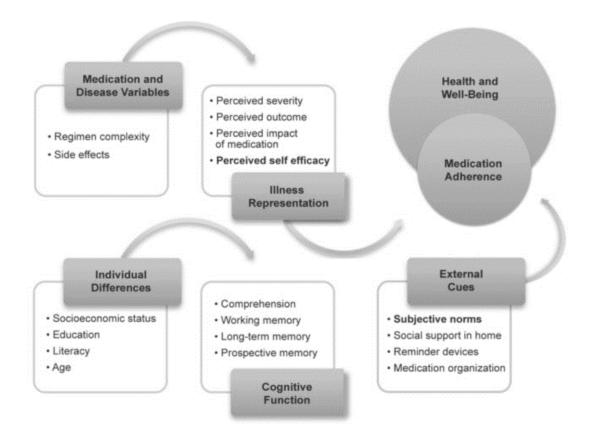


Figure 11. Medication adherence telehealth platform. This figure demonstrates health beliefs and behaviors associated to adherence (eMedOnline, 2012).

Schneiderman (1999) stated psychosocial treatment studies provide a method for conducting causal investigations within a clinical environment. They can also inform the researcher about relationships between psychosocial or bio-behavioral processes on the one hand and disease on the other. Stone (2011) highlighted that minorities have a very low rate of medical care and HAART compliance than others living with HIV/AIDS; some of the barriers facing minorities living with HIV/AIDS that impact their adherence values are (a) lack of financial stability, (b) side effects of the medication, (c) mobility,

(d) mental health and substance abuse issues, (e) expediency, and (f) poor support team of family and friends (Konkle-Parker et al.,2 007). Therefore, a qualitative approach to understand these barriers is equally necessary.

Summary

Although interest in the global expansion of HAART under the context of HIV treatment as prevention (TasP) has been reintroduced, a population-level sustainability of this strategy has not been documented (Julio et al., 2014). Rodrigues (2008) noted the Global Leadership against HIV/AIDS, Tuberculosis, and Malaria Reauthorization Act of 2008 was signed to allocate a sum of \$50 billion to the President's Emergency Plan for AIDS Relief (PEPFAR) and other health programs. There must be proper use of funds in order to reach the masses of people that need treatment.

Proper healthcare and compliance with HAART, safer sex methods and behavior changes are all ways to reduce the harsh impact that HIV/AIDS can have upon the human body. Previous research studies already revealed that expanding HAART has contributed to a decrease in morbidity, mortality and HIV transmission (Julio et al., 2014), but Reed at al. (2009) shares that 28% of HIV infected persons from 18 states during 2000 and 2004, were not linked to care within three month of finding out their HIV stats. This is considered delayed entry into care. Entrance into care needs to be as easy as possible.

This failure to link patients to care is of concern, because it has shown that the sooner that a person with HIV/AIDS starts HAART, the more likely they are to improve their health and prevent additional comorbidities or a decline in CD4 counts or increase in viral loads (Beer et al, 2012). While HAART enrollment and compliance is an issue

for a number of reasons previously discussed (e.g., location of medical facility, enrollment requirements, and financial cost play a vital role in adherence), this is a particular challenge when one considers the many disparities faced by the African American community.

As previously discussed in this chapter, Population Reference Bureau (2013) highlighted that more African Americans are living with HIV or have already died from AIDS in the United States than any other racial or ethnic group. Minorities, especially African Americans, are underserved by the AIDS Drug Assistance Program (ADAP) (Horneffer & Yang, 2013), and continue to experience significant imbalances in medical care, linkage to care, and HAART implementation (Stone et al., 2009). The current themes in the literature pertaining to African Americans and HAART compliance resonate with the commonalities of barriers being access to care, financial concerns, comorbidities, and poor behavior choices that increase the risk of HAART success due to other lifestyle issues such as drugs, or homelessness.

Recent procedures such as testing and treating early on when a person is diagnosed with HIV, focusing on linkage to care, retention of medical care, and prevention hold great promise for women and minorities with HIV in the U.S. (Stone, 2011). Although these forms of intervention are promising, Morin et al. (2011) communicated that implementing multilevel interventions and evaluation of the HIV/AIDS epidemic impact poses challenges to traditional research paradigms because they do not consider evaluation and efficiency of studies that respond to implementation challenges (Morin et al., 2011). This study filled the gap in terms of implementation

challenges that may be thwarting multilevel interventions by identifying adherence barriers to healthcare for African Americans with HIV/AIDS on antiretroviral medications.

Chapter 3: Research Method

Introduction

The findings of this research project can lead to social changes by affording African Americans living with HIV/AIDS an advanced quality of life. This spearheaded change by being able to improve their health through access to healthcare by proposing solutions capable of limiting barriers affecting their compliance with their planned treatment regimen. This presented opportunity for these individuals to gain employment, sustain relationships, improve financial stability, be present for follow up medical visits, and volunteer with local public health agencies that are geared towards persons infected with HIV/AIDS as consumers. Having the capacity to be an asset and productive citizen in their community had a ripple effect when their family, friends or coworkers see this behavior that led to a positive economic impact as well. Individually and collectively these indicators impacted social change in a progressive manner.

Setting of the Study

AID Atlanta, Inc. and Fulton County Health and Wellness are the two nonprofit agencies that will be essential in conducting this research. Servicing persons living with HIV/AIDS since its inception in 1982, AID Atlanta, Inc. continues to prove itself as a leader in the battle against HIV/AIDS in metropolitan Atlanta and is the Southeast's oldest, largest, and most comprehensive AIDS Service Organization (ASO) (AID Atlanta, Inc., 2014). The mission of AID Atlanta, Inc. is to reduce new HIV infections and improve the quality of life of its members and the community by breaking barriers and building community by providing primary healthcare services, AIDS Drug

Assistance Program (ADAP) assistance, case management, a linkage and retention to care program, and educational programs (AID Atlanta Inc., 2014).

Fulton County Health and Wellness HIV/AIDS Primary Care Clinic is a Ryan White funded public health center that offers services for persons living with HIV (Fulton County Georgia, 2011). Services at the clinic range from primary medical care services, dental services, case management, ADAP assistance, educational and behavioral health services, Tuberculosis screening and treatment, STD medical care screening and treatment, and linkage and retention services (Fulton County Georgia, 2011). At present their primary care clinic has more than 1,100 active clients who receive services.

Surveys were given to study participants at ADAP appointments and medical visits. I escorted study participants to a private exam room or clinician office to complete their surveys. All surveys were collected by me daily.

Research Design and Rationale

By using mixed methods, I was able to collect data from surveys that participants completed, and was able to analyze data inclusive of multilevel perspectives. I collected quantitative and qualitative data concurrently; I used the convergent mixed-method design. I chose this type because I analyzed the two data sets separately and then merged the results during interpretation.

Overall, I chose this method to capture multidimensional intelligence that produced a well-defined understanding of HAART compliance through data on behaviors, emotions and existing barriers. My study benefited from both of these

methods, which is why I selected the mixed methods route using primarily qualitative methods.

Research Questions and Hypotheses

There were four research questions in this study: two qualitative and two quantitative. The qualitative questions encompassed information that the clients shared about barriers to HAART and what their personal experiences have been.

The quantitative questions focused on the level of compliance with HAART and medical care. The quantitative questions helped to generate additional responses that further supported the qualitative research element of this study.

Qualitative Research Questions

- **RQ 1.** What are the barriers causing African Americans living who with HIV/AIDS to have lower adherence rates with HAART than persons of other ethnic groups?
- **RQ 2.** How can barriers for medical treatment of African Americans living with HIV/AIDS be eliminated?

Quantitative Research Questions

RQ 3. Will attending two primary care visits within six months of being linked to care increase the rate of compliance for African Americans on HAART living with HIV/AIDS?

 H_01 : Attending two primary care visits within six months of being linked to care will not increase the rate of compliance for African Americans on HAART living with HIV/AIDS.

- $H_{\rm A}1$: Attending two primary care visits within six months of being linked to care will increase the rate of compliance for African Americans on HAART living with HIV/AIDS.
- **RQ 4.** Will African Americans living with HIV/AIDS who have been out of care for 12 or more months have a low linkage to care rate?
 - H_02 : African Americans that have been out of care for 12 or more months while living with HIV/AIDS will not have a low linkage to care rate.
 - H_A 2: African Americans that have been out of care for 12 or more months while living with HIV/AIDS will have a low linkage to care rate.

Concept of Study

The central concept of this study was being successfully linked to care may have a direct impact on HAART compliance and retention to care. If successful, a person living with HIV/AIDS will have a better quality of life due to improved health, and, in turn, will be able to have more productive lives and have an impact on positive social change. As far as HAART is concerned though, several variables have a potential impact on HAART compliance as it relates to the concept of this study (Figure 12).

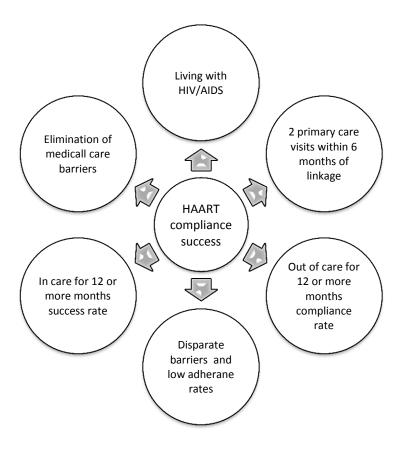


Figure 12. Concept of study variables that may impact HAART. The graph represents the different variables that may affect a person's decision to remain compliant with HAART treatment following a diagnosis of HIV+ and subsequent enrollment in HAART regimen.

Role of the Researcher

I served as the investigator in this research study. As the investigator, I had a direct encounter with clients by asking them to complete surveys and by collecting the surveys when participants completed them each day. When a study participant agreed to participate in the research study, I escorted them to a private office and gave them the consent form to read and study survey to complete. If desired, study participants kept a

copy of the consent form. My relationship with the clients remained professional at all times.

As a manager working at the Fulton County Health and Wellness HIV/AIDS

Primary Care Clinic, part of my duties was to manage the day to day operations in the clinic. This included working closely with physicians, physician assistants, nurses, behavioral health clinicians, a psychologist, case managers and ADAP coordinators. I did not have any personal relationships with any of the clients. Their role as a participant had no direct impact on their day to day work functions or professional expectations and duties. The outcome and validity of data collected was not impacted by the role of anyone at the Fulton County Health and Wellness HIV/AIDS Primary Care Clinic. Once the study concluded all completed surveys were stored in a locked file cabinet and will remain there for five years, as required, and then they will be destroyed.

Methodology

Participant Selection Logic

Maxwell (1997) shares that purposive sampling is a sampling type by which "particular settings, persons, or events are deliberately selected for the important information they can provide that cannot be gotten as well from other choices" (p. 87). The target population for this study was 45-55 African Americans living with HIV/AIDS that have been, or are taking HAART and that are presently receiving medical care for their HIV/AIDS. The sampling strategy used was to identify clients who were on ADAP and coming into the clinic for their 6-month recertification visit. Additionally, the selection logic was designed to address the qualitative focus and collect limited data on

the quantitative elements of the study that will influence qualitative findings. There were some quantitative questions that were not answered unless "yes" was a response. These questions led to answers that supported qualitative data findings of this research study.

The criteria for participant selection were that a person must be infected with HIV/AIDS. In order to be a patient at the Ryan White clinic or AID Atlanta, Inc. a person had to be infected with HIV or have an AIDS diagnosis. Clients also had to be (a) receiving medical care for their HIV infection, (b) 18 years of age or older, and (c) be HAART experienced. With the new recommendations of the implementation of HAART almost all of the clients at these two clinics had HAART experience. The relationship between saturation and sample size was not a major concern. Saturation happened due to the nature of the study participants being infected with HIV/AIDS and having some sort of experience with HAART.

Instrumentation

Quantitative/Qualitative Components

Excluding demographic information, the survey tool (Appendix A) consisted of 12 questions that study participants answered. There were two open ended (qualitative) questions and 10 multiple choice questions (quantitative). The quantitative questions supported the qualitative focus of this research study. The multiple-choice questions helped to identify any trends in the collected data. Based upon this mixed use of questions, a mixed method analysis was appropriate. I used the Southeast AIDS Training and Education Center (SEATEC) survey for the Georgia Statewide Client Satisfaction survey as a reference in creating my survey.

The SEATEC survey was administered at AIDS service organizations around Georgia, including Fulton County Health & Wellness and AID Atlanta, Inc. Given the wide use of this survey, it was safe to assume the original survey tool was tested for validity and reliability before allowing agencies to use it in order to collect data from their clients. All electronic and paper survey data collected by SEATEC was cleaned and analyzed in aggregate and by agency using IBM SPSS (version 21.0) and Microsoft Excel (version 2013).

The self-administered survey (a) required less time than face to face interviews, (b) was cost efficient, (c) allowed the client privacy assurance, and (d) encouraged clients to answer delicate personal questions (Singleton & Straits, 2002).

Participation and Data Collection

Case managers and ADAP coordinators had daily appointments scheduled with clients living with HIV/AIDS. At these appointments, AID Atlanta, Inc. case managers and ADAP coordinators assisted in passing out flyers for the research study. These flyers had my contact information and information about the study on it. Each participant completed a consent form acknowledging their willingness to participate in this study by completing the survey. When a study participant agreed to participate in the research study, I placed them in a private office and gave them the consent form to read and study survey to complete. If desired, study participants kept a copy of the consent form. The consent form was the cover page for the survey. I was always available to discuss the study and collect data onsite for all study participants.

I will keep all raw data and completed surveys in a locked file cabinet in my home office for five years. No follow up contact is needed with the study participants. All of the data was collected and put into SPSS and analyzed I collected both quantitative and qualitative data concurrently (parallel form).

Threats to Validity

SEATEC had previously tested the original survey for reliability and validity. The only possible threat of validity in this research study may be clients not completing every question of the survey. The importance of this will be stressed at the beginning of the survey and again, after the clients finishes the survey. They will be asked to ensure each question has been answered. Talbert (2007) noted that research studies steered to assess behaviors are most effective for quantitative analysis of descriptive data.

Furthermore, threats to internal validity will be eliminated because there will be no design contamination with the survey. Compensatory rivalry will not be an issue because there will be no goods or services exchanged for study participation, and selection criteria will not change. Threats to external validity will be reduced because there will be no selection bias, experimental treatment, or physical performance experiments conducted.

Ethical Procedures

Ethical procedures of this research study were to ensure that each survey completed was anonymous and that no identifying information was captured as part of the survey. Laws and policies were in place to help protect the health of all persons by controlling the occurrence of diseases and prevention and treatment for the masses.

I obtained approval from the Walden University Institutional Review Boards (IRB #07-12-16-0134863) and letters of cooperation from the target agencies (Appendix B & C) prior to collecting any data. There was a cover page to the survey that served as the consent page. This page told the clients about the survey, what their results are to be used for and to obtain their consent. The survey was anonymous. I did not use this survey to report HIV/AIDS status or diagnosis. There were no physical or mental risks to any of the survey participants. Study participants were not asked to take any additional medications than what they were currently taking in their HAART regimen. Additionally, no study participants were asked or required to start taking HAART for participation in this study. Data collected will be kept in a locked file cabinet and I will be the only person with access to the completed surveys.

Data Analysis Plan

The selected data analysis describes the statistical procedure utilized to answer the research questions selected for this study. The data collected for this single research study was qualitative and quantitative in nature. Creswell (2009) noted the use of mixing data sets will allow a clearer understanding of the research problem than if just one was used alone.

Once all completed surveys had been received, I organized the data. Qualitative and quantitative data was separated. Serving as the primary component of this study, I analyzed my qualitative data results from both open-ended questions by grouping results into themes. I looked for similarities and differences to assess if there was a significant relationship between disparate barriers of HAART adherence rates and barriers for

medical care. Each response was given a code making it possible to analyze the frequency of repeated answers. I coded the common answers by name and group/code the less common answers as "other."

Being able to capture responses to open ended questions on the survey tool did not present a problem with this program. The open ended qualitative questions asked about barriers they have experienced that interfered with their medical care and compliance to their HAART regimen.

Upon the completion of data collection and evaluation, quantitative data was imported into SPSS (version 21.0) software program. To ensure the process of importing data was successful, all imported data was verified by data cleaning to ensure the validity of data. Nominal data such as gender was assigned a numeric value for analysis. The gender selections included male, female, and transgender.

Descriptive statistics in latest version SPSS (version 21.0) software program was used in order to analyze data collected from study participants. SPSS (version 21.0) was utilized to perform multiple linear regression analyses that will measure the impact of HAART compliance, linkage to care rates, and existing barriers. Hypothesis testing was conducted using linear multiple regression as well to show the degree of dependent variables and the prediction of independent variables.

Survey Design

Qualitative Research Questions

RQ 1. What are the barriers causing African Americans living who with HIV/AIDS to have lower adherence rates with HAART than persons of other ethnic groups?

- Survey question #7 asks the participant what options/barriers caused then to stop HAART.
- Survey question #10 asks the participant to share what barriers interfere with their medical care.
- **RQ 2.** How can barriers for medical treatment of African Americans living with HIV/AIDS be eliminated?
 - Survey question #10 asks the participant to share what barriers interfere with their medical care.
 - Survey question #11 asks the study participants can barriers for medical treatment for HIV/AIDS be eliminated.
 - Survey question #12 asks the participant are they pleased with their prescription therapy they are taking at the moment.

Quantitative Research Questions

- RQ 3. Will attending two primary care visits within six months of being linked to care increase the rate of compliance for African Americans on HAART living with HIV/AIDS?
 - Survey question #1 asks how long has a participant been in medical care for HIV.
 - Survey question #2 asks the participant how long have they been on HAART.
 - Survey question #8 asks the participant have they been able to attend two primary care visits within the past six months.

RQ 4. Will African Americans living with HIV/AIDS who have been out of care for 12 or more months have a low linkage to care success rate?

- Survey question #2 asks the participant how long have they been on prescription therapy (HAART).
- Survey question #3 asks the individual have they ever been out of care for more than 12 months.
- Survey questions #4 and #5 are only answered if the participant said yes to survey question #3.
- Survey question #6 asks the participants if being in medical care on a regular basis (at least 12 months) helped with HAART compliance.
- Survey question #8 asks the participant have they attended 2 primary care visits within the past 12 months.

Summary

This chapter focused on the use of the mixed research methodology for this particular research study. The logic of this study assessed the impact of barriers to HAART compliance and linkage to care for persons infected with HIV/AIDS. This chapter focused on the setting of the study, theoretical foundation, research design and rationale, role of the researcher in the study, methodology, collecting my own data, threats to validity, and ethical procedures that must be considered.

Chapter 4 will focus on data collection, data analysis, study results and trustworthiness. Chapter 5 will have topics of discussion, conclusions, and

recommendations on HAART, ways to improve linkage to care, eliminating, and reducing barriers to HAART and medical care.

Chapter 4: Results

Introduction

The main objective of this research study was to determine what where the existing adherence barriers to healthcare for African Americans with HIV/AIDS that were taking HAART. I assessed a group of adult minorities living with HIV/AIDS that were taking HAART. I investigated how existing barriers have impacted adherence to HAART. The purpose of Chapter 4 is to present the results of statistical analyses from the data collected using the research design presented in Chapter 3. In this particular chapter, I will describe the findings of this mixed methods approach, primarily qualitative study, question by question. I will discuss the interpretation of the study results, conclusions and recommendations for further research in Chapter 5.

Research Questions and Hypotheses

The study was conducted to answer the following research questions and test the hypotheses of the questions.

Qualitative Research Questions

- **RQ1.** What are the barriers causing African Americans living with HIV/AIDS to have lower adherence rates with HAART than persons of other ethnic groups?
- **RQ2**. How can barriers for medical treatment of African Americans living with HIV/AIDS be eliminated?

Quantitative Research Questions

RQ3. Will attending two primary care visits within six months of being linked to care increase the rate of compliance for African Americans on HAART living with HIV/AIDS?

 H_01 : Attending two primary care visits within six months of being linked to care will not increase the rate of compliance for African Americans on HAART living with HIV/AIDS.

 $H_{\rm A}1$: Attending two primary care visits within six months of being linked to care will increase the rate of compliance for African Americans on HAART living with HIV/AIDS.

RQ4. Will African Americans living with HIV/AIDS who have been out of care for 12 or more months have a low linkage to care rate?

 H_02 : African Americans that have been out of care for 12 or more months while living with HIV/AIDS will not have a low linkage to care rate.

 H_A 2: African Americans that have been out of care for 12 or more months while living with HIV/AIDS will have a low linkage to care rate.

Community Partners and Setting of the Research Study

AID Atlanta, Inc. and Fulton County Health & Wellness are the two nonprofit agencies that were essential in conducting this research. Servicing persons living with HIV/AIDS since its inception in 1982, AID Atlanta, Inc. continues to prove itself as a leader in the battle against HIV/AIDS in metropolitan Atlanta and is the Southeast's oldest, largest, and most comprehensive AIDS Service Organization (ASO) (AID

Atlanta, Inc., 2014). The mission of AID Atlanta, Inc. is to reduce new HIV infections and improve the quality of life of its members and the community by breaking barriers and building community by providing primary healthcare services, AIDS Drug Assistance Program (ADAP) assistance, case management, a linkage and retention to care program, and educational programs (AID Atlanta Inc., 2014).

Fulton County Health and Wellness HIV/AIDS Primary Care Clinic is a Ryan White funded public health center that offers services for persons living with HIV (Fulton County Georgia, 2011). Services at the clinic range from primary medical care services, HAART, dental services, case management, ADAP assistance, educational and behavioral health services, Tuberculosis screening and treatment, STD medical care screening and treatment, and linkage and retention services (Fulton County Georgia, 2011).

Data Collection

Case managers and ADAP coordinators had daily appointments scheduled with clients living with HIV/AIDS. At these appointments, AID Atlanta, Inc. case managers and ADAP coordinators assisted in passing out flyers for the research study. These flyers had my contact information and information about the research study on it.

When a study participant spoke to me face to face, or contacted me and agreed to participate in the research study, they were placed in a private office and were given a consent form to read that explained the qualifications for participants, the purpose of the study, procedures and duration, sample questions, volunteer nature of the study, risks and benefits of being in the study, lack of payment compensation, privacy, and contact

information. The participant consent form acknowledged their agreement to participant in the study. If desired, study participants kept a copy of the consent form. This consent form was the cover page for the survey. Once the study participants gave their consent to participate they were given an anonymous survey to complete. Once the surveys were completed, I collected them and placed them in a locked file cabinet daily. No one else had access to the surveys.

Data Analysis

This data analysis plan explains the results of descriptive statistics and linear regressions that was used to answer the research questions selected for this study. The data collected for this single research study was qualitative and quantitative in nature. Once all completed surveys were received, I organized the data. Qualitative and quantitative data was separated. Serving as the primary component of my study, I analyzed my qualitative data results from both open-ended questions by grouping results into themes. In order to analyze the qualitative data to this survey I tracked themes in which there was a repetition of words. These were words that the survey respondents used a lot to answer the survey questions.

Using SPSS (version 21), I was able to generate a list of all the unique words in a text and I counted the amount of times each word occurred. Having a word frequency list made it very straightforward to look at the categories that were forming from the theme word frequency. I looked for similarities and differences to assess if there is a significant relationship between disparate barriers of HAART adherence rates and barriers for medical care. Each response was given a code making it possible to analyze the

frequency of repeated answers. I coded the common answers by name and group code the less common answers were coded as "other."

Upon the completion of data collection and evaluation, quantitative data was imported into SPSS (version 21.0) software program. To ensure the process of importing data was successful, all imported data was verified and cleaned to ensure the validity of data. I used descriptive statistics in SPSS (version 21.0) software program in order to analyze data collected from study participants. SPSS (version 21.0) was utilized to perform multiple linear regression analyses on quantitative data that measured the impact of HAART compliance, linkage to care rates, and existing barriers.

Descriptive Statistics Demographics of Study Participants

The target population for this study was African Americans living with HIV/AIDS that have been, or are taking HAART and presently receiving medical care for their HIV/AIDS. In order to be a patient at the Ryan White clinic or AID Atlanta, Inc. a person had to be infected with HIV or have an AIDS diagnosis. Clients must also have been (a) receiving medical care for their HIV infection, (b) 18 years of age or older, and (c) be HAART experienced.

Gender, Age and Marital Status of Study Participants

Of the 51 study participant's a majority, 30 (58.8%), were male. There were 15 (29.4%) female and 6 (11.8%) transgender study participants (Table 1). The age of study participants ranged from 18 years of age to persons 60 and above (Figure 13). The majority of study participants (n = 19) were between the ages 30-39 years (37.3%), followed by 14 participants between 40-49 years of age (27.5%) (Figure 13). Shown in

Table 2 and Figure 14, the majority of the study participants (n=34; 66.7%) were single followed by married (n=9; 17.6%).

Table 1

Gender of Study Participants

XX 71 .	•		1 0
What	18	vour	gender?
, , mar	10	, 0 41	genaer.

		Frequency	Percent	Valid Percent	
	Male	30	58.8		
Valid	Female	15	29.4		
Valid	Transgender	6	11.8		
	Total	51	100.0		

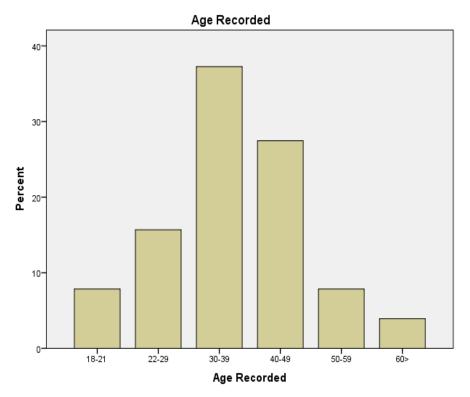


Figure 13. Age in years of study participants.

Table 2

Marital Status of Study Participants

What is your marital status?

		Frequency	Percent	
	Single	34	66.7	
	Married	9	17.6	
Wali d	Widowed	3	5.9	
Valid	Divorced	3	5.9	
	Separated	2	3.9	
	Total	51	100.0	

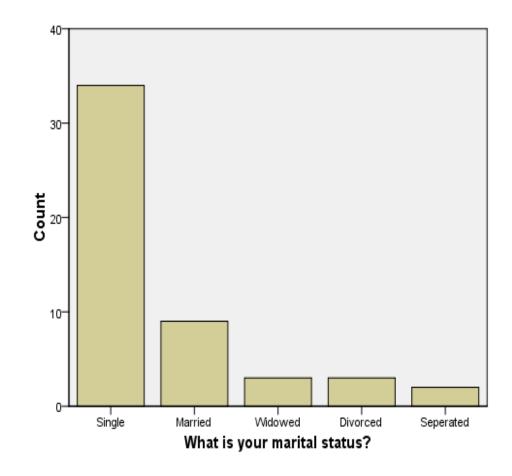


Figure 14. Marital status of study participants

Medical Care and Prescription Therapy Experience

Medical Care Duration

Thirteen study participants (25.5%) had been in care 6-10 years, followed by 12 participants (23.5%) that had been in care 3-5 years. An equal number (10) of study participants had been in medical care 3-5 years and 16 or more years (Table 3). In care 16 or more years were 6 of 51 study participants (Table 3).

Table 3.

Duration of medical care in years

How long have you been in medical care?

		rong nave j		
		Frequency	Percent	-
	1-2	12	23.5	-
	3-5	10	19.6	
3 7 1' 1	6-10	13	25.5	
Valid	11-15	6	11.8	
	16 or more	10	19.6	
	Total	51	100.0	

Prescription Therapy Experience

Looking at the duration of prescription therapy for study participants, Table 4 and Figure 15, show that majority of study participants, 16 participants (31.4%), were on prescription therapy 1-2 years, followed by 12 participants (23.5%) that were on prescription therapy 3-5 years. Comparing these statistics with the 7 participants (13.7%) on prescription therapy 16 or more years, there is a large gap of approximately 24% between those that were on prescription therapy the shortest and longest duration.

Table 4

Duration of prescription therapy experience in years

How long have you been on prescription therapy?

		Frequency	Percent	
	1-2	16	31.4	
	3-5	12	23.5	
V al: d	6-10	7	13.7	
Valid	11-15	9	17.6	
	16 or more	7	13.7	
	Total	51	100.0	

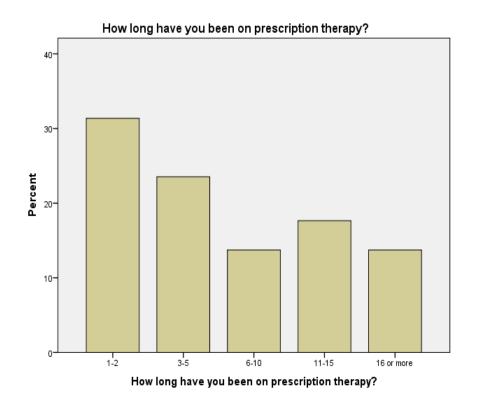


Figure 15. Duration of prescription therapy experience in years

Prescription Therapy Satisfaction

The ability to attend medical visits, feel as though your needs are met, and that you have a part in selecting your own prescription therapy can have a positive influence to HAART and regular medical visits that improve adherence.

Unhealthy behaviors, psychological concerns, incarceration, illness and financial concerns had an impact on the satisfaction of our study participant's satisfaction of HAART. Table 5 exhibits that 37 study participants (72.5 %) were pleased with their current prescription therapy, versus 14 (27.5%) who were not pleased with their current prescription therapy.

Table 5
Satisfaction of prescription therapy

Are you pleased with your prescription therapy?

		Frequency	Percent	-
	Yes	37	72.5	
Valid	No	14	27.5	
	Total	51	100.0	

The ability to attend regular primary care visits allowed CD4 tests and viral load tests laboratory work to be completed in a timely manner.

The results of these tests continue to have a direct impact on prescription therapy options. Primary care visits were also used as a means to measure adherence as it relates to viral load, CD4 count and HAART resistance. If any of the clients missed their scheduled appointments the staff at each clinic would call them to reschedule. This was one of the actions taken by each clinic to help improve their retention to care numbers and influence

6-month primary care visits. In this study 88.2% (45) participants had attended 2 primary care visits within the past 6 months (Table 6).

Table 6

Ability to attend 2 primary care visits within the past 6 months

Have you been able to attend 2 primary care visits within the past 6 months?

		Frequency	Percent	₹r€	e	ec	q	υ	1	e	21	n	ıC	y		Pe	21	î	26	e	1	r	1	t																				
	Yes	45	88.2										4	15					8	38	8	3		2							_	_	-	-	-	-	-	-	-	-	<u>-</u>	-	<u>-</u>	-
Valid	No	6	11.8											6					1	l	1	1		8																				
	Total	51	100.0										5	51				1	()(()	١.	0																				

Table 7 exhibits 70.6% (36) of study participants had previously been on a HAART patient assistance program while waiting for their ADAP to be approved, while 29.4% (15) had never had to use patient assistance and where able to apply without any issues. For individuals with financial limitations, the cost of HAART was a factor in delaying HAART or having to stop taking HAART for an undisclosed time frame.

Table 7

AIDS Drug Assistance Program Experience

Have you ever been on Patient Assistance while pending ADAP?

		Frequency	Percent
	Yes	36	70.6
Valid	No	15	29.4
	Total	51	100.0

Retention to Medical Care

Retention to medical care is essential to HAART compliance. Of the 51 study participants, 49% (25) had at some point been out of medical care for more than 12 months and 51% (26) had not been out of medical care for more than 12 months (Table 8).

Table 8

Have you ever been out of medical care for more than 12 months?

Have you ever been out of medical care for more than 12 months?

		Frequency	Percent
-	Yes	25	49.0
Valid	No	26	51.0
	Total	51	100.0

HAART and Medical Care Noncompliance

Noncompliance to HAART occurs for a variety of reasons. The participants in this study listed several of these. Figure 16 notes missed doctor visits was the primary reason that 30 (24.4%) study participants identified as the reason they stopped taking HAART. In addition, 17 (13.8%) said that cost was a factor, medication side effects 16 (13%), access to pharmacy 13 (10.6%), and lack of transportation 12 (9.8%) were reported as the 5 most common reasons study participants stopped taking HAART.

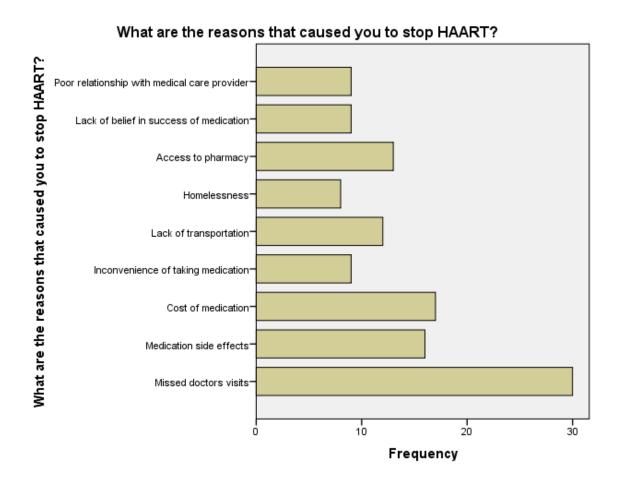


Figure 16. Reasons that caused study participants to stop taking HAART.

Examining Table 9, it shows responses from study participants noted that 94.1% (48) of them had been in medical care on a regular basis for at least 12 months and that 5.9% (3) of participants that had not been in medical care on a regular basis.

Table 9. Has being in medical care on a regular basis (at least 12 months) helped with HAART compliance?

Table 9

Has being in medical care on a regular basis (at least 12 months) help with compliance

Has being in medical care on a regular basis (at least 12 months) help with compliance

		Frequency	Percent
	Yes	48	94.1
Valid	No	3	5.9
	Total	51	100.0

Of the 25 individuals captured in Table 8, there were a variety of variables selected on the survey as to why they had experienced being out of medical care for more than 12 months (Table 10). Table 10 shows that financial concerns were the reason that majority (22.8%) of study participants noted as the main reasons for their 12 or more month medical care hiatus. This was trailed by lack of support system from family or friends (17.5%) and tired of going to doctors' appointments (15.8%).

Understanding the importance of medical care and that everyone has their own self identifying circumstances of needing it, often times when someone drops out of medical care, they usually reengage in medical care. Figure 17 displays that of the 25 study participants that had been out of medical care for more than 12 months, 16 study participants shared that sickness was the most common factor that caused them to get back into medical care and continue HAART, followed by the need for medication, as noted by 11 study participants. Figure 17 displays that needing medication was the second most documented response along with acquiring a new medical provider (7) and

financial changes (4).

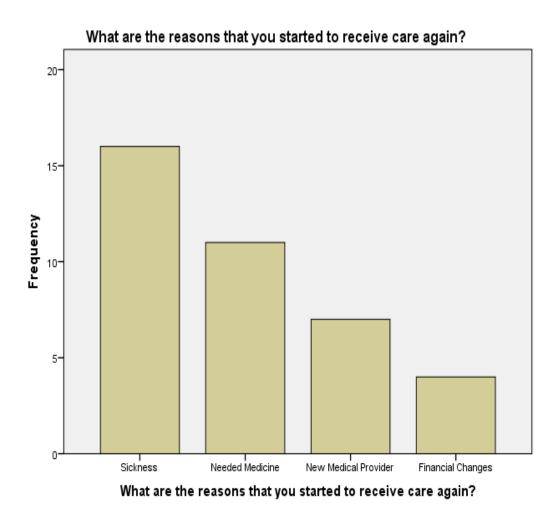


Figure 17. Reasons that study participants started to receive care again.

Table 10.

What are the reasons that caused you to be out of medical care for more than 12 months?

Reasons that caused you to be out of medical care more than 12 months?

		Frequency	Percent	
	Additional health challenges	7	12.3	
	Lack of transportation	7	12.3	
	Homelessness	3	5.3	
	Lack of support system from family and friends	10	17.5	
Valid	Tired of going to doctor appointments	9	15.8	
	Financial concerns	13	22.8	
	Incarcerated (Jail or Prison)	7	12.3	
	Other	1	1.8	
	Total	57	100.0	

Results of Research Questions

Qualitative Research Questions

RQ1. What are the barriers causing African Americans living with HIV/AIDS to have lower adherence rates with HAART than persons of other ethnic groups?

Although study participants had medical care appointments scheduled, there were existing barriers that caused lapses in their medical care. Upon analyzing the data for this study, the results showed study participants listed several barriers they have faced or are currently dealing with, that impact their medical care and adherence to HAART. Of the 25 (49%) study participants that had been out of medical care for more than 12 months, financial concerns were listed as the most common barrier (22.8%). Not having the

support from family and friends was a barrier to study participants (17.5%), as well as being tired of going to doctor appointments (15.8%).

Listed as the primary barrier for poor medical care and HAART adherence, financial concerns are multifaceted. Nonstable income played a role in how a person is able to navigate the actions needed for HAART compliance. Without a stable income, proper housing is an issue, prescription purchases decrease, nutritional meals did not exist due to the factor of cost, and basic self-care and hygiene needs can be problematic.

An additional barrier reported was a lack of support system from family and friends impacted some (10) of our study participant. Without a proper support system, some individuals living with HIV/AIDS find it (a) difficult to ask for help when and if needed, (b) confide in others about their experiences, (c) be held accountable for their actions and (d) trust others. Additional health challenges (12.3%), lack of transportation (12.3%), and incarceration (12.3%) were also barriers in medical care that had a direct influence on HAART noncompliance.

Additional health challenges presented other opportunities for additional stressors such as taking more medication and having to attend more doctor visits for other health issues. Lack of reliable transportation as a barrier, could come in many forms. Study participants (12.3%) that did not have their own vehicle, relied on family or friends to get to their medical appointments. Other means of transportation that were used to make appointments were the buses or the trains within the public transportation system. If someone who depended on public transportation cannot afford travel fare, they end up

missing their medical care appointments if they are unable to be provided with alternate means of transportation.

Three of the 51 study participants, who had been out of medical care for more than 12 months, reported homelessness as a barrier to medical care. Homelessness, by itself, is a very unfortunate situation to be in. However, being homeless and living with HIV/AIDS presents challenges of safety, poor nutrition, noncompliance, financial strain and often mental health concerns (Konkle-Parker, Erlen, & Dubbert, 2007).

Although study participants had medical care appointments scheduled, there are existing barriers that have caused lapses in their medical care. Upon analyzing the data for this study, the results showed study participants listed several barriers they have faced or are currently dealing with, that impact their medical care and adherence to HAART. Of the 25 (49%) study participants that had been out of medical care for more than 12 months, financial concerns were listed as the most common barrier (22.8%). Not having the support from family and friends has been a barrier to study participants (17.5%), as well as being tired of going to doctor appointments (15.8%).

Listed as the primary barrier for poor medical care and HAART adherence, financial concerns are multifaceted. Nonstable income plays a role in how a person is able to navigate the actions needed for HAART compliance. Without a stable income, proper housing may be an issue, prescription purchases may decrease, nutritional meals may not exist due to the factor of cost, and basic self-care and hygiene needs can be problematic. Another barrier reported was a lack of support system from family and friends impacted some (17.5%) of our study participants. Without a proper support

system persons living with HIV/AIDS may find it (a) difficult to ask for help when and if needed, (b) confide in others about their experiences, (c) be held accountable for their actions, and (d) trust others. Additional health challenges (12.3%), lack of transportation (12.3%), and incarceration (12.3%) were also barriers in medical care that had a direct influence on HAART noncompliance.

Additional health challenges presented other opportunities for additional stressors such as taking more medication and having to attend more doctor visits for other health issues. Lack of reliable transportation as a barrier, could come in many forms. Study participants (12.3%) that did not have their own vehicle, relied on family or friends to get to their medical appointments. Other means of transportation that were used to make appointments were the buses or the trains within the public transportation system. If someone who depended on public transportation could not afford travel fare, they missed some of their medical care appointments if they are unable to be provided with alternate means of transportation.

RQ2. How can barriers for medical treatment of African Americans living with HIV/AIDS be eliminated?

Of the 51 study participants, 32 (66.7 %) documented that lowering the cost of HAART would eliminate their largest barrier or financial issues. Having pharmaceutical companies to lower the cost of HAART medication would be beneficial to those persons who are not on a patient assistance program, ADAP or have insurance to cover the cost. As discussed in chapter 2, unfortunately, these medications are very costly and the average cannot afford them. If a person cannot afford HAART, they will not be able to

adhere to a prescription therapy regimen. More than 10% of study participants said that access to medical clinics can be a barrier.

Depending on the location of local medical clinics, distance from their residence may be a factor. Having access to an increased number of clinics would make it easier to see doctors on a regular basis without having to wait so long for scheduled follow up appointments. This would also possibly help with the transportation issue that 4.2% of the 51 study participants said is a barrier to medical treatment. As noted in Figure 18, 9.4% of study participants said that having better medical care while incarcerated would definitely alleviate a huge barrier in their care while they are incarcerated.

In addition to having an increased number of medical clinics, study participants would benefit from gas vouchers, public transportation tokens or prepaid transit cards. Side effects can interfere with medical treatment. Almost 2% of study participants reputed that side effects of taking HAART interfere with their medical care. Side effects varied from person to person, yet some of the most common side effects are diarrhea, fatigue, nausea, and vomiting.

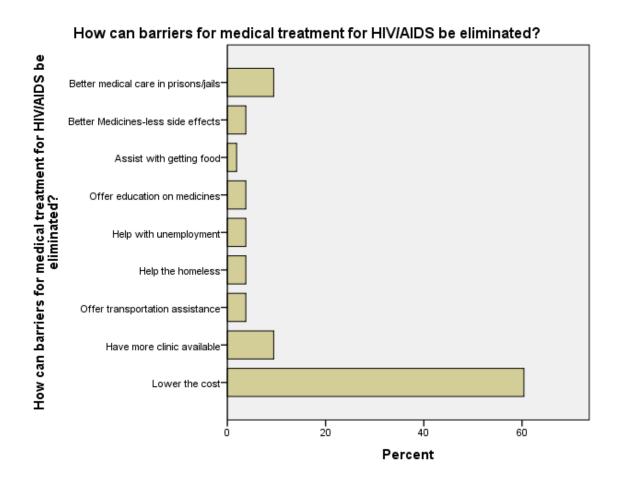


Figure 18. How can barriers for medical treatment of HIV/AIDS be eliminated?

Table 11 How can barriers for medical treatment of HIV/AIDS be eliminated?

		Frequency	Percent
	Lower the cost	32	26.0
	Have more clinic available	5	4.1
	Offer transportation	2	1.6
	assistance		
	Help the homeless	2	1.6
Valid	Help with unemployment	2	1.6
valiu	Offer education on	2	1.6
	medicines		
	Assist with getting food	1	.8
	Better Medicines-less side	2	1.6
	effects		
	Total	48	39.0
Missing	System	75	61.0
Total		123	100.0

Quantitative Research Questions

RQ3. Will attending two primary care visits within six months of being linked to care increase the rate of compliance for African Americans on HAART living with HIV/AIDS?

 H_01 : Attending two primary care visits within six months of being linked to care will not increase the rate of compliance for African Americans on HAART living with HIV/AIDS.

 $H_{\rm A}1$: Attending two primary care visits within six months of being linked to care will increase the rate of compliance for African Americans on HAART living with HIV/AIDS.

Table 12 *Model Summary of medical care predictors.*

Model Summary

Model	R	R Square	Adjusted R	Std. Error of the
			Square	Estimate
1	.685 ^a	.469	.458	.240

 a. Predictors: (Constant), Has being in medical care on a regular basis (at least 12 months) help with compliance.

Table 13
The analysis of variance (ANOVA). A two-way ANOVA.

 $\textbf{ANOVA}^{\textbf{a}}$

Model		Sum of Squares	df	Mean Square	F	Sig.
	Regression	2.482	1	2.482	43.235	.000 ^b
1	Residual	2.813	49	.057	i	
	Total	5.294	50			

- a. Dependent Variable: Have you been able to attend 2 primary care visits within the past 6 months?
- b. Predictors: (Constant), Has being in medical care on a regular basis (at least 12 months) help with compliance

Table 14 Correlation coefficient of dependent variable of primary care visits.

Coefficients^a

Mode	I	Unstandardize	ed Coefficients	Standardized Coefficients	t	Sig.
		В	Std. Error	Beta		
	(Constant)	.063	.035		1.807	.077
	Has being in medical care	.938	.143	.685	6.575	.000
1	on a regular basis (at least					
	12 months) help with					
	compliance					

a. Dependent Variable: Have you been able to attend 2 primary care visits within the past 6 months?

The overall model of the linear regression analysis was significant, R^2 =.469, adjusted R^2 = .458, F(1, 49) = 43.24, p < .001. Specifically, being in medical care on a regular basis accounted for 46.9% of the total variance in attending primary care visits. The outcome of this analysis confirms my hypotheses (H_A1) that attending two primary care visits within six months of being linked to care increased the rate of compliance for African Americans on HAART living with HIV/AIDS.

Regarding Tables 8 and 11, there is a direct correlation between being able to attend 2 primary care visits within the past 6 months and being in medical care on a regular basis (at least 12 months) that improved compliance rates. Showing an increase in compliance, 88.2% (45) study participants were able to attend 2 primary care visits within the past 6 months. Survey results also showed 94.1% (48) study participants reported that being in medical care on a regular basis (at least 12 months) helped improve their compliance rate for HAART.

RQ4. Will African Americans living with HIV/AIDS who have been out of care for 12 or more months have a low linkage to care rate?

 H_02 : African Americans that have been out of care for 12 or more months while living with HIV/AIDS will not have a low linkage to care rate.

Table 15

Model Summary of Predictor of medical care.

			Mod	el Summary	
Model	R	R	Adjusted	Std. Error of the Estimate	
		Square	R Square		
	.3	.128	.110	.30	7
1	58				
	а				

a. Predictors: (Constant), Have you ever been out of medical care for more than 12 months?

Table 16
The analysis of variance (ANOVA). A two-way ANOVA.

ANOVA

ANOVA						
Model		Sum of Square	df	Mean Square	F	Sig.
		square				
	Regression	.679	1	.679	7.206	.010 ^b
1	Residual	4.615	49	.094		
	Total	5.294	50			

- a. Dependent Variable: Have you been able to attend 2 primary care visits within the past 6 months?
- b. Predictors: (Constant), Have you ever been out of medical care for more than 12 months?

Table 17

Correlation coefficient of dependent variable.

-		Coef	ficients		_	
Mode	el	Unstanda	ardized	Stan	t	Sig.
		Coeffic	ients	dardi		
				zed		
				Coeff		
				icient		
				s		
		В	Std.	Beta		
			Error			
	(Canatant)	1.001E-	.061		.000	1.000
	(Constant)	013				
	Have you	.231	.086	.358	2.684	.010
1	ever been out					
1	of medical					
	care for more					
	than 12					
	months?					

The overall model of the linear regression analysis was significant, R^2 = .469, adjusted R^2 = .458, F(1, 49) = 7.206, p < .001. Specifically, being in medical care on a regular basis accounted for 46.9% of the total variance in attending primary care visits. The outcome of this analysis confirms my hypotheses (H_A1) that attending two primary care visits within six months of being linked to care increased the rate of compliance for African Americans on HAART living with HIV/AIDS.

Concerning Table 8, 49% (25) of study participants reported being out of care for more than 12 months. If a person is not in care, they are not able to receive ongoing HAART. This results in low linkage to rates. Taking a look at Table 9, survey results also

showed 94.1% (48) study participants reported that being in medical care on a regular basis (at least 12 months) helped improve their compliance rate for HAART.

Evidence of Trustworthiness

Research studies should always be able to show reliability, validity, and trustworthiness. As a researcher, it was my responsibility to ensure that my research findings where accurately reflecting study participants experiences and to leave out any preconceived notions that I may have had. Schreier (2012) noted when it comes to research, people should be able to unmistakably follow the analysis and conclusion of study results without any confusion.

Summary

Descriptive analysis and linear regressions were used in order to analyze my study findings. This chapter was to share the findings of my research study. Chapter 5 will discuss my research findings and conclusion. I will also document my recommendations and the positive social changes that can happen as a result of my findings.

Chapter 5: Interpretation of Findings

Introduction

The purpose of this research study was to explore the potential findings that would lead to positive social changes by allowing African Americans living with HIV/AIDS to have an advanced quality of life and lead to positive change by being able to improve their health. This presented opportunity for these individuals to gain employment, sustain positive relationships, to improve financial stability, present for follow up medical visits and to even volunteer with local public health agencies that are centered on HIV/AIDS patients as consumers. As previously stated, a mixed methods approach, primarily qualitative, was used for the nature of the research study. Due to the content of the research questions and information that were collected, this approach was most sufficient. This helped to prevent bias.

Concept of Positive Social Change

Stressful situations in life can help to tear down a person's beliefs, health status, faith and relationships with others. Increasing awareness and helping to provide a clear understanding of what causes such stressors and barriers, gives facts that can produce a clear avenue of what needs to happen in an effort to address them. HAART compliance influences social change, social position, personal and professional relationships, financial stability, and quality of life. Having the ability to identify, reduce or eliminate barriers of HAART adherence is definitely a positive attribute.

As shared in Chapter 2, when a parent is infected with HIV/AIDS, the quality of their health may have a direct impact on the dynamics of their family. These dynamics

may result in an increased responsibility load for others, including children, in the home. When a person is HAART compliant and living a better quality of life, there are fewer instances that family members will have to take on additional care responsibilities.

Allowing better attendance at work and school can lead to less stress and increased successes that can be shared within families and their communities.

Family connections are a huge part of the African American community.

Knowing that a lack of support from family and friends was identified as a barrier to HAART compliance, processes to improve the dynamics of relationships with loves ones is critical. This social change is multileveled. It is a positive social change within marriages, parent to child relationships, caregiver relationships, sibling relationships, friendships and social relationships. Having the capacity to be an asset and productive citizen in their community has a ripple effect. When family, friends or coworkers see this behavior that led to a positive economic impact, it may perhaps influence them to encourage their loved ones to continue with these behaviors and work collectively to ensure it becomes habitual.

As a result of this research project, results can directly impact positive social change. Results can lead to positive social changes by allowing African Americans living with HIV/AIDS to have an advanced quality of life and extended longevity leading to positive behavior changes by being able to improve their health. Increasing self-accountability and self-confidence that an individual has transfers to increased social activity. This would, in turn, allow more opportunities for gainful employment, sustaining positive relationships, improving financial stability, being present for follow

up medical visits and volunteering with local public health agencies that are centered on HIV/AIDS patients as consumers. This also reveals potential to have a positive social change on community development. Individually and collectively these indicators impact social change in a progressive manner and initiates progressive civic engagement and civic dialogue.

Furthermore, in order to make a positive social change there should be an understanding of what treatment barriers are and why they exist. Knowing specific barriers will allow for the implementation of policies and procedures, or programs that will have a direct impact on eliminating or reducing such barriers. For example, if transportation is a barrier, prepaid public transportation vouchers can be distributed to clients to ensure that the cost of transportation for their follow up visit is covered. If education on HAART is needed, speakers can attend Self Help Group Meetings or give informal education sessions in the local health centers while clients wait for their appointments. Thinking out of the box about creative ways that impact positive social change can lead to an increase in healthy behavior change and knowledge about things that directly impact a person's well-being.

Interpretation of the Findings

Ninety four percent of participants in this study reported being in medical care on a regular basis (at least 12 months) helped with HAART compliance. When a client adheres to HAART they have a higher chance of being healthier than someone who does not adhere to HAART. Again, this plays a vital role in retention to care. If a client has a high retention to care rate, their CD4 count and viral load counts are able to be

monitored. This has a direct impact on their physicians having a greater understanding of how effective their HAART regimen is and how their body is reacting to any side effects that may be present. This will allow the assessment of prescription therapy options as well as the impact of any contraindications. It is important for patients to feel as though they have an active part in the decision made that impact their care. Regular medical care visits also help to establish the physician-patient relationship. It is important for clients to be educated on any unhealthy behaviors that are known so that they can work with their physician to create an action plan and referrals to help them manage their HIV/AIDS diagnosis, as well as other things that may have a negative impact on their health.

Eliminating common barriers such as prescription cost, transportation issues, the time it takes for follow up appointments and unstable support from their loves ones will have a substantial impact on the quality life of a person living with HIV/AIDS. Ensuring that a client has the benefit of receiving their follow up appointments, prescription refills, and referrals at their medical care appointments can reduce the need for interim visits that can be prevented.

The linear regression outcome for RQ3 showed the overall model of the linear regression analysis was significant, R^2 = .469, adjusted R^2 = .458, F(1, 49) = 43.24, p < .001. Specifically, being in medical care on a regular basis accounted for 46.9% of the total variance in attending primary care visits. The outcome of this analysis confirms my hypotheses (H_A 1) that attending two primary care visits within six months of being linked to care increased the rate of compliance for African Americans on HAART living with HIV/AIDS. The linear regression outcome for RQ4 highlighted the overall model of the

linear regression analysis was significant, R^2 = .469, adjusted R^2 = .458, F(1, 49) = 7.206, p < .001. Specifically, being in medical care on a regular basis accounted for 46.9% of the total variance in attending primary care visits. The outcome of this analysis confirms my hypotheses (H_A 1) that attending two primary care visits within six months of being linked to care increased the rate of compliance for African Americans on HAART living with HIV/AIDS.

Limitations of the Study

The intention of trustworthiness is to authenticate the argument that the researchers' findings are worthy of interest being given (Elo et al., 2014). Analysis strategies should aspire to support trustworthiness by reporting the process of content analysis accurately (Schreier, 2012). There were no major limitations in completing my research study. The only limitation presented was the ability to ensure that all honest and accurate information was captured and that each survey was completely filled out by the study participants in higher HAART rates. Creswell (2009) noted validity is whether one can draw meaningful and useful inferences from scores on the instruments (Creswell, 2009). Frankfort-Nachmias and Nachmias (2008) shared validity wants to ensure that what is being measured is actually the intended target of measurement. The concept of validity for measurement deals with (a) content validity, (b) empirical validity, and (c) construct validity. Content validity the attributes of concept are completely covered by the measurement instrument (Frankfort-Nachmias & Nachmias, 2008).

Recommendations

Having consistent and taking part of access to healthcare is a major role in improving the quality of life for persons living with HIV/AIDS. The duration of medical care must improve. Helping to ensure that clients are in medical care should be one of the primary goals of every medical provider team. If a person is not in care, they cannot be fully HAART adherent. HAART has been successful in prolonging life expectancy and decreasing the viral load of HIV in the human body (Cahill & Valadez, 2013). Persons on HAART must adhere to strict guidelines in order to reduce their viral load and increase their CD4 cells. Finding the prescription therapy regimen that works for them and that they are please with is crucial. Follow up medical care visits must be addressed.

Physicians and medical clinicians, such as Physician Assistants, Nurse

Practitioners, and Registered Nurses should always remind their clients of the importance of attending follow up medical visits. Most follow up appointments are scheduled 3-6 months out. Reminder calls for follow up appointments can be helpful in improving the attendance rate for medical visits since some clients may lose their appointment cards, or forget their appointment date.

As noted in Chapter 1, financial support for ADAP has tapered over the past few years resulting in a waitlist for program enrollment, formulary reductions for various medications and reduced coverage for HAART (Horneffer & Yang, 2013). To further complicate issues, ADAPs were being inundated by persons who needed financial assistance, and there was a rapid increase of persons on the ADAP waiting list between the months of January 2010 through May 2011 (Figure 3).

Financial strains are major. Helping to ensure that case managers and ADAP coordinators are staffed sufficiently to meet the issue of supply and demand is a must. This will help to reduce the length of time that it takes to get an ADAP appointment scheduled. Without an ADAP appointment a person cannot be approved for a PAP that will cover the financial expense of their HAART.

Addressing the issue of transportation would be vital to reducing this barrier. Providing transportation vouchers for public transportation will assist with this, so will pre-paid Uber gift cards for those persons that do not live near a train station or bus stop. Getting a person to schedule an appointment and keep that appointment are 2 of the key components of HAART implementation and adherence.

Implementing satellite clinics will give more options to attend medical care appointments. With more medical care clinics available, some of the satellite locations may be closer to residence or shelter for some clients. This may also improve the time it takes to see a physician and go through the steps of starting HAART. Satellite clinics can be successful with implementing HAART, completing follow up visits, and counseling (Okonkwo et al, 2014).

Retention in HIV care is an essential measure for achieving long-term survival while living with HIV/AIDS (Thompson et al., 2012). When medical care is not a regular component of HAART the chances of being noncompliant increase and the potential for declining in health may occur as a result of prescription refills ending, ADAP lapses, lack of financial coverage for HAART, laboratory monitoring for viral load and CD4 counts are not completed, viral load increases and CD4 count decrease.

Establishing different support groups for clients to attend alone, and then another support groups to attend with their loved ones, could help reduce the lack of support from their family and friends. It is one thing to talk about what others deal with, but it is totally different to hear it from someone who is dealing with face to face.

Homelessness, reported by itself is a very unfortunate situation to be in. However, being homeless and living with HIV/AIDS presents challenges of safety, poor nutrition, noncompliance, financial strain and often mental health concerns (Konkle-Parker, Erlen, & Dubbert, 2007). With an increase in the homeless population, mobile HIV testing units could be used to do HIV testing at homeless shelters and local parks where many homeless people gather. If someone tests positive for HIV, that person would receive an appointment to see a physician. Again, satellite clinics would help to reduce the wait time to receive a medical care appointment with a physician. The connection between these two things could help to increase HAART adherence rates through linkage to care efforts.

Unsuccessful implementation of the aforementioned recommendations can leave the immune system at risk for opportunistic infections due to noncompliance with HAART. HAART has been shown to decrease morbidity and mortality rates and reduce mental health issues in persons living with HIV/AIDS (Hartzell, Janke & Weintrob, 2008).

Implications

If a person is not pleased with his/her treatment regimen, that could interfere with HAART adherence and their overall quality of life. Medical care is a critical component to HAART compliance, suppressed viral loads and quality of life. Persons with a history

of medical care have a much higher retention to care rate than those who have never been in medical care (Marks, Gardner, Craw, & Crepaz, 2010). Persons living with HIV/AIDS taking HAART and attending regular medical visits are more likely to have suppressed viral loads than those who see their providers intermittently (Giordano et al., 2007). A person on HAART may have to deal with some less than ideal challenges, such as multiple medication regimens, strict intake schedules, nutrition restrictions and adverse reactions (Weiss et al., 2003).

Patient satisfaction impacts adherence in medical care and HAART (Dang, Westbrook, Black, Rodriguez-Barradas & Giordano, 2013). When patients are not pleased with their HAART they are less likely to continue their prescribed treatment regimen. This can lead to drug resistance, viral load increase and CD4 decrease. This exposes the need to improve the overall care experience as an innovative method for optimizing HIV outcomes that lead to improved adherence (Dang, Westbrook, Black, Rodriguez-Barradas & Giordano, 2013).

Incarcerated persons living with HIV/AIDS do not always know their HIV status until, and if, they are tested while serving their sentenced time (Iroh, Mayo, & Nijhawan, 2015). If an incarcerated person knows that they are living with HIV/AIDS they having a higher probability of being linked to care and stated on HAART (Iroh, Mayo, & Nijhawan, 2015). African Americans are less than likely to be aware of their HIV status, start HAART and medical care, or have a low viral load count than other ethnic group (Iroh, Mayo, & Nijhawan, 2015).

In Georgia, HIV/AIDS diagnosis cases are legally required to be reported to the HIV/AIDS Epidemiology Section (HAES) (Georgia Department of Public Health, n.d.). The Georgia Department of Public Health (DPH) (n.d.) noted Georgia has a dual reporting system that legally requires both health care providers and laboratories to report cases of HIV/AIDS. This is supposed to be completed within 7 days of diagnosis. Cases are reported using a case report form that is sent to the HIV/AIDS surveillance program (DPH, n.d.). Gostin (2008) notes threats pertaining to disease and illness are inexorably spread to neighboring countries, regions and even continents through travel and environmental factors. By having laws and policies in place sets the standard for federal and state government public health programs to follow in order to protect their citizens in the respective areas. Ethical consideration and ethical awareness is definitely something that I considered when creating the survey for this research project.

Irrespective of gender, persons living with HIV/AIDS experience physical and/or emotional violence from people that they are in relationship with, implying that HIV status disclosure can be a risky perilous experience with partner shame, abuse, ill-treatment, and financial abandonment (Colombini, James, & Ndwiga, 2016). These fears can have a serious impact on medical care and increased HIV/AIDS rates

Kelly and Kalichman (2002) acknowledged HAART nonadherence destabilizes the possibility of reduction in HIV transmission. HAART has been successful in prolonging life expectancy and decreasing the viral load of HIV in the human body (Cahill & Valadez, 2013). Persons on prescription therapy must adhere to strict

guidelines in order to reduce their viral load and increase their CD4 cells. Finding the prescription therapy regimen that works for them and that they are please with is crucial.

Burke et al. (2003) documents dissatisfaction with medical care has been shown to impact treatment underutilization, discontinuity of care and poor clinical outcomes. Patients have explicit desires and requests for services when they are in medical care (Tateke, Woldie, & Ololo, 2012). As shared in Chapter 2, Stone et al. (2001) noted there is a greater rate of self-reported adherence among persons whose HAART is less complicated than other prescription therapy.

The more complex a person's HAART is, the less likely they are to grasp details of all of the components of HAART. The HIV Causal Collaboration (2011) documented that persons who are compliant with their prescription regimen experience a higher rate of healthy living and lower healthcare expenses during their lifetime since they are less likely to access medical care than those persons who are less compliant with their prescription regimen (Fleishman et al., 2010).

Creswell (2009) noted validity is whether one can draw meaningful and useful inferences from scores on the instruments (Creswell, 2009). Frankfort-Nachmias and Nachmias (2008) shared validity wants to ensure that what is being measured is actually the intended target of measurement. The concept of validity for measurement deals with (a) content validity, (b) empirical validity, and (c) construct validity. Content validity the attributes of concept are completely covered by the measurement instrument (Frankfort-Nachmias & Nachmias, 2008).

Conclusion

Dr. Chavez highlights that quantitative research looks at numbers, stats and rates and looks at the where, when and what; however, qualitative asks with words how and why and looks to tell the meaning of such (Laureate Education, Inc., 2008). There is a gap in literature that focuses on the noncompliance of African Americans living with HIV/AIDS who are on HAART. Although studies have been conducted on HAART, not many have focused on the noncompliance and barriers of African Americans and HAART alone.

Research studies should always be able to show reliability, validity, and trustworthiness. The intention of trustworthiness is to authenticate the argument that the researcher's findings are worthy of interest being given (Elo et al., 2014). Analysis strategies should aspire to support trustworthiness by reporting the process of content analysis accurately (Schreier, 2012). HAART compliance data can be quantitative by analyzing the quantity of clients that were compliant or noncompliant with HAART during given time frames.

HAART compliance or noncompliance data can be also qualitative for the reason that it allows individuals to express their beliefs, behaviors, and rational for actions. This could provide additional clarity surrounding the results of the quantitative data.

HIV/AIDS infection can be very difficult in terms of coping with the diagnosis, and medical care and HAART compliance may not be a priority to infected persons if other pressing issues such as food, shelter, income, incarceration or behavioral health issues exist.

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Appendix A: HIV/AIDS HAART Compliance and Primary Care Survey

Thank you for taking the time to answer the following questions. All of the responses that you provide will be confidential. Your feedback will be analyzed and used to improve primary care services, with a focus on prescription therapy. If you have any questions about the survey, please contact Angela Corbin at 404-613-1267.

What is your	What is your	What is your	What is your ethnicity?
gender?	age?	marital Status?	
o Male	○ 22-29	○ Single	o Black/or African
o Female	○ 30-39	o Married	American
o Transgender	o 40-49	o Widowed	o White, Non-Hispanic
	○ 50-59	o Divorced	○ Hispanic or Latino
	○ 60 +	○ Separated	o Asian or Asian
			American
			○ American Indian or
			Alaskan Native
			o Other

1. How long have you been in medical care for HIV?

- o 1-2 Years
- o 3-5 Years
- o 6-10 Years
- o 11-15 Years

2.	How 1	ong have you been on prescription therapy for HIV?
	0	1-2 Years
	0	3-5 Years
	0	6-10 Years
	0	11-15 Years
	0	16 or more years
3.	Have	you ever been out of medical care for HIV for more than 12 months?
	0	Yes
	0	No
4.	If you	answered Yes to #3, please select a reason below (Check all that apply):
	0	Other health challenges
	0	Lack of transportation
	0	Homelessness
	0	Lack of a support system from family or friends
	0	Tired of going to doctor's appointments
	0	Financial concerns
	0	Incarcerated (Jail or Prison)
	0	Other, please specify reason:
5.	If you	answered Yes to #3, please select a reason below that you started to receive
	care a	gain:
	0	Sickness

o 16 or more years

	0	Needed medicine
	0	New medical provider
	0	Financial changes (ex. loss of job or benefits)
	0	Other, please specify reason:
6.	Has be	eing in medical care on a regular basis (at least 12 months) helped you stay
	compl	iant with your medications:
	0	Yes
	0	No
7.	Have a	any of the options below caused you to stop taking your prescription
	therap	y for HIV? (Check all that apply):
	0	Missed doctors' appointments
	0	Side effects of medication
	0	Cost of medication
	0	Inconvenience of taking medication
	0	Lack of transportation to doctors' appointments
	0	Homelessness
	0	Access to pharmacy
	0	Lack of belief of success of treatment
	0	Poor relationship with medical provider
	0	Other, please specify reason:
8.	Have y	you been able to attend two (2) primary care visits with your physician

within the past six (6) months?

	0	Yes
	0	No
9.	Have y	you ever been on a patient assistance for medicine while pending ADAP
	approv	al?
	0	Yes
	0	No
10.	Do you	a feel that adherence to HIV prescription therapy is not always successful?
	Why o	r why not?
11.		a believe that there are barriers for medical treatment for HIV/AIDS? If so, an they be eliminated?
	110 ()	
12.	Are yo	u pleased with your prescription therapy that you are taking at the
	momen	nt?
	0	Yes
	0	No

Appendix: B: Letter of Collaboration from Fulton County Health & Wellness

Letter of Cooperation from a Research Partner



DEPARTMENT OF HEALTH AND WELLNESS

99 Jesse Hill Jr., Drive, S.E. Atlanta, Georgia 30303

Fulton County Health & Wellness Primary Care Clinic Sheree Gardner Behavioral Health Clinician sherce.gardner@fultoncountyga.gov (404) 612-4181

June 14, 2016

Dear Angela Corbin,

Based on my review of your research proposal, I give permission for you to conduct the study entitled Adherence Barriers to Healthcare for Minorities with HIV/AIDS on Antiretroviral Medications within the Fulton County Health & Wellness Primary Care Clinic. As part of this study, I authorize you to recruit clients at their medical visits and conduct a survey to assess barriers and healthcare views clients living with HIV/AIDS. These surveys will be anonymous and no follow up contact will be needed from any clients that participate. Individuals' participation will be voluntary and at their own discretion.

We understand that our organization's responsibilities include providing a confidential environment whereas clients can complete the research survey in private, adhering to Health Insurance Portability and Accountability Act (HIPAA). No supervision will be required to administer surveys to clients. I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the student's supervising faculty/staff without permission from the Walden University IRB.

Sheree Gardner, PhD Behavioral Health Clinician

"To Promote, Protect and Assure the Health and Wellness of the People of Fulton County"

Appendix C: Letter of Collaboration from AID Atlanta, Inc.

Letter of Cooperation from a Research Partner



Letter of Cooperation from a Research Partner

LaTonya M. Wilkerson AID Atlanta Latonya.wilkerson@aidatlanta.org (404) 870-7780

June 23, 2016

Dear Angela Corbin,

Based on my review of your research proposal, I give permission for you to recruit from AID Atlanta case managed patients for the study entitled Adherence Barriers to Healthcare for Minorities with HIV/AIDS on Antiretroviral Medications. As part of this study, I authorize you to recruit clients at their case management visits and conduct a survey to assess barriers and healthcare views clients living with HIV/AIDS. These surveys will be anonymous and no follow up contact will be needed from any clients that participate. Individuals' participation will be voluntary and at their own discretion.

We understand that you will work with the site to provide confidential space whereas clients can complete the research survey in private, adhering to Health Insurance Portability and Accountability Act (HIPAA). No supervision will be required to administer surveys to clients. I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the student's supervising faculty/staff without permission from the Walden University IRB.

LaTonya M. Wilkerson

Director of Quality and Compliance

AID Atlanta, Inc.

Sincerely.