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Clinical Influences on Patient Retention in HIV Treatment at VA Medical Center

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Clinical Influences on Patient Retention in HIV Treatment at VA Medical Center

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2013

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An abstract of a thesis submitted to the Faculty of the Rollins School of Public Health of Emory University in partial fulfillment of the requirements for the degree of

Master of Public Health
In Global Health
2015

Abstract

Clinical Influences on Patient Retention in HIV Treatment at VA Medical Center

By

Matthew Heyward Wessinger

Social determinants of health create significant disparities in disease burden and access to health care in the United States. Within the HIV-infected population, clear disparities in HIV infection and retention in HIV treatment exist in the United States based around these social determinants. Among the population of veterans in the United States, disparities in HIV diagnosis, care, and outcomes are as severe or more severe as in the overall population. However, differences in demographics and the unique structure of the VA health system can lead to differences in veterans' access to HIV care. In the following project, we examine how the HIV positive patient's experience of healthcare at the Atlanta Veterans Affairs Medical Center (AVAMC) influences their retention in HIV treatment. We used secondary analysis of qualitative data to determine the barriers that inhibited retention for participants with an external locus of control and identify the attitudes that facilitated retention for participants with an internal locus of control. Results identified three central interrelated elements of the clinic experience that influences retention in care. For the external locus of control group, clinic waiting time, their level of confidence in clinicians, and customer service acted as barriers to retention within the clinical setting. For the internal locus of control group, patience with structural issues, level of confidence in clinicians, and interpersonal connections facilitated higher rates of retention in HIV treatment. The findings of this study provide the foundation for further research to design clinic interventions to improve clinic-based barriers to retention in treatment for HIV positive patients in the AVAMC.

The Patient Experience and Veterans' Retention in HIV Treatment at the Atlanta VA Medical Center

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Acknowledgements

I would first like to thank the members of my thesis committee, Monique Hennink and Vince Marconi, for providing me the opportunity to work with this data in the wake of hectic change of plans regarding my practicum. I also would like to thank them for their continued support and feedback during analysis and writing of my thesis. I also want to extend this thanks to Bonnie Kiser, who plays an equally important role in providing consultation throughout the thesis-writing process. I would like to thank all of the individuals involved in the collection of the data for providing a rich source of information that will hopefully prove useful for other research questions and secondary analyses. I would like to thank the faculty in the Religion and Public Health Collaborative, especially John Blevins, Mimi Kiser, and Deb McFarland, for helping me locate this opportunity to work with my thesis committee members after the change of plans that I experienced. I would like to thank David Rimland and Eugene Farber for providing consultation in the early phases of my work.

On a more personal level, I would like to thank my parents and sister for their constant support of my academic endeavors and the love they have shown me throughout my life. I also would like to thank my family members and friends who have served and are serving in the armed forces of the United States. As I have grown older, I have gained more and more connections with the military, and found that this thesis allowed me to contribute to the improvement of a system that will care form them after they have served to protect the citizens of the United States. On that note, I would like to thank everyone who has served and is currently serving in the United States military for their sacrifice. My hope is that the information in this thesis will be used to further improve the Veterans Affairs Health facilities so that all who served may receive the care they need once their time on active duty is completed.

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CHAPTER I. INTRODUCTION

Context of Project

Health is not an area of equality for all individuals living in the United States. According to CDC's Health Disparities Report, race, education level, socioeconomic status (SES), and gender hold notable associations with morbidity and mortality outcomes, as well as levels of access to insurance and preventive care (CDC, 2013). These gaps in health outcomes can be attributed to underlying societal structures- known as Social Determinants of Health- that stratify individuals in a population by determinants such as income, education, occupation, social class, gender, and ethnicity/race (Solar & Irwin, 2010). Stratification by these characteristics can have harmful impacts on health outcomes through several secondary mechanisms: material conditions, behaviors, biological factors, and psychosocial factors (Solar & Irwin, 2010). These secondary determinants then interact with health care systems to impact population level access to health care, the disease burden, and health outcomes of different population groups.

The disparities in health that occur in the United States are prevalent in access to care and disease burden across population groups. CDC reports and independent studies indicate that indicators of access to healthcare such as insurance coverage, vaccine coverage, and usage of preventive services differed significantly based on education level, socioeconomic status, gender, and race/ethnicity (CDC, 2013; Lasser, Himmelstein, & Woolhandler, 2006). Disparities in health care access were similar to those that occurred in disease burden, especially burden of HIV infection (CDC, 2014). In addition, HIV infection prevalence differed significantly based on region of the country, and mode of transmission (Meditz et al., 2011; McMahon, Wanke, Terrin, Skinner, & Knox, 2011).

Given that HIV is considered to be somewhat of a chronic disease, access to HIV care extends beyond diagnosis and initial treatment. The model for HIV treatment often occurs in what is known as a continuum of care with multiple stages from diagnosis to viral suppression (Mugavero, Amico, Horn, &

Thompson, 2013). There is a notable level of overall decline in the proportion of HIV-infected individuals that are retained at each stage of HIV care. However, we once again see disparities in how individuals are retained in HIV care based on similar stratification groups that have been discussed previously. Across the stage of HIV care, blacks and Hispanics / Latinos have lower retention levels than whites and men are retained less than women (Hall et al., 2013). Secondary characteristics such as lack of insurance, mental illness, substance abuse, and lack of supportive services have also been shown to reduce the likelihood of HIV-care linkage and retention as well (Mugavero et al., 2013). Given that HIV is a disease that can have negative psychological, social, and health-related effects and tends to affect individuals who suffer at the hand of social determinants of health, it is evident that social and structural determinants can cause interference at the various stages of HIV care.

Problem Statement

Clear disparities in HIV infection and retention in HIV treatment exist in the United States based around social determinants that have been well identified in research. Within the population of veterans in the United States, disparities in HIV diagnosis, care, and outcomes are as severe or more severe as in the overall population (Dept of Veterans Affairs, 2012; CDC, 2012). Research on the continuum of care in the context of the Atlanta Veterans Affairs Medical Center provides insight into the problems of retention in HIV treatment that occur among the veteran population. The importance of high levels of retention to ART adherence and viral suppression is somewhat divided (Mangal et al, 2014), but is still generally supported as being beneficial for HIV-related outcomes and survival (Thompson et al, 2012; Higa, 2014; Brennan, 2014; Okeke, 2014; Giordano et al., 2007).] Improving HIV retention through improving the patient experience has been recommended previously in literature (Giordano, 2011) and fits well with the WHO's Social Determinants of Health Model (Solar & Irwin, 2010). The clinical setting has also been proposed as the most effective venue for interventions targeting ART adherence through Direct Observed Therapy (Hart et al., 2010). Improving retention in HIV treatment increases the exposure of patients to the clinicians, allowing for more opportunities to effectively improve ART adherence, receive treatment for co-existing conditions, and ultimately improve viral suppression.

While the nature of the "cascade" effect along the continuum of HIV care has been well illustrated (Mangal et al., 2014; Hallet & Eaton, 2013; Mugavero et al., 2013), there has been little research examining why retention in HIV treatment tends to be much lower than rates of linkage into HIV treatment. Human Health Behavior Theories lay groundwork for understanding how individuals make health-related decisions based on environment and innate characteristics. However, these theories are more useful as explanatory mechanisms and do not always provide solutions or recommend interventions to improve behavior-related health issues. There is a need for a body of qualitative research that explores the specific issues and barriers that contribute to individuals' decisions about their retention in HIV treatment. Qualitative research also allows for an examination of the context of care and the complexity of influences on decisions related HIV retention and patients perceptions of treatment. Given that the clinical setting is the location where the most effective interventions targeting HIV treatment retention and ART adherence have improved (Hart et al., 2010), it would be useful to gain a better understanding of the experiences of patients in the clinical setting and how their experience influence their adherence to HIV treatment.

Purpose of Project

In this study we examine how the patient healthcare experience at the Atlanta Veterans Affairs Medical Center (AVAMC) influences veterans' retention in HIV treatment. Specifically, the project aims to accomplish the following: 1) identify the aspects of the clinical experience where patients encounter barriers that negatively impact retention; 2) describe differences in patients' abilities to overcome barriers to care and remain retained in HIV treatment.

CHAPTER II. REVIEW OF RELEVANT LITERATURE

The following review of relevant literature will provide the necessary context to the aims and objective of this project. First, the review will examine social determinants of health and their relevance to HIV and the veteran population. Second, the review will examine health disparities that occur in HIV disease burden, access and utilization of HIV care, and HIV-related health outcomes. Third, the review will discuss issues in the health of the veteran population in the United States in terms of general health issues, access to care, and HIV-specific issues. Fourth, the HIV care framework that is one of the foundations of this project will be further described. Fifth, a number of human health behavior theories will be described and justified in their relevance to explaining patients' decisions about retention in HIV treatment. Sixth, the review will provide summaries of the interventions that have occurred at various stages of the HIV continuum of care, including: linkage to care, ART adherence, and retention. Finally, the review will provide an overview of research about the patient experience in relation to some of the aspects of the clinical experience that were important to our study population.

Social Determinants of Health

Health is not an area of equality for all individuals living in the United States. According to CDC's Health Disparities Report, race, education level, socioeconomic status (SES), and gender hold notable associations with morbidity and mortality outcomes, as well as levels of access to insurance and preventive care (CDC, 2013). These gaps in health outcomes can be attributed to underlying factors identified by the World Health Organization as Social Determinants of Health (Solar & Irwin, 2010). Essentially, the Social Determinants of Health Framework identifies "structural determinants," identified as all social, political, and structural mechanisms in a society. These societal structures stratify individuals in a population by determinants such as income, education, occupation, social class, gender, and ethnicity/race (Solar & Irwin, 2010). Stratification by these characteristics reinforces the structural determinants and impacts health outcomes through several secondary mechanisms: material conditions, behaviors, biological factors, and psychosocial factors (Solar & Irwin, 2010). These secondary determinants then interact with health care systems to impact population level access to health care, the disease burden, and health outcomes of different population groups.

The United States is known for its relatively poor access to healthcare when compared to other industrialized nations (Davis & Ballreich, 2014). Within the United States population, there exist disparities between groups in their ability to access healthcare. We can see through the 2013 CDC Health Disparities that many health outcomes differ by factors included in the WHO model. Insurance coverage rates differed by SES, education, gender, and ethnicity/race. Low SES, having an education level lower than a college degree, being female, and being Hispanic or African American were associated with lower insurance coverage than reference groups (CDC, 2013). Vaccine coverage trends also reflect significant disparities by racial group, with Hispanics and African-Americans having lower rates of coverage than non-Hispanic whites (CDC, 2013). Preventive services and actions (screenings, check-ups) were less frequently used by Non-whites compared to whites and by the uninsured compared to the insured (Lasser, Himmelstein, & Woolhandler, 2006). Unequal levels of health care accessibility within a population means that certain groups will likely bear a greater disease burden than others. Indeed, we see that similar characteristics that are associated with lower health care access are also associated with greater burden of disease.

Disparities in disease burden between stratification groups that result from structural determinants of health are especially prevalent with relation to HIV-infection. The supplemental CDC report on HIV status in the United States illustrates that HIV infection prevalence is significantly higher for minorities, women, MSM, and other demographic minorities (CDC, 2014). In some cases, belonging to multiple demographic groups compounded the risk of HIV infection (CDC, 2014). Disparities in HIV-disease burden between stratification groups also occur based on secondary health determinants to impact health outcomes. Evidence indicates that living in the southern United States (Meditz et al., 2011), having lower education, living in poverty, and contracting HIV via sexual transmission can negatively impact health outcomes related to HIV (McMahon, Wanke, Terrin, Skinner, & Knox, 2011).

It is evident that structural and secondary health determinants impact stratification groups in a population in similar ways to negatively impact likelihood of HIV diagnosis and the likelihood of negative HIV-associated health outcomes. Poor access to HIV care based on health determinants provides an explanation for similarities in disease burden and health outcomes. Given that HIV is considered to be somewhat of a chronic disease, access to HIV care extends beyond diagnosis and initial treatment. The model for HIV treatment often occurs in what is known as a continuum of care with multiple stages from diagnosis to viral suppression (Mugavero, Amico, Horn, & Thompson, 2013). There is a notable level of overall decline in the proportion of HIV-infected individuals that are retained at each stage of HIV care. However, we once again see disparities in how individuals move through HIV care based on similar stratification groups that have been discussed previously. Across the stage of HIV care, blacks and Hispanics / Latinos have lower retention levels than whites, men are retained less than women, and MSW are retained less than MSM (Hall et al., 2013). Secondary characteristics such as lack of insurance, mental illness, substance abuse, and lack of supportive services have also been shown to reduce the likelihood of HIV-care linkage and retention as well (Mugavero et al., 2013). Given that HIV is a disease that can have negative psychological, social, and health-related effects and tends to affect individuals who suffer at the hand of social determinants of health, it is evident that social and structural determinants can cause interference at the various stages of HIV care.

The Veteran's Affairs Clinics provide an opportunity for a case study of how a health system can address issues in maintaining patients along the stages of HIV care. According to the Social Determinants of Health model, intermediary determinants of health -material circumstance, behaviors, genetics, and psychosocial characteristics- interact with the health system to make an impact on health and well-being (Solar & Irwin, 2010). Health Systems can therefore make the biggest impact on changing an individual's ability to access healthcare in that individual's interactions with the health system. A closer look at the patient experience at Veteran's Affairs Clinics can provide insight into how Veteran's Affairs facilities can have an immediate impact on individual patient retention in HIV care. Conducting an examination of the patient experience aligns well with the current period of reform for the Office of Veteran's Affairs regarding how they interact with and handle patient access to care. Their particular model therefore provides an opportunity for a case study as to how a health system can make an impact on health outcomes through the experience patients have within that system.

HIV/AIDS-Related Health Disparities

Disparities in HIV Disease Burden

As mentioned above, the burden of disease differs significantly across groups stratification groups created by social structures in a community's culture, politics, and social norms. Such stratification groups can be identified non-exclusively as education level, gender, ethnicity/race, and social class. Regular CDC reports illustrate the varying rates of disease that occur between these population groups. According to the most recent of these reports, HIV status in the United States states that the rate of HIV diagnosis in 2010 was 8 times higher for African Americans and 2 times higher for Hispanic Americans when compared to the rate of HIV diagnosis for White Americans (CDC.gov Johnson, 2013). Further CDC reports indicated that Blacks/African Americans and Hispanics/Latinos had the highest rates of HIV diagnosis for men and women (CDC, 2010). Overall and within racial/ethnic groups, women tended to have lower rates of HIV diagnosis than men (CDC, 2010; Johnson, 2013) However, women in minority ethnic groups had higher rates of infection than white women (CDC, 2010; Johnson, 2013). Individuals with lower SES tended to have higher/lower levels of HIV diagnosis than higher levels of SES (Johnson, 2013). Across all racial/ethnic groups, individuals living in areas with higher proportions of the population below the federal poverty line had higher rates of HIV diagnosis (CDC, 2010). The same held true for both genders, and all modes of transmission (CDC, 2010). Individuals with lower levels of education also tended to have higher rates of HIV infection than individuals with higher levels of education (Johnson, 2013). Across all racial/ethnic groups, genders, and modes of transmission, individuals living in census tracts with higher proportions of the population having less than a high school diploma had higher rates of HIV diagnosis (CDC, 2010).

Disparities in Access and Utilization of HIV Care

Overall, the United States has relatively low levels of access to its healthcare system. The United spends the largest percentage of its GDP on healthcare and has the highest per capita spending of any industrialized nation (Bloomberg, 2014). In spite of this, the United States consistently ranks near the bottom of lists of other industrialized nations in healthcare access and efficiency. Compared to other industrialized nations, the United States had the highest percentage of individuals report inability to obtain necessary or recommended health care due to cost constraints (Davis & Ballreich , 2014). Individuals in the United States also reported the lowest levels of access for primary care and emergency care (Davis & Ballreich , 2014). These rates were especially high for individuals earning less annually than the median national income (Davis & Ballreich , 2014). As a result of low measurements for access, the United States also has the lowest scores for health care equity. This is clear in the disparities in disease burden and health outcomes that occur due to apparent disparities in health care access and utilization. In terms of insurance coverage, low SES, having an education level lower than a college degree, being female, and being Hispanic or African American are associated with lower insurance coverage than reference groups (CDC, 2012).

Disparities in insurance coverage occurred in similar patterns as disparities in how patients utilized preventive services. For colorectal cancer screenings (the second leading cause of death that affects both men and women), Native Americans and Hispanics had lower coverage than non-Hispanic blacks or non-Hispanic whites (CDC, 2013). For other preventive tests- such as PAP smears, PSA screenings, influenza vaccinations, and mammography screenings, Hispanic and African-American populations had lower rates of coverage than white Americans (Fiscella, Holt, Meldrum, & Franks, 2006). Studies in elderly populations show that this trend holds for African Americans and Hispanics for colorectal screenings, influenza vaccinations, and mammograms (Chen, Diamant, Pourat, & Kagawa-Singer, 2005). When examining how these patterns fit in relation to HIV testing, results were somewhat different. Compared to whites, African Americans and Hispanics are more likely to have been tested at any point in life or in the past several months (Ebrahim, Anderson, Weidle, & Purcell, 2004). Diagnosis rates can also reflect some disparity in likelihood of HIV testing. Indeed, the rates of diagnosis are relatively higher in minority populations than among white Americans.

Disparities in HIV testing followed similar patterns as disparities in how patients progressed in HIV-related care. Minority groups consistently have lower levels of progression through HIV care than white Americans (CDC, 2013). Within racial groups, there were disparities between the genders in HIV care utilization. Among Hispanic men and women diagnosed with HIV, men were less likely to progress to later stages of HIV care than women (Gant, Bradley, Hu, Skarbinski, Hall, Lansky, 2014). Among the black population diagnosed with HIV, men received lower levels of care than women at each stage of the continuum of care (Whiteside, Cohen, Bradley, Skarbinski, Hall, Lansky, 2010). When looking at modes of transmission, lower levels of linkage to care and viral suppression were observed for injection drug users compared to individuals who were infected from heterosexual activity (Gant et al., 2014). Individuals younger than 26 years of age also received less care at each stage than individuals 26 years or older (Whiteside et al., 2010). Among the entire population, Hall also observed lower levels of care for younger age groups than older age groups (Hall et al., 2013). Non- demographic characteristics, such as lack of insurance, mental illness, substance abuse, and lack of supportive services have also been shown to reduce the likelihood of HIV-care linkage and retention as well (Mugavero et al., 2013).

Disparities in HIV-Related Health Outcomes

Inequalities in HIV disease burden tended to follow similar patterns of inequality as levels of health outcomes and mortality related to HIV. One study from Meditz indicated that women, nonwhite individuals, and individuals living in the southern United States tend to have worse HIV-related outcomes and are more likely to experience HIV-related health events (Meditz et al., 2011). Another study from McMahon indicated that individuals who were less educated, live in poverty, and contracted HIV via sexual transmission were more likely to experience mortality related to HIV (McMahon et al., 2011). In terms of mortality, Blacks/African Americans had much higher HIV-related mortality than any other race (CDC, 2012; McGinnis et al., 2003). Older individuals tended to have higher rates of HIV-related mortality than younger individuals as well (CDC, 2012). In terms of attaining viral load suppression, African Americans tend to have greater odds of failing to attain a suppressed viral load than whites. Individuals on public insurance or who are uninsured also tend to have greater odds of failing to attain a suppressed viral load than individuals with private insurance (Mugavero et al., 2009). One group that is heavily dependent on public insurance and the public healthcare system is the veteran population in the United States. Before examining influential factors on how veterans progress through HIV care, it is important to understand the specific health burdens for the veteran population.

Veterans' Health

The Current State of Health Among United States Veterans

Before we examine the experience of patients at Veterans' Affairs Clinics, it is important to understand the current state of health among the veteran population in the United States. The health of veterans in the United States is dependent on several factors, given that their military occupations put them in situations of greater risk than others. This can often lead to long term health effects of physical and psychological nature that are not typical of the general population. An example is veterans who served in the Chemical Corps during the Vietnam War who were exposed to defoliant ("agent orange"). Compared to non-Vietnam War veterans, this group was at a greater risk for chronic conditions such as diabetes, hepatitis, and chronic respiratory condition (Kang et al., 2006). Cyprel found that occupational levels of exposure to herbicides by Vietnam veterans led to a greater risk of mortality from all causes, respiratory illness, respiratory cancers, and other forms of cancer compared to non-veterans (Cypel & Kang, 2010).

Military service also influences veterans' risks for chronic and mental health conditions. A CDC report showed that veterans have significantly more chronic health issues and psychological issues as they grew older compared to civilians (Kramarow, Pastor, 2012). This was supported by a study from Wilmoth indicating that veterans have worse health than non-veterans as they age, even if they may report better health at other points in the aging process (Wilmoth, London, Parker, 2010). Age (or when veterans served) was previously presented as a predictor for psychiatric disorder in a 1990 paper from Norquist. According to the findings, increased risks for psychiatric disorders manifested only for veterans serving after 1975 compared to non-veterans (Norquist, Hough, Golding, Escobar, 1990). Worse physical health outcomes for relatively younger active-duty veterans when compared to non-veterans have been found more recently, as well (Teachman, 2011). Hoerster's study of men at various stages of their military career also found that veterans were more likely to report fair or poor health, have received a diagnosis for cancer or arthritis, have cardiovascular disease, and a history of depression or anxiety disorder (Hoerster et al., 2012). In a similar study of women at various stages of their military career, veteran women reported a higher incidence of mental health conditions and chronic disease than civilian women (Lehavot, Hoerster, Nelson, Jakupcak, & Simpson, 2012).

The evidence on the health effects of military service are not completely in agreement. One study suggests that selection bias related to how individuals are recruited into the military can make veterans a poor representation of the general male population (Conley & Heerwig, 2012). After adjusting for this bias, the same study found little to no difference in health outcomes and mortality in veterans compared to representative civilian counterparts (Conley & Heerwig, 2012). Other studies have also found no association between veteran status and mental health outcomes like depression and anxiety (Gould, Rideaux, Spira, Beaudreau, 2014). There is a much greater body of evidence, as indicated above, that veterans generally suffer more negative health outcomes later in life than non-veterans.

There is also conflicting information on the role of combat experience in predicting health outcomes among veterans. In a retrospective study of a cohort of Gulf War and Gulf Era veterans, Gulf War veterans were at a significantly higher risk for many chronic diseases at 10 year follow-up than veterans who did not serve in the Persian Gulf (Kang, Li, Mahan, Eisen, & Engel, 2009). In the same study, Gulf War veterans were at a significantly greater risk of PTSD and other mental health disorders than veterans who did not serve in the Persian Gulf (Kang et al., 2009). This study indicates that serving in a combat role places veterans at a greater risk for negative health outcomes than simply serving in the military. However, an earlier cross-sectional study from Elsen suggests that health outcomes did not differ very much between deployed and non-deployed veterans from the same cohort (Eisen et al., 2005). Another study from Hotopf indicates that Gulf War veterans had higher self-reports of ill-health than veterans from the same era who did not serve in the Persian Gulf (Hotopf et al., 2003). Similar effects were found when comparing risk of stroke, cancer, hypertension, and lung conditions in Vietnam War veterans to Vietnam era veterans (Brooks, Laditka S., & Laditka J., 2008). This conflict of information extends into comparisons between veterans and the general population. One study suggests that selection bias related to how individuals are recruited into the military can make veterans a poor representation of the general male population (Conley & Heerwig, 2012). After adjusting for this bias, the same study found little to no difference in health outcomes and mortality in veterans compared to representative civilian counterparts (Conley & Heerwig, 2012).

Veterans' Access to Healthcare

It is a common conception that United States veterans receive easily accessible healthcare from the Veteran's Affairs facilities. Indeed, VA patients experience reductions in institutional barriers compared to patients at other health care institutions. The integrated model of the VA creates an environment where costs are typically based on patient income and other eligibility criteria. The use of electronic medical records also allows for VA patients to utilize VA hospitals as the sole provider of their healthcare services. While recent policy changes have increased coverage to almost all veterans under the VHA, a system of prioritizing patients means that access is not equitable (Woolhander et al., 2005). This is partially related to insufficient budget increases to satisfy increasing enrollment after reforms were made to the Veteran's Health Act (Woolhander et al., 2005). The level of understanding of their coverage is often low among veterans as well. VHA reports state that less than 50% of veterans have at least "some" understanding of their benefits for healthcare, education, life insurance, burial, and home loans (Dept Veterans Affairs & Westat, 2010). This level of understanding decreases with each age group veterans (according to when they served) (Dept Veterans Affairs & Westat, 2010). Over the past year, 18.7% of veterans reported never using the services at the VA and of these, around 24% attributed their lack of use to difficulties with access (Dept Veterans Affairs & Westat, 2010). In terms of insurance coverage, around 1.3 million veterans are uninsured with 31.6% of those individuals living below 100% of the federal poverty line (Haley & Kenney, 2013). Many of the individuals who are uninsured also receive incomes that make them ineligible for coverage from the VA (Woolhander et al., 2005). Being uninsured has a great impact on veterans' ability to satisfy their health needs, with 41.2% reporting unmet health needs compared to only 12.7% of insured veterans (Haley & Kenney, 2013). When compared to the general population, uninsured veterans have less or as little access to care as uninsured non-veterans (Woolhander et al., 2005). In terms of the distribution of veterans' dependence on the VA for health care, around 6.2% to 18% rely solely on the VA for health benefits, while 42.1% rely at least partially on the VA for health benefits (Hynes et al., 2007; Nelson, Starkebaum, & Reiber, 2007). Veterans who are less educated, have higher VA priority, and who identify as part of a racial minority are the most likely to rely solely on the VA services for healthcare benefits (Hynes et al., 2007; Nelson et al., 2007). While it is commonly thought that the Office of Veteran's Affairs provides free and reduced healthcare to all veterans, this is clearly not the case. Veterans in the United States remain a neglected population even when in the realm of their own healthcare system.

HIV in Veterans

The exact rate of HIV is difficult to measure, but in 2011 there were 25,271 HIV-infected veterans who received care at a VHA facility (Dept of Veterans Affairs, 2012). The vast majority of these veterans are men (97%), which differs from the general population gender distribution where men are around 75% of HIV infected individuals (CDC.gov, 2011). African Americans are the largest racial/ethnic group that makes up HIV-infected individual in care at VHA (48%), 40% of veterans receiving HIV care at VHA facilities are white, and 7% are Hispanic or Latino. The rate of Africans is similar in the general population of the United States (44%), while the proportion of HIV-infected Hispanics in the general population is higher (21%). HIV-infected individuals receiving care at VHA facilities are generally older than HIV infected individuals in the general population (Dept of Veterans Affairs, 2012; CDC, 2012). Around 70% of HIV-infected individuals at the VHA are older than 50 years of age while only 9% of the general HIV-infected population are older than 55 years of age (Dept of Veterans Affairs, 2012; CDC, 2012). Therefore, the HIV-infected veteran population is likely older, has a different gender distribution, and suffers from higher rates of chronic disease and mental health issues than the general population. Given that the HIV-infected veteran population faces many barriers to health care retention, it is important that the factors that influence retention be further examined.

HIV Care Frameworks

Before we can further examine issues with retention in HIV-care, it is important to explore several different ways to examine HIV Care. One framework, the Continuum of Care, has previously been mentioned and will act as the primary model for this study. However, many other models examining human health-related behavior present other ways to consider how individuals progress through HIV care. These other models can work with the Continuum of Care to create a fuller picture of patient behavior along the continuum.

Current knowledge proposes that "treatment as prevention" is the most effective way to reduce HIV prevalence and prevent new HIV infections. However, there are flaws in this strategy in that it requires high levels of engagement in HIV care after individuals are diagnosed (Del Rio & Mayer, 2013). In 2010, the National HIV/AIDS Strategy initially created the Continuum of Care for HIV treatment as a monitoring tool for goals for patient engagement in care set for 2015. At the request of the Office of National AIDS Policy, the Institute of Medicine created a continuous framework depicting important data indicators and supportive services that became the continuum of HIV care (Del Rio & Mayer, 2013). This framework illustrates the steps in linking and adhering to HIV treatment in a linear fashion and includes indicators for how successfully people are progressing from one stage to the next (Figure 1). This model has been criticized because it implies that HIV patients can only enter care at one location – testing- and does not account for individuals who are lost to care and re-enroll in treatment later (Hallet & Eaton, 2013). Hallet and Eaton propose a model similar to that of the IOM, but propose that there is a "side door" effect that must be accounted for in their framework. Mugavero et al. also supported this notion of the "side door" with his framework demonstrating the reintegration of patients that dropped out of care for any reason. This process of patients moving in and out of HIV Care is referred to as "churn" (Mugavero et al., 2013).

This continuum framework has been recently applied to the HIV- infected veteran population at the Atlanta VA Hospital in a paper from Mangal et al. Mangal describes the continuum of care using the following steps for care: (1) estimation of total number of individuals living with HIV, (2) individuals living with HIV who had received a diagnosis, (3) patients linked with HIV care, (4) Patients who were retained in care, (5) patients eligible for Antiretroviral Therapy (ART), (6) the number of patients prescribed ART, and (7) people living with HIV who had obtained a status of viral suppression (Mangal, Rimland, & Mugavero, 2014). One important fact to note about the steps of HIV care is the pattern of loss that occurs along the process. From testing, to initiating care, to adherence, to suppressing viral load, a proportion of individuals is lost for one reason or another. This had been traditionally referred to as the "cascade of care" (Mangal et al., 2014; Hallet & Eaton, 2013; Mugavero et al., 2013). In the context of the Atlanta VA Hospital, the amount of loss from stage to stage is notably lower than the average for the nation. However, there are still significant proportions of individuals with HIV who are not virally suppressed. Given that the most popular strategy for HIV prevention is the test-and-treat method, it is crucial that the leakages in this cascade of care be reduced. This starts with linkage into care, but also depends on high retention in HIV treatment. At each stage along the continuum of care, there are a number of environmental and individual level factors that impact an individual's decision to continue or discontinue care. It is important to understand some of the important theories about how multiple levels of influences can impact the health behaviors of an individual.

Human Health Behavior Theories

The idea of social determinants impacting health outcomes introduces the notion that individual health behavior is influenced by a multitude of factors. In general, human health behavior is based on characteristics or factors that are intrinsic -or inherent to each individual- and factors that are external - or that potentially could influence multiple individuals. As the medical community has shifted away from reductionist practices in diagnosis and treatment, several theories have emerged to illustrate the complexity of human behavior and health outcomes. These theories differ in how they explain the influence of these factors on health behavior, but many propose that changes to the individual can occur as a result of changes in higher level factors. This means that examining some of these human health behavior theories can aid in finding a framework that most effectively explains determinants of retention in HIV care. In turn, that framework could be used to determine how to influence contributing factor to human behavior in order to induce health behavior change. Therefore, the following theories will be examined to illustrate different ways that human health behavior can be influenced: (1) Biopsychosocial Theory, (2) Sociocultural Theory, (3) the Socio-ecological Model, (4) resilience factors, (4) Self-Determination Theory, (5) the Health Belief Model, and (6) time-inconsistent preferences. Each theory will provide insight into how to consider influences on human health behavior and ultimately will aid in determining an effective area of intervention for improving retention in HIV care.

Biopsychosocial Theory

The biopsychosocial model of health is an extension of a more general social theory called psychosocial theory. A basic definition of the term "psychosocial" reads, "pertaining to the influence of social factors on an individual's mind of behavior, and to the interrelation of behavioral and social factors (Oxford English Dictionary)." So, the realm of psychosocial theory focuses on the effects of social structures on health outcomes through mediating psychosocial factors and how these effects are simultaneously mediated by psychosocial factors (Martikainen, Bartley, & Lahelma, 2002). Martikainen et al. discuss the use of psychosocial theory in epidemiology as a way to examine how social determinants of health can influence causal mechanisms of disease in different social or population groups. In the 1980s, George Engel adapted psychosocial theory to the realm of clinical medicine, insisting that social and individual factors must be considered alongside biological factors in causal pathways for disease (Borrell-Carrio, Suchman, & Epstein, 2004). Engel's "Biopsychosocial Model," rejected the traditionally dualist, detached method of clinical care for a strategy that included complexity science, structural causality, and relationship centered-care (Borrell-Carrio et al., 2004). Complexity science refers to a random multitude of causes and feedback loops that can lead to a health outcome, along with the interactions patients have within a system - in this case, a health system (Litaker, Tomolo, Liberatore, Stange, & Aron, 2006). Complexity science therefore rejects the effectiveness of linear cause and effect models of diagnosis in favor of a more inclusive model of causal mechanisms for disease. Structural causality attempts to take the multitude of factors considered in complexity science and form them into a hierarchy.

Creating a hierarchy improves care the ability of providers to effectively address the highest priority factor in the causal mechanism of a health outcome (Borrell-Carrio et al., 2004). Relationship-centered care emphasizes caring and consideration of the emotional and psychological impact of symptoms and the disease on patients (Borrell-Carrio et al., 2004). The quality of the patient provider relationship has been shown to have a significant impact on patient adherence, trust, and ultimately health outcomes (Beach, Keruly, & Moore, 2006; Schneider et al., 2004; Earl et al., 2013). Biopsychosocial theory provides a model for improved patient care through consideration of multiple levels in causal mechanisms of disease, including emotional and psychological impacts of disease on the patient. The proposed expansion of causal mechanisms culminates in improving the patient provider relationship so that treatment can be more effective administered by providers and more effectively adhered to by patients, ultimately resulting in improved health outcomes.

Sociocultural Theory

Sociocultural theory is relatively new development in human behavior theory. While it holds roots in social and cultural anthropology, as well as the psychological work of Lev Vygotsky, sociocultural theory encompasses a perspective that is used across many fields. In general, sociocultural perspective asserts that human behavior is influenced by a complex web of culture, environmental cues, social pressures, and social context (Mcleod, 2014). Ordonez and Marconi recently used the sociocultural perspective to enhance the classical paradigm of human behavior for HIV infection. According to the classical paradigm, environment (developing character) and genetics (defining temperament) contribute to personality, which interacts with human agency and external factors to determine how humans behave in response to their life experiences (Ordonez & Marconi, 2012). In this way, it becomes easier to understand how HIV infections tend to occur more frequently in vulnerable populations. Individuals who are in vulnerable population groups are more likely to have been exposed to environmental conditions that could leave them less able to adjust health behaviors to avoid diseases such as HIV. Triesman, Angelino, and Hutton illustrated this well with the case of a patient with complex psychiatric personality disorders rooted in their environment where they grew up prior to their infection. It became apparent that different treatment protocols were needed in order to enable patients with complex psychiatric disorders to navigate complex HIV treatment programs (Triesman, Angelino, & Hutton, 2001). The inclusion of the sociocultural perspective therefore allows us to examine the linkage between the childhood and contemporaneous social environment with experiences that a person may encounter in various aspects of the healthcare environment. Including the notion that some patients may be less capable of overcoming barriers to treatment than others allows us to better identify why some patients are able to be retained in HIV treatment while others are not. This means that examination of human behavior and human experiences can be narrowed or broadened to as many venues of the environment as desired.

Socio-Ecological Model

The Socio-ecological model was developed by Urie Bonfenbrenner in response to the restricted views of psychological development that were held in the 1970's. Bonfenbrenner proposed that the environment has an important impact in individual development that could be conceptualized in two interdependent ways. The first conceptualization proposes that human development occurs through complex, regular interactions with persons, objects, and symbols in the immediate environment of an individual- known as "proximal processes" (Bonfenbrenner, 1994; Bonfenbrenner, Friedman, & Wachs, 1999). The nature of "proximal processes" varies based on characteristics of the individual, the environment where the processes occur, and the outcomes that are impacted by processes (Bonfenbrenner, 1994; Bonfenbrenner et al., 1999). Examples of this conceptualization have occurred through studies illustrating that proximal processes of mother to child interactions can act as a buffer to the negative impacts of poor environment and circumstances (i.e. lower SES and lower birth weight). Bonfenbrenner also found that proximal processes showed their greatest benefits in the most advantaged environments and that the protective effects have diminishing returns. In other words, better proximal process have greater effects on individuals with the poorest development measures than on individuals who already have adequate development measures, provided that they occur in the most advantageous environment available (Bonfenbrenner et al., 1999).

The second conceptualization of the Socio-ecological model describes the ecological environment as a set of "nested structures" (Bonfenbrenner, 1994). These nested structures include the following; microsystems, mesosystems, exosystems, macrosystems, and chronosystems. Microsystems include the nature of the proximal process that occurs for an individual and where these processes occur (i.e. the school or the home). Mesosytems are the linkages and processes between microsystems (i.e. school's impact on home). Exosystems are linkages and processes between a setting that does not contain the developing individual and a system where the individual is contained (i.e. parent's workplace impact on the home which impacts school performance). Macrosystems embody overarching cultures or subcultures that determine practices or beliefs in the environment where an individual develops (e.g. nuances that arise from cultural traditions); Finally, chronosystems added a new dimension to the environment by allowing the socioecological model to account for changes that occur in all nested structures of the environment over time (Bonfenbrenner, 1994).

The socioecological model provides insight into the importance of our interpersonal and direct interactions on human development and human behavior. A study from Langer and Rodin in 1979 examined the effects of promoting independence among nursing home residents on health outcomes. Individuals who received the intervention of independence promotion showed substantially better psychological and physical health outcomes when compared to controls who remained dependent heavily on nursing home staff (Langer & Rodin, 1976). While this study is somewhat dated, it does provide an example of the impact of proximal processes on an older age group and shows that changes can still occur beyond the critical childhood years. The proximal processes that occur within a healthcare system, therefore, could potentially have a positive impact on individual health behaviors by helping individuals overcome barriers to care in their environment.

Resilience Processes

Resilience Processes became popular in the 1980's, especially after the studies of Michael Rutter on resilience and child development (Rutter, 1987). Rutter asserts that "protective factors" are rooted in resilience, but must be viewed as processes rather than static characteristics of a person. A particular character trait, therefore, may act as protective in one scenario but harmful in another. Generally, processes or factors that can increase resilience fall into three large categories, psychological health, use of social capital from social support networks, and a sense of self-worth (Rutter, 1987; Farber et al., 2000; Hussen 2014). Farber, et al. attempted to quantitatively determine associations between resilience and quality of life factors and core beliefs. Higher levels of resilience were associated with better mental health, physical health, belief in benevolent people, increased self-worth, belief in a meaningful world, and increased self-control (Farber, et al., 2000). Hussen identified these factors as contributing to high levels of resilience in some HIV positive health workers in Ethiopia. Resilience is related to other concepts of human behavior like locus of control and self-efficacy in that all three can contribute to how a person deals with adversity. Resilience factors allow for the creation of a more complete picture of how an individual reacts when obstacles oppose their ability to carry out a certain action or behavior.

Self-Determination Theory

Self- Determination Theory (SDT) is a recently developed theory proposed by Deci and Ryan. At its core, SDT is concerned with the different ways that people are motivated to act in various circumstances (Deci & Ryan, 2000). Motivation occurs along a continuum ranging from internal to external, and is typically coupled with another idea known as regulation or internalization. Regulation essentially refers to how well some individuals internalize values or external sources of motivation (Deci & Ryan, 2000). The determinants of an individual's level of motivation and regulation revolve around what are known as the "psychological needs": autonomy, competence, and relatedness (Vansteenkiste &

Ryan, 2013). Experiences that support these psychological needs facilitate improvements in internalization of external motivations for the individual (Deci & Ryan, 2000). In this way, individuals are not bound to one portion of the continuum, but can move based on the current situation. Experiences impacting motivation therefore have an influence on a person's location along the continuum for future scenarios Vansteenkiste & Ryan, 2013).

Self- Determination Theory has major implications for creating programs that induce health-related behavior change. SDT provides a perspective that encourages recognition of how behavior mediates health outcomes in order to impact individual experiences and how those experiences influence motivation (Ryan, Patrick, Deci, & Williams 2008). This is particularly true in the healthcare environment, specifically at the level of the clinic. If characteristics of a healthcare climate are made to promote autonomy, competence, and relatedness, then they can have a positive impact on the ability of patients to become more internally motivated (Ryan et al., 2008). A growing body of research has found that autonomy-supporting aspects of healthcare climates can have positive impacts on satisfying the basic psychological needs of the individual (Ng et al., 2012). A systematic review of this body of literature also found that satisfaction of basic psychological needs had moderate to strong associations with improvements in patient welfare, including improved mental health and beneficial health behaviors (Ng et al., 2012). A specific example of how the clinical environment can improve patient autonomy comes from Pollak et al., who observe improvements in patient autonomy when physicians used reflective statements and empathy in their patient-provider interactions (Pollak et al., 2011). Patient autonomy, and presumably health behaviors, can therefore be improved at the level of the health clinic. This holds great significance for the current study as it focuses on patient experiences in the clinical environment and their impact on health behaviors related to HIV.

Health Belief Model & Locus of Control

The Health Belief Model is a similar model for human behavior to that of Social Cognitive Theory in psychology (Maiman & Becker, 1974). Social Cognitive theory proposes that behavior is influenced by a set of expectancies and incentives. The expectancies are related to (a) how events or environmental cues are connected, (b) potential consequences of an action, and (c) a person's belief that they can complete an action (self-efficacy) (Rosenstock, Strecher, & Becker, 1988). Incentives refer to how an individual values the outcome of a certain action or behavior change (Rosenstock et al., 1988). The Health Belief Model is similar but is more specifically geared towards health-related behaviors (Rosenstock et al., 1988; Rosenstock, 1966; Rosenstock, 1974). Generally, the Health Belief Model asserts that health related behavior changes depend on the following aspects: the existence of a relevant health concern, an individual believing that they are susceptible to that health concern, and an individual believing that a certain change in behavior will protect them from that health concern (Rosenstock et al., 1988; Rosenstock, 1966; Rosenstock, 1974).

Changing human health behavior in the realms of the Health Belief Model and Social Cognitive Theory depends partially on two other underlying principles: self-efficacy and locus of control. While both are similar, there is an important distinction that makes these two concepts interdependent. Locus of Control is considered to be a characteristic of the self, more concerned with whether outcomes or events are attributable to an individual's actions or the derived from an outside source (Rotter, 1966). Self-efficacy is more specific to individual situations and is more concerned with an individual's ability to complete an action or a change in behavior (Bandura, 1977). The concepts of self-efficacy and locus of control can be oriented in a 2x2 framework that can conceptualize individual compliance to behavior change (Figure 2) (Rosenstock et al., 1988). Individuals with high self-efficacy and an internal locus of control are most likely to comply with a desired health behavior because they believe their actions can improve their health and that they are capable of making a behavior change. On the opposite end of the spectrum, individuals with low self-efficacy and an external locus of control may have the lowest compliance because they do not believe a change in behavior will benefit their health and they do not feel capable of making such a change anyway. In the middle are individuals who believe that their behavior can affect their health but do not feel capable of making a change (internal locus of control and low self-efficacy), and individuals who feel capable of changing their behavior, but do not believe such a change will benefit their health (high self-efficacy, external locus of control).

Time-Inconsistent Preferences

Given that HIV treatment requires a long time commitment for patients, it is important to consider how human behaviors related to health may change over time. The concept of time-inconsistency from behavioral economics encompasses the tendencies of individuals to prefer a certain choice at one stage in time, but may change their mind at a later point. In general, time-inconsistency asserts that individuals tend to consider their present circumstances more than those that may occur in the future when making decisions that will impact their future behaviors (Bhattacharya & Lakdawalla, 2004). In terms of HIV treatment, it may be easier to engage a newly diagnosed person into care while their HIV is still new or when they are in worse health. However, as treatment begins to make improvements in their health, it may become harder for individuals to continue attending care because the sense of urgency has diminished. For these individuals, there is a bias towards the present (present-bias) whereby gratification of immediate needs is sought rather than considering future benefits of delaying that gratification.

A handful of studies have looked interventions targeting time-inconsistent preferences related to health issues such as smoking and obesity. Using incentive systems, smoking cessation and weight loss was notably greater in intervention groups than among individuals in the control group for each study (Gine, Karlan, & Zinman, 2010; Volpp et al. 2008; Volpp et al., 2009). These are known as contingency management or conditional cash transfers depending on whether the outcome is incentivized. Evidence is therefore present that ensuring greater levels of commitment or investment into a health behavior change can have long-lasting effects on behavior change and ultimately overall health. It is important to note that these studies were conducted in settings where individuals were all involved in the same care center or place of work (in one case, the setting was a Veterans Affairs Medical Center in Philadelphia). There is some controversy over the duration of effectiveness of incentive programs informed by behavioral economics at a policy level (Loewenstein, Asch, Friedman, Melichar, & Volpp, 2012). However, if interventions occurred at a facility level, this would allow for interventions or policies to take forms that work best for each patient population. There is a growing experience of using commitment contracts that actually invest the patient in determining the goals which have been found to endure beyond the termination of the incentive whereas conditional cash transfers and contingency management often result in an extinguishing of the behavior modification.

Summaries of Health Behavior Theories

Exploring each of these theories allows for the examination of factors in HIV treatment retention from many different angles. The biopsychosocial model allows for the consideration of various causes of disease beyond those that are biologically based. Socio-Ecological and Sociocultural theories provide a lens through which the impacts of the clinical environment can impact patients' decisions about retention in HIV treatment. Socio-Ecological theory goes a step further and provides an explanation for how interpersonal or direct interactions can provide a buffer for negative aspects of the clinical environment. This idea of improving an individual's ability to overcome obstacles is reflected in resilience processes, as well. Finally, Self-Determination Theory and the Health Belief Model allow us to more closely examine differences at the individual level in terms of source of motivation or level of belief that can influence the ability of a person to adopt a health behavior. According to each theory, interventions can be conducted to alter or adapt to the innate characteristics of an individual to create a desired health behavior change (retention in HIV treatment, in this context). Using theories that capture the individual and environmental aspects of Human Health Behavior, we are able to create the most complete framework possible for analyzing factors in retention in HIV treatment for a given individual or population. Through this analysis, ideal strategies for intervention can be optimally informed and designed. The effectiveness of programs aimed to improve individuals' commitment to a health behavior change exhibited in studies targeted at time-inconsistent preferences also provides guidance for the type of interventions that could be created to improve retention in HIV treatment.

Interventions Along the Continuum of Care

As described above, the Continuum of Care for HIV requires high proportions of HIV infected individuals to move through each stage of care in order to the current "treatment as prevention" strategy to be effective at reducing the prevalence and incidence of HIV/AIDS (Del Rio & Mayer, 2013). In its current state, the continuum of care has been described by some as a "cascade," with decreasing proportions of patients progressing to the next step along the continuum (whoever said this?). As of 2013, an estimated 82% of the HIV-infected population are diagnosed, 66% engage with HIV care, 37% are retained in HIV Care, 33% are prescribed Antiretroviral Therapy (ART), and 25% reach viral suppression (CDC.gov, 2013). Clearly, the largest drop occurs between engagement in HIV care and retention in care. This sharp decrease is the focus of this study, but it is important to examine what interventions have been implemented at other stages of the continuum. Of particular importance are interventions that target engagement in care and ART adherence (those who move from ART prescription to Viral Suppression).

Linkage to Care

A wide variety of interventions have been implemented to improvement linkage of newly diagnosed HIV-infected individuals to HIV treatment. Several systematic reviews have assessed the overall effectiveness of these interventions. The most promising results came from case-management and peer support, while limited support was observed for incentives and delivery service reform. Several randomized control trials indicated that supporting patients through strengths-based case management led to greater linkage to care within 6 months of diagnosis (Brennan, Browne, & Horban, 2014; Okeke, Ostermann, & Theilman, 2014; Gardner et al., 2005). Strengths-based case management refers to case managers creating a crisis navigation plan that is based on identified strengths of each patient (Okeke et al., 2014). Other studies have found that use of peer supporters and integration of counseling and HIV care tend to improve enrollment in HIV care (Govindasamy et al., 2014). Providing incentives in the form of food, finances, or medical incentives was observed to have some beneficial effects on improving patient linkage to care or initiation or ART (Brennan et al., 2014; Govindasamy et al., 2014). Finally, changing delivery of service by sending reminders for linkage to care to mobile phones showed limited support in one review, and was overlooked in others (Brennan et al., 2014). The most promising results for improving linkage to care occurred with interventions that focused on improving the capacity of patients to decide to initiate HIV treatment. Case management allows for individualized counseling that can potentially create great improvements in health behavior for individuals who may have low levels of self-efficacy or more external sources of volition.

Adherence (ART Adherence)

The effectiveness of interventions that target adherence to antiretroviral therapy (ART, also referred to as HAART) has proven to be difficult to quantify. Systematic reviews and meta-analyses of trials and interventions conducted in developed or high resource countries indicate that interventions targeting ART adherence are generally ineffective (Scanlon & Vreeman, 2013; Mathes, Pieper, Antoine, & Eikermann, 2013; Beith & Johnson, 2006; Fogarty et al., 2002). Adherence, as whole can be somewhat difficult to assess, but ART adherence is especially difficult because of a lack of uniformity of the definition for adherence among researchers (Beith & Johnson, 2006). Occasionally, motivational interviews or individualized counseling interventions will generate statistically significant improvements in adherence for the intervention group (Mathes et al., 2013; McDonald, Garg, & Haynes, 2002; Golin et al., 2006). In other instances, individual studies have demonstrated the effectiveness of mobile phone SMS reminders at improving adherence in low-resource areas (Pop-Eleches et al, 2011; Lester et al, 2010). The greatest successes at improving ART adherence have been shown in studies where the intervention is direct observed therapy (meaning, that medication is taken under the supervision of a medical professional) (Hart et al., 2010), which is possibly the most intensive of the interventions. This finding is aligned with McDonald's statement in his systematic review of many different types of adherence interventions that effective adherence interventions tend to be labor intensive, complex, and unpredictable (McDonald et al., 2002). Simoni concludes in her systematic review that clinical interventions aimed at improving ART adherence should be comprehensive and multi-faceted so that interventions can be as dynamic as the behaviors they wish to change (Simoni, Amico, Pearson, & Malow, 2008).

Indeed, evidence indicates that increasingly direct interventions may be needed to impact ART adherence. Increasing directness means that interventions will likely need to occur more frequently in the clinical setting. The location of ART prescription after Retention in Care along the Continuum of HIV Care supports this idea that presence in the clinic for appoints could be associated with adequate ART adherence. Therefore, it is important to examine the possibility of improving retention in care so the improvements can occur downstream in ART prescription and ultimately suppression of viral load.

Retention in Care (Appointment Keeping)

Retention in care or appointment keeping can have great implications on health outcomes for diseases that are chronic in nature. It is widely acknowledged that maintaining high levels of retention in HIV care is crucial for improving health outcomes through ART adherence (Thompson et al, 2012; Higa, 2014; Brennan, 2014; Okeke, 2014). Even in the setting of the VA, poor rates of retention to HIV treatment have been associated with lower rates of survival among HIV-infected individuals (Giordano et al., 2007). However, the importance of retention for improvements in ART adherence and viral suppression has been called into question in a recent study from Mangal (Mangal et al, 2014). On the other hand, the variety of definitions for retention makes it difficult to compare the measured effects of retention across studies. A number of studies have attempted to examine the impact of retention on the progression of patients to later stages of HIV care. Several studies point to incremental improvement in diabetes-related outcomes as appointment keeping improves (Schectman, Schorling, & Voss, 2008; Parker et al., 2012).

As described above, the proportion of the HIV infected population who progresses to the Retention in Care stage along the HIV Continuum of Care is much lower than the proportion who engage (CDC, 2013). However, improvements in retention have occurred using a few of the interventions that were successful in improve linkage to HIV care. Primarily, these were the more labor-intensive interventions such as case management and individualized counseling. Systematic reviews of interventions targeted at improving retention observed success with the Strengths-Based Case Management techniques described above (Brennan et al., 2014; Okeke et al., 2014; Higa, Marks, Crepaz, Liau, Lyles, 2012). Thompson et al.'s recommendations for retention in HIV care also include Strengths-Based Case Management as well as intensive outreach for newly diagnosed HIV-infected individuals (Thompson et al, 2012). Evidence was also shown for effectiveness from interventions that included more passive tactics such as posters in waiting rooms, brief promotional messages given to patients by providers, and reminder calls (Higa, 2012). Whether interventions are comprehensive and direct or passive, it is clear that these interventions must be effective in order to have downstream benefits on ART adherence and viral load.

Retention can be impacted in several areas of the healthcare environment. The failures of many interventions to significantly improve adherence can be attributed to their observational design, where external variables can interfere with adherence (Brennan et al., 2014; Gardner et al., 2005). This somewhat explains why Direct Observed Therapy was most effective at improving ART adherence. However, interventions can occur in the clinical setting have been shown to improve patients' abilities to overcome obstacles that occur outside of the direct monitoring of a physician (Pollack et al., 2011). Human health behavior theories emphasize the notion that the capacity of individuals to act in ways that are beneficial for their health simply for the sake of that benefit can be increased. One of the major areas where this capacity can be improved is in the clinical setting and the experiences that patients have while attending appointments in the clinic. It is mentioned above that there is conflicting evidence of the importance of retention in maintaining high levels of ART adherence, but there are parallel benefits that can come from high levels of retention in HIV treatment. Improving retention in HIV treatment at a population level provides greater access to screenings other important health behavioral education that is indirectly related to HIV. An example would be improved access to prevention education and strategies for co-infections, which are quite common in individuals with HIV (Dep. Health and Human Services, 2012).

Patient Experience

A report release by the Robert Wood Johnson Foundation asserts that improving patient experience can have positive impacts on patient outcomes through improved engagement and adherence (Robert Wood Johnson). This has been supported by independent research on the impact of patient experiences on health outcomes. Specifically, research tends to focus on communication between patients and clinicians, which consistently demonstrates the most benefits on health outcomes (Manary, Boulding, Staelin, & Glickman, 2013; Stewart, 1995). The level patient-provider communication has been shown to impact health outcomes through mechanisms such as trust, self-efficacy, and knowledge were the mechanisms through which health improvements occurred (Street, Makoul, Arora, & Epstein, 2009; Beach, Keruly, & Moore, 2006; Earl et al., 2013; Schneider et al., 2004). In addition, it has been shown that interactions with health providers of similar cultural or ethnic backgrounds as patients can improve patient trust in their provider (Earl et al., 2013; Gordon, H.S., Street Jr., R. L., Sharf, B. F., Kelly, A., Souchek, J., 2006; Doescher, M. P., Saver, B. G., Franks, P., Fiscella, K., 2000) Self-efficacy has been shown to be an especially important pathway between positive patient experiences and improvements in health outcomes related to chronic diseases (Street et al., 2008; Zachariae et al., 2003).

Research on the patient experience has primarily been focused on the interactions between providers and patients and how these interactions directly impact health outcomes or impact mediators of health behavior. Treatment of chronic diseases has been identified as situations where the patient experience is especially important for improvements in health outcomes. However, research on other aspects of the patient experience is less available or only available in poor quality studies (Manary et al., 2013; Rubin, Owens, & Golden, 1998). Some studies have been conducted on the influences of the physical environment of clinics primarily focuses on patient safety, and not on health behavior mediators

(Ulrich, Quan, Zimring, Joseph, Choudhary, 2004). However, the evidence for the effects of structural barriers in the clinic on the patient experience is less available.

Conclusions

Clear health disparities exist in the United States based around social determinants that have been well identified in research. These disparities become particularly evident for HIV in the distribution of diagnosis, access to care, and HIV-related outcomes. Within the population of veterans in the United States, disparities in HIV diagnosis, care, and outcomes are as severe or more severe as in the overall population. Within the current Continuum of Care model for HIV treatment, there is a “cascade” effect as decreasing proportions of patients progress from one stage of care to the next, leading to large discrepancies between the number of HIV-infected individuals who are diagnosed and the number who reach viral suppression. Human health behavior theory provides multiple theories that create a complete picture of how interventions can improve the health of patients through encouragement and support of self-efficacy and internal volition. Interventions have been fairly successful at linking newly diagnosed HIV-infected individuals to HIV-care, but less successful at improving levels of Retention in care and therefore ART adherence. In order to increase the number of HIV-infected individuals who retained in HIV treatment, interventions that encourage autonomy and self-efficacy in a direct manner must be identified and implemented.

One of the most direct ways that the medical community can impact individual health behaviors of patients is in the clinical setting. Since some patients are more internally motivated in their health behaviors than others, it is important that the experiences at the clinical setting bolster self-efficacy and internalization- especially in patients who may have lower levels of these health behavior mediators. Therefore, it is important to identify which aspects of the patient experience could be improved based on patient feedback. Much quantitative work has been conducted in the field of assessing the effective of environmental interventions in the clinic, but there is a need for qualitative research to inform the development of future interventions. Qualitative research can provide depth and nuance in findings that can help individualized interventions to a certain clinic or population group. In the case of the Atlanta Veterans' Affairs Hospital, the following qualitative research will be used to identify the aspects of the clinical experience that may cause individuals with lower internal volition to be lost from HIV-treatment.

CHAPTER III. MANUSCRIPT

Title Page

Clinical Influences on Patient Retention in HIV Treatment at VA Medical Center

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Contribution of Student [required for Rollins thesis; not for publication]

My involvement in this project began over the summer of 2014. I was connected with the members of the thesis committee and this dataset in the aftermath of a sudden cancelation of my previous practicum plans. I began writing thick descriptions for data collected as part of the VA RETAIN study (which never produced published material) to fulfill practicum requirements for an MPH. As the summer progressed I became deeply interested in the data and wanted to use it for a thesis looking at what influenced retention in HIV treatment. From that point forward, I consulted experts, conducted literature reviews, and continued with writing thick descriptions to construct my research question. After developing my question, I conducted the analysis that led the findings presented in this thesis. I was also responsible for writing and preparing of the manuscript, as well as the creation of the frameworks that are included.

Abstract

Social determinants of health create significant disparities in disease burden and access to health care in the United States. Within the HIV-infected population, clear disparities in HIV infection and retention in HIV treatment exist in the United States based around these social determinants. Among the population of veterans in the United States, disparities in HIV diagnosis, care, and outcomes are as severe or more severe as in the overall population. However, differences in demographics and the unique structure of the VA health system can lead to differences in veterans' access to HIV care. In the following project, we examine how the HIV positive patient's experience of healthcare at the Atlanta Veterans Affairs Medical Center (AVAMC) influences their retention in HIV treatment. We used secondary analysis of qualitative data to determine the barriers that inhibited retention for participants with an external locus of control and identify the attitudes that facilitated retention for participants with an internal locus of control. Results identified three central interrelated elements of the clinic experience that influences retention in care. For the external locus of control group, clinic waiting time, their level of confidence in clinicians, and customer service acted as barriers to retention within the clinical setting. For the internal locus of control group, patience with structural issues, level of confidence in clinicians, and interpersonal connections facilitated higher rates of retention in HIV treatment. The findings of this study provide the foundation for further research to design clinic interventions to improve clinic-based barriers to retention in treatment for HIV positive patients in the AVAMC.

Introduction

Healthcare is not an area of equality for all individuals living in the United States. According to CDC's Health Disparities Report, race, education level, socioeconomic status (SES), and gender hold notable associations with morbidity and mortality outcomes, as well as levels of access to insurance and preventive care (CDC, 2013). In the case of diseases like HIV which require long term treatment protocol, these same factors can influence how successfully patients progress through care to reach viral suppression (Hall et al., 2013; Mugavero et al., 2013). In addition, treatment of HIV relies heavily on the creation and maintenance of health behavior change in infected individuals. Treatment regimens should therefore attempt to reduce specific barriers to behavior change that occur for different groups of infected individuals.

In the United States, the veteran population is a group that can be at greater risk for chronic disease, mental health issues, and other conditions that also require long term treatment. The veteran population has also received increased attention in terms of the quality of healthcare they receive from Veterans Affairs Medical Clinics. In terms of HIV, the prevalence in the veteran population is difficult to measure, but in 2011 there were 25,271 HIV-infected veterans who received care at a VHA facility (Dept of Veterans Affairs, 2012). Evidence also suggests that veterans have fewer issues with progression through HIV treatment compared to the general population. However, the veteran population and the care provided by VHA facilities have recently come under scrutiny for the quality of care their facilities provide to patients. Therefore, it is reasonable to suspect that there are aspects of the clinical setting at VHA facilities that could impact the progressions of veterans through HIV treatment.

In the qualitative research presented, we use human health behavior theories to classify HIV-infected veterans who are enrolled in treatment at the AVAMC based on their locus of control and source of motivation for attending HIV treatment. We then use previously collected data to understand how the clinical experience impacts retention in HIV treatment in each group of participants. This research is particularly relevant because of the lack of qualitative work on HIV treatment retention for the veteran population and the potential benefits that improving retention could have on ART adherence and viral suppression in the veteran population.

Background

HIV Health Disparities and the Veteran Population

The disparities in health that occur in the United States are prevalent in access to care and disease burden across population groups. CDC reports and other research indicate that indicators of access to healthcare such as insurance coverage, vaccine coverage, and usage of preventive services differed significantly based on education level, socioeconomic status, gender, and race/ethnicity (CDC, 2013; Lasser, Himmelstein, & Woolhandler, 2006). Disparities in health care access were similar to those that occurred in disease burden, especially burden of HIV infection (CDC, 2014). HIV infection prevalence differs significantly based on region of the country, and mode of transmission (Meditz et al., 2011; McMahon, Wanke, Terrin, Skinner, & Knox, 2011). Within the veteran population in the United States, disparities in HIV diagnosis, care, and health outcomes are equally severe or more severe as in the overall population (Dept of Veterans Affairs, 2012; CDC, 2012). In addition, members of the veteran population may face unique psychiatric or mental health issues (Norquist, Hough, Golding, & Escobar, 1990; Kramarow & Pastor, 2012;), and issues related to environmental exposures (Kang et al., 2006; Cypel & Kang, 2010). However, recent studies of veterans' health find that their outcomes may not occur in prevalences greater than in the civilian population (Conley & Heerwig, 2012; Gould, Rideaux, Spira, Beaudreau, 2014). In any case, it is apparent that veterans are either more susceptible or equally susceptible to conditions that can interrupt access and retention in HIV treatment when compared to the civilian population.

The Continuum of HIV Care and Health Behavior Theory

Given that HIV is now considered to be a chronic disease, access to HIV care extends beyond diagnosis and initial treatment. The model for HIV treatment often occurs in what has become known as a continuum of care with multiple stages from diagnosis to viral suppression (Mugavero, Amico, Horn, & Thompson, 2013). There is a notable level of overall decline in the proportion of HIV-infected individuals that are retained at each stage of HIV care. However, we once again see disparities in how individuals are retained in HIV care based on characteristics such as race, education level, socioeconomic status, and gender. Across the stage of HIV care, blacks and Hispanics / Latinos have lower retention levels than whites and men are retained less than women (Hall et al., 2013). Secondary characteristics such as lack of insurance, mental illness, substance abuse, and lack of supportive services have also been shown to reduce the likelihood of HIV-care linkage and retention as well (Mugavero et al., 2013). Human health behavior theory also provides insight into how individuals living with HIV might make decisions about HIV treatment. Theories such as those in the Health Belief Model and Self-Determination theory help explain how individuals can have varying capacities for behavior change (Deci & Ryan, 2000; Rosenstock et al., 1988; Rotter, 1966; Bandura, 1977). Time-Inconsistent Preferences expands on these ideas by including a chronological component in which individuals' decisions can become dynamic as their environment changes over time (Bhattacharya & Lakdawalla, 2004). Sociocultural and the socio-ecological models provide an introductory framework to how an individual's behavior can be impacted and changed by their immediate environment (Mcleod, 2014). Finally resilience processes explains how some individuals are able to overcome obstacles to behavior change more easily than others (Rutter, 1987). When all of these theories are considered simultaneously, we are able to understand how the same environment may facilitate a desired change in health behavior for some individuals while impeding the desired change for others.

Research on the continuum of care in the context of the Atlanta Veterans Affairs Medical Center provides insight into the problems of retention in HIV treatment that occur among the veteran population. The importance of high levels of retention to ART adherence and viral suppression is somewhat divided (Mangal et al, 2014), but is still generally supported as being beneficial for HIV-related outcomes and survival (Thompson et al, 2012; Higa, 2014; Brennan, 2014; Okeke, 2014; Giordano et al., 2007). Improving HIV retention through improving the patient experience has been recommended previously in literature (Giordano, 2011) and fits well with the WHO's Social Determinants of Health Model (Solar & Irwin, 2010). The clinical setting has also been proposed as the most effective venue for interventions targeting ART adherence through Direct Observed Therapy (Hart et al., 2010). Improving retention in HIV treatment increases the exposure of patients to the clinicians and providers, allowing for more opportunities to effectively improve ART adherence and ultimately improve viral suppression.

While the nature of the "cascade" effect along the continuum of HIV care has been well illustrated (Mangal et al., 2014; Hallet & Eaton, 2013; Mugavero et al., 2013), there has been little research examining the reasons why retention in HIV treatment tends to be much lower than rates of linkage into HIV treatment. There is a need for a body of qualitative research that explores the specific issues and barriers that contribute to individuals' decisions about their retention in HIV treatment. Given that the clinical setting is the location where the most effective interventions targeting HIV treatment retention and ART adherence have improved, it would be useful to gain a better understanding of the experiences of patients in the clinical setting and how their experience influence their attendance to HIV treatment.

Research Questions

In this study we examine how the patient healthcare experience at the Atlanta Veterans Affairs Medical Center (AVAMC) influences veterans' retention in HIV treatment. Specifically, the project aims to accomplish the following: 1) identify the aspects of the clinical experience where patients encounter barriers that negatively impact retention; 2) describe differences in patients' abilities to overcome barriers to care and remain retained in HIV treatment.

Methods

Data

Qualitative data were used for this secondary analysis, consisting of in-depth interviews with HIV positive veterans enrolled in treatment at the AVAMC. Twenty-five in-depth interviews were conducted, 16 of which were with individuals who had not attended an HIV appointment in the past 8 months. Of those 16 individuals, 4 reported receiving HIV treatment at other locations (e.g. another VA or private clinics). The remaining 9 in-depth interviews were conducted with individuals who were currently attending HIV treatment at the AVAMC. At the time of each interview, participants were not aware of their classification as a "case" or a "control." Although, they were asked to report the date of their last attended treatment appointment in order to confirm the accuracy of AVAMC records. A semi-structured interview guide was used to inquire about participants' military experience, their HIV diagnosis, experience with HIV-related stigma, their support network, and their experiences in the AVAMC. Data were already coded for themes of patients' emotions, the military & health, HIV, HIV treatment, the AVAMC, and influences on missed appointments.

Data Analysis

We used the Grounded Theory (Bryant & Charmaz, 2007) approach to data analysis because it allowed for the creation of frameworks that were based in participants' responses and captured the complexity of influences on HIV retention and participants perceptions of HIV retention. Data were already coded and entered into MaxQDA11, a software package to facilitate textual data analysis. Existing codes were used to search data to facilitate detailed descriptions of patient experiences related to retention in HIV care. This primarily consisted of close reading of text segments by code and developing descriptions of participants' responses in each group. We then regrouped participants based on trends that emerged in their perceptions of the clinical experience. Next, we compared descriptions of the clinical experience across groups in order to determine the core elements of the clinical experience for each group. We then examined participants' descriptions of those core elements within each group. Finally, we created frameworks describing the connections between each element and their impact on retention in HIV treatment for each group of participants.

Through an iterative process of reviewing data through repeated readings, we distinguished two types of patients: those who demonstrated an external locus of control and those with an internal locus of control. Human health behavior theory also informed our classification of participants' responses as exhibiting an external or internal locus of control. Participants were categorized as having an internal locus of control if they identified themselves as "most responsible for managing their HIV treatment." Participants in this group used more self-driven language when describing their HIV care and discussed the importance of being invested in their own HIV treatment. While participants in this group also identified family members or AVAMC staff as people who aid in the management of their HIV treatment, these were secondary sources of support to themselves. Conversely, participants categorized in the external locus of control group did not identify themselves as the person who was "most responsible for managing their HIV treatment" but relied on external support, typically from a spouse or family members who were most responsible for managing their HIV care. They did not exhibit self-driven language related to their HIV care, nor did they convey a sense of being invested in their HIV treatment.

Identifying Core Elements

For the creation of conceptual frameworks and developing theory, we compared the descriptions of the clinical experience provided by participants in each participant group. To identify aspects of the clinical experience that patients indicated as impacting their retention in HIV treatment, descriptions of the clinical experience were compared between patient types. For the external locus of control group, we identified the following core elements of the clinical experience from participants' responses: *Clinic Waiting Time*, *Level of Confidence in Clinicians*, and *Customer Service*. For the internal locus of control group, we identified slightly different core elements of the clinical experience from participants' responses: *Structural Issues*, *Level of Confidence in Clinicians*, and *Interpersonal Connections*.

Conceptual Frameworks

We used participants' descriptions of the clinical experience to create separate frameworks for each locus of control group. The aim of the frameworks was to capture the influence of the clinical experience on retention in HIV treatment for each locus of control group. The descriptions that informed the first framework focused on barriers to care that were experienced by individuals with an external locus of control and how these barriers negatively affected retention in HIV treatment. The descriptions that informed the second framework focused on the attitudes and behaviors that allowed for patients in the group with an internal locus of control to more effectively overcome barriers to care. Classifying participants based on locus of control allowed us to distinguish barriers to care that arose in the clinical setting for patients that were most vulnerable to failed retention. We were also able to identify the attitudes that enabled participants in the internal locus of control group to overcome those barriers. In this way, the framework for the internal locus of control group provides insight into the benefits that reducing clinical barriers can have on the attitudes and retention for participants in the external locus of control group. After identifying the core concepts in each group, deeper analysis within groups and for each individual was conducted to determine how links between each aspect of the clinical experience manifested. In terms of the frameworks, the illustrated linkages captured the general trends in how each aspect of the clinical experience was connected. Finally we verified each framework primarily through repeated readings of the data from each group in order to ensure the complexity of responses was accurately represented.

Results

Participant experience of the clinic and retention in care was markedly different by their locus of control. Therefore, results are presented from participants with an external locus of control followed by participants with internal locus of control. Three core elements of the clinic experience were identified as influences on retention in care and loss to follow-up, and each will be described separately. For participants with an external locus of control, these elements of the clinic experience acted as barriers to retention, while for participants with an internal locus of control, the elements facilitated their retention in care.

External Locus of Control

Participants with external locus of control reported three core spheres of influence on their poor retention in HIV care: clinic waiting time, level of confidence in clinicians, and customer service (as shown in Figure 1). Each sphere of influence is interconnected with others and culminates in the central outcomes of discomfort, dehumanization and low self-efficacy. Each sphere of influence is described separately below.

Clinic Waiting Time

A common issue for participants with an external locus of control was the long wait times for treatment at the AVAMC, with participants frequently waiting several hours for treatment, despite having arrived at the scheduled time. Almost every participant reported a long wait as part of their clinic experience, even if they did not describe it as connected to their decision of whether or not to attend treatment. These participants were discouraged by long waiting time, which they perceived as a double standard in punctuality for participants and the VA. If participants arrived late for their appointment time, they were asked to reschedule, but it was seen as acceptable for clinicians to allow participants to wait beyond the appointment time.

In addition, participants perceived a high burden was placed on them for the management of their HIV care, whereby they felt that their sacrifice of time for travel, parking, and waiting for their appointments were compounded by the high frequency of appointments that were required for check-ups, laboratory tests, and filling prescriptions. Participants believed that a more streamlined process was achievable based on their experiences at private clinics and at other VA facilities where they previously received care. Several participants expressed a desire to refill prescriptions at nearby pharmacies and conduct their blood work at clinics closer to their homes, to circumvent the long waiting time at the AVAMC. Alleviating issues of insufficient staffing was cited as a major way to decrease waiting time, and participants were frustrated that the AVAMC had not adopted what they perceived to be a simple and effective solution.

Long waiting time laid the foundation for participants' expectations that they would receive lower quality care than they deserved from the AVAMC. Participants perceived the inaction of the AVAMC to improve the length of waiting time as an indicator of the value that the AVAMC placed on their care.

Participants questioned the value of attending HIV treatment if they were not going to receive care in an efficient manner. In this way, the negative experiences with waiting time pre-disposed participants to have negative perceptions in spheres of influence that occurred later in each appointment.

Level of Confidence in Clinicians

The next sphere of influence reported by participants related to their level of confidence in clinicians and AVAMC. Nearly every participant with an external locus of control reported that they did not develop a meaningful relationship with clinicians at the AVAMC, largely due to having a new clinician providing care at each appointment. Participants also described their interactions with clinicians as superficial and rushed. For example, participants were asked the same basic health questions at each appointment, and visits only lasted 15-20 minutes, leaving little time for patients to discuss most of their health concerns. The juxtaposition of brief interactions with clinicians after such long waiting times, alongside the superficial nature of their interactions, led participants to feel undervalued. This feeling was reinforced when participants interacted with non-physicians during times when they usually interacted with clinicians. This usually took the form of interactions with students or individuals involved with research studies. Some participants of African-American background stated that these interactions were reminiscent of historical events such as Tuskegee that have left tension between the medical and African-American communities.

Feelings of disconnect in interactions with clinicians increased participants' feelings of being undervalued. Participants reported poor communication with clinicians, who they described as detached and dismissive. Participants felt that clinicians frequently were not listening to their health concerns, especially if they were not HIV-specific issues. Some participants would not even bring up some health issues to clinicians in anticipation that they would not receive the appropriate level of care. Ultimately, participants recognized that the quality of their relationship with clinicians at the AVAMC was closely tied to the level of consistency in who provided their HIV treatment and expressed a desire for more consistency in order develop more meaningful relationships with clinicians at the AVAMC.

Customer Service

The customer service sphere characterized references to policies, services, and non-clinician staff at the AVAMC. Participants felt that customer service at the AVAMC provided little support and accommodation to assist participants in remaining in HIV care. Issues with the scheduling system were prominent among participants, who felt that the system contributed to the uneven burden of care management described above. Participants are expected to attend HIV treatment every three months, but they cannot automatically schedule these appointments at regular intervals or even during a previous appointment. Instead, participants must call at a later time in order to schedule each appointment. In addition, participants reported difficulties with rescheduling appointments, especially if they needed to reschedule an appointment to renew their ART prescription before their refills expired.

Poor communication between staff and participants regarding missed appointments was identified as another area where customer service was unsupportive. If a participant missed a treatment visit and did not receive any follow-up communication, they believed this indicated a lack of commitment to their health on the part of the VA. In the setting of the clinic, detached attitudes among AVAMC staff led participants to feel that they had nowhere to turn for help in the ID Clinic. Participants described the process of being a patient at the AVAMC as a battle and attributed this feeling to low levels of accommodation provided by AVAMC staff. In fact, when participants did reach out for assistance, they believed that staff spent more time giving reasons why they could not help participants than discussing how to accommodate them.

Central Outcomes

The experiences captured in each sphere of influence and the resulting attitudes that arose for participants in each sphere culminated in overall experiences of discomfort, dehumanization, and low self-efficacy. Discomfort was an acute effect of experiences in each sphere of influence. At an individual appointment, a participant would feel discomfort when encountered with any of the barriers described above. Dehumanization describes the cumulative effects of repeated negative experiences that undermine the participants' sense of value as a participant and a human being. Several participants specifically referred to the overall experience of care as "unhumanizing." Ultimately, participants adopted the apathetic attitudes that they perceived in the practices of the AVAMC and applied them to their own participation in HIV treatment. Participants began to believe that attending HIV treatment was not worth the effort that attendance required, which led to diminishing effects on participant self-efficacy.

Internal Locus of Control

Participants with an internal locus of control reported three core spheres representing attitudes and behaviors that influenced their successful retention in HIV care: patience with structural issues, confidence in clinicians, and camaraderie from interpersonal connections (Figure 2). Each sphere is interconnected and culminates in the central outcomes of resilience, optimism, and investment. Each sphere and the associated attitudes and behaviors are described separately below.

Patience with Structural Issues

Participants with an internal locus of control expressed greater patience when they encountered structural barriers to care during their clinical experience. Participants expressed an understanding for why structural issues like long waiting time and staffing inadequacies can occur and were able to take on a more positive attitude towards these issues. Participants downplayed the length of the waiting time they experience at the AVAMC, pointing out that they believed waiting time had shortened and were comparable to waiting time at other care locations. Participants also described a causal relationship between staffing inadequacies and long waiting time but felt that staffing inadequacies were attributable to causes outside the control of the Atlanta VA. Participants believed that financial constraints placed on the AVAMC after "budget cuts" during a "bad economy" led to an understaffed and overworked AVAMC system that continued to show dedication to improving participant care.

Despite the issues faced in the structural sphere of their clinical experience, participants held lenient attitudes towards them due to the high quality of the care they received from the VA. Participants' positive experiences with clinicians and other AVAMC staff instilled confidence in the level of care they received and the dedication of the AVAMC to making improvements in care delivery. In this way, the potentially negative experiences in this sphere are countered by positive experiences in the other spheres of the clinical experience.

Confidence in Clinicians

Participants with an internal locus of control reported feeling protected under the care of clinicians at the AVAMC. Some participants in this group reported having a consistent clinician, but many reported having a different physician at each appointment. Participants who received consistent care from the same clinician described developing a close relationship and expressed increased motivation to remain involved in care and to only receive care from a single clinician. Participants who did not receive consistent care from the same clinician still had a great deal of trust in the clinicians because of the clinicians' high level of expertise and positive attitudes. However, these participants acknowledged that if they had an HIV-related emergency or if their health began to worsen, they would prefer to have a consistent physician who knew the more specific details of their medical history. While there were reports of isolated interactions with clinicians who seemed detached, clinicians were generally described as compassionate, caring, knowledgeable, having good communication skills, and providing care and consultation beyond the realm of HIV.

The relationships developed between participants and clinicians acted as an additional source of motivation to attend HIV treatment. Participants were more likely to comply with treatment either out of a sense of loyalty to their clinician or because their clinician had learned how to effectively motivate the participant. Participants with close bonds to their clinician also perceived attending HIV treatment visits as a way to maintain their friendship. For participants who did not have a consistent clinician or who occasionally had a negative experience with a clinician, the interpersonal connections that were developed with AVAMC staff provided an adequate level of motivation to return to treatment.

Interpersonal Connections

Interpersonal connections that participants established with staff at the AVAMC provided a sense of camaraderie that fostered successful retention in HIV care. Participants described staff providing caring demeanors in the clinic that can offset inconsistency or negative interactions with clinicians. Participants also felt that the staff in the ID clinic provided crucial emotional support and always seemed interested in the lives of participants. A handful of participants recalled times when staff provided emotional support when participants struggled in the initial phases of treatment.

The sense of camaraderie that most participants gained from the relationships they established with staff at the AVAMC played a significant role in their motivation to return to care. Many participants described visiting the ID clinic as being similar to visiting with old friends, and one participant even described their appointments as the highlight of their month. Attending treatment, therefore, had a social component that further facilitated participants' retention in HIV care.

Central Outcomes

The experiences captured in each sphere of attitudes and behaviors for participants with an internal locus of control culminated in resilience, optimism, and investment. Resilience is a characteristic that was likely developed in participants prior to entering HIV treatment, but positive experiences and a support network within the AVAMC may have reinforced and increased resilience in each participant. The resilience of participants usually manifested itself as optimism in the face of issues in structural aspects of the clinical experience or the occasional negative interaction with clinicians or staff. Finally, most participants acknowledged the importance of becoming personally invested in HIV treatment. Some participants attributed investment in care to innate characteristics, but many participants believed that the relationships that were developed at the AVAMC and the importance of HIV treatment to their health helped increase their sense of investment in HIV treatment.

Discussion

In the qualitative analysis presented, we examined the impacts of the clinical experience on retention in HIV treatment among veterans enrolled in treatment at the Atlanta VA Medical Center. We identified a framework of three interconnected spheres of influence that contributed to participants' success of retention in HIV treatment. For the external locus of control group, the clinical experience presented barriers that negatively impacted patients' attitudes and inhibited their retention in HIV care. For the internal locus of control group, the participants exhibited behaviors and attitudes that served as mechanisms for them to overcome barriers to care in the clinic and remain retained in HIV care.

Participants entered treatment at the with varying levels of capacity for behavior change prior to entering the clinical setting. Human health behavior theory asserts that individuals with a more internalized locus of control have a greater tendency to adopt behavior change (Rosenstock, 1988). In this case, the desired behavior change is retention in HIV treatment, which ultimately can have impacts on ART adherence and viral suppression (Thompson et al, 2012; Higa, 2014; Brennan, 2014; Okeke, 2014; Giordano et al., 2007). By dividing participants based on locus of control, we were able to make a distinction between the patients most vulnerable to failed retention in HIV treatment from the patients who are most likely to progress through HIV treatment successfully. We were then able to distinguish barriers to care that arose in the clinical setting for the external locus of control group and the attitudes that enabled participants in the internal locus of control group to overcome those barriers. In this way, the framework for the internal locus of control group provides insight into the benefits that reducing clinical barriers can have on the attitudes and retention for participants in the external locus of control group.

The clinic setting can have negative influences on participant retention in HIV treatment. Participants encountered what they described as dehumanizing treatment in each of the core elements of the clinical experience. They identified the long waiting time, detached demeanors or clinicians and staff, and an uneven burden of care management as indicators that the AVAMC was not committed to caring for its patients. Participants reflected this lack of commitment in their attitudes towards HIV treatment: they were less likely to see the value of HIV treatment, feel capable of attending treatment, or trust the quality of care they were receiving. Therefore, participants' attitudes of self-worth and self-efficacy in the context of HIV treatment were greatly influenced by the value they perceived was placed on their HIV care by the AVAMC.

Participants' attitudes and behaviors also acted as mechanisms that facilitated retention in HIV treatment. Participants in the internal locus of control group reported generally more positive experiences in the clinical setting, particularly in their interpersonal connections with staff and clinicians. The positive relationships were described as the greatest strength of the AVAMC and fostered a greater level of trust among participants in the care that they were receiving. Participants still encountered structural issues such as long waiting times and staffing inadequacies but did not view these issues as indicators of their value as patients or the value placed on their health by the VA. Instead, participants sympathized with the difficulties faced by the AVAMC as they attempted to treat a large patient population with limited human and financial resources. Therefore, participants in the internal locus of control group were able to find strengths in the AVAMC more easily than participants in the other group. This bolstered their pre-existing levels of resilience against barriers that may occur in the clinic and improved their motivation to attend their HIV treatment appointments.

Changes to the clinical environment could reduce barriers to care and potentially improve attitudes that facilitate participants' ability to overcome barriers. Reducing barriers that arise for the patients that are most vulnerable to poor retention in HIV treatment could lead to changes in attitudes that further improve their chances of successful retention in HIV treatment. In the context of the AVAMC, improvements in clinic waiting time, provider continuity, patient education, and provider communication could lead to higher rates of retention in HIV treatment. Decreasing the length of waiting time for appointments would diminish patients' frustrations by reducing the time commitment required out of patients at each appointment. This could be accomplished through the hiring of more clinicians or tactics to decentralize care (telemedicine, down-referrals, etc.) Improving provider continuity would help increase feelings of trust between patients and clinicians, which would improve patients' motivation to regularly attend treatment appointments. This could be accomplished through increased hiring of clinicians as well as through educating patients about how to more effectively schedule appointments with a consistent physician. Patient education should also include improving patients' understanding of other services offered by the AVAMC to improve their experience such as online medication refills

(MyHealthEVet) and proper rescheduling of appointments. Finally, provider communication should be improved through cultural sensitivity training. This would improve communication skills of providers and improve patients' trust in clinicians, which would contribute to improvements in patients' motivation to attend HIV treatment.

Conclusions

We identified three central interrelated elements of the clinic experience that influence retention in care. For the participants with an external locus of control, long clinic waiting time, their low level of confidence in clinicians, and negative experiences with customer service acted as barriers to retention within the clinical setting. These experiences indicated to participants that the AVAMC placed little value on providing HIV treatment. This perception negatively influenced participants' attitudes of self-worth and self-efficacy in the context of HIV treatment and contributed to their inability to attend HIV treatment. For participants with an internal locus of control, patience with structural issues, their high level of confidence in clinicians in spite of clinician inconsistency, and interpersonal connections with AVAMC staff facilitated higher rates of retention in HIV treatment. These patients were able to maintain an optimistic view of their clinical experience despite issues that were encountered. This allowed these participants to become invested in HIV treatment and facilitated their retention in HIV treatment. The findings of this study provide the foundation for further research to design clinic interventions to improve clinic-based barriers to retention in treatment for HIV positive patients in the AVAMC.

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Figures

Figure 1: Clinical Experience & Attitudes of HIV Patients with External Locus of Control

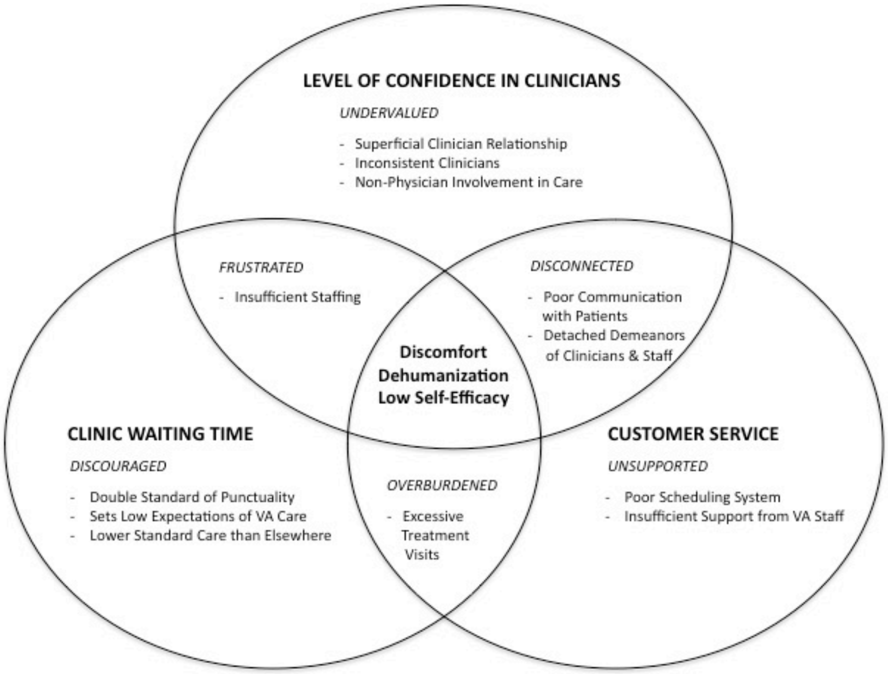
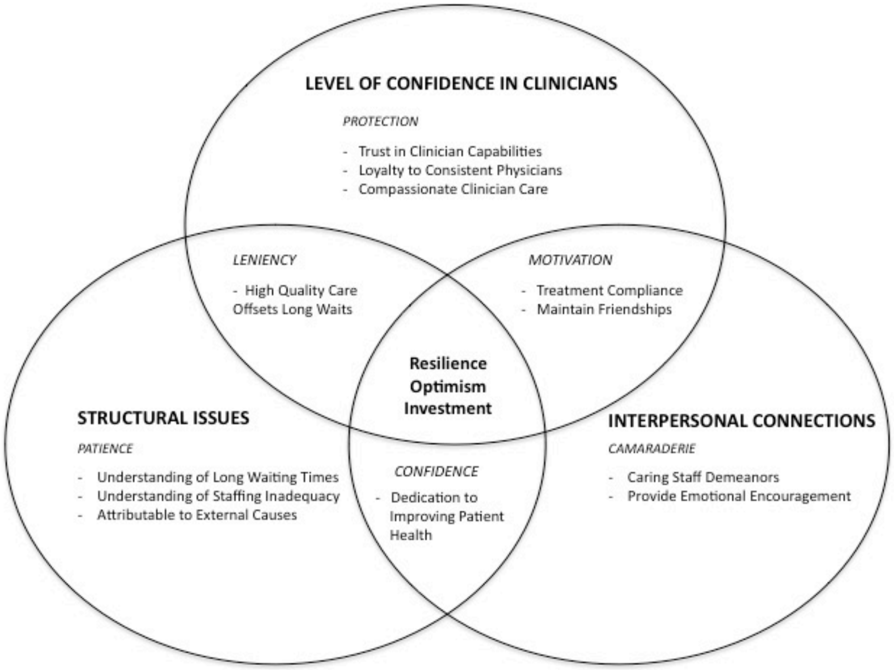


Figure 2: Clinical Experience & Attitudes of HIV Patients with Internal Locus of Control



CHAPTER IV. DISCUSSION AND PUBLIC HEALTH IMPLICATIONS

Public Health Context

Compared to other industrialized nations, the United States ranks poorly in indicators for health outcomes (Bloomberg, 2014;Davis & Ballreich, 2014). One major contributor to the United States' poor health indicators are the disparities that occur in healthcare access (Davis & Ballreich, 2014). Within the United States, insurance coverage rates and use of preventive health services differ significantly based on several social determinants of health identified by the WHO (CDC, 2013). Lower access to care for vulnerable populations places them at a greater risk of bearing a greater burden of disease than less vulnerable groups (CDC, 2013), which negatively impacts outcome measures at a national level. This is particularly true with relation to HIV, a disease that has a higher prevalence in vulnerable populations (CDC, 2014; Meditz et al., 2011; McMahon, Wanke, Terrin, Skinner, & Knox, 2011). The passing of the Affordable Care Act marks a recent attempt to expand health access to vulnerable groups by restructuring federal insurance programs (Cope, 2013). However, expanding the volume of people on insurance programs could lead to issues as the number of individuals demanding health services outpaces the production of primary care professionals. One way to reduce the volume of patients seen in clinic is to improve preventive health measures. Preventive health measures such as health education programs and community-based interventions can prevent and have beneficial effects on chronic conditions, which are some of most common reasons for physician visits among adults and increases the amount of time needed for the clinic visit (Stauver et al., 2013).

However, these preventive health measures may require the patient to become more actively invested in their health than is traditionally expected in most clinical settings. Changes to better preventive and other health behaviors can be optimized within the context of a trusting and empowering patient-provider relationship (Gupta, Brenner, Ratanawongsa, & Inadomi, 2014; Marelich & Murphy, 2010; Schneider, et al., 2004). Therefore a dramatic shift needs to occur whereby the clinic visit becomes an opportunity for patients to gain insights into their health, identify holistic ways to prevent and treat acute and chronic conditions, and feel allied with the provider in accomplishing the patient's healthcare goals. This would contrast most clinic visits where time limitations force a focus on addressing acute complaints and urgent needs and do not provide time for physicians to address health risk assessment and behavior modification which requires psychosocial counseling, education, and motivation (Dugdale, Epstein, & Pantilat, 1999; Rhoades, McFarland, Finch, & Johnson, 2001; Marvel, Epstein, Flowers, & Beckman, 1999). Ultimately, the current model discourages many patients from attending regularly scheduled visits (Davis et al., 2014) possibly because their health needs are not felt to be addressed by the provider, the underlying health risk behaviors may not be fully understood or appreciated by the patient, or the patient may feel judged by the provider for their failing health.

Human health behavior theories provide frameworks for how individuals make decisions about behavior change related to health. As the medical community has shifted away from reductionist practices in diagnosis and treatment, several theories have emerged to illustrate the complexity of human behavior and health outcomes. These theories provide insight into the impact of the environment on decision making (Mcleod, 2014; Bonfenbrenner, 1994; Bonfenbrenner, Friedman, & Wachs, 1999), differences in source of motivation of control for behavior change (Deci & Ryan, 2000; Rosenstock et al., 1988; Bandura, 1977; Rotter, 1966), and the dynamic nature of decision making influences over time (Bhattacharya & Lakdawalla, 2004). Studies have shown that interventions in the clinical setting can target and influence changes in intrinsic characteristics that determine capacity for behavior change (Street, Makoul, Arora, & Epstein, 2009; Beach, Keruly, & Moore, 2006; Earl et al., 2013; Schneider et al., 2004; Street et al., 2008; Zachariae et al., 2003).

Public Health Implications

The clinic setting is the environment where care providers have the most direct impact on patients. A large body of evidence has demonstrated that patient-provider communication can improve health outcomes through mechanisms such as trust, self-efficacy, and knowledge (Street, Makoul, Arora,

& Epstein, 2009; Beach, Keruly, & Moore, 2006; Earl et al., 2013; Schneider et al., 2004). Less evidence has examined the impacts of the physical aspects or other aspects of the clinical setting (Ulrich, Quan, Zimring, Joseph, Choudhary, 2004; Manary et al., 2013; Rubin, Owens, & Golden, 1998). This study provides information about a specific clinical setting's environment and its patient base in order to provide guidance for clinic-specific interventions to improve healthcare delivery and the characteristics of patients that could facilitate positive behavior change.

The research presented here provides an innovative examination of barriers to retention that occur in the clinical setting and the negative impacts of those barriers on the attitudes towards retention in care among patients with an external of control. The findings provide insights into the benefits that positive attitudes and an internal locus of control can have on their ability to overcome barriers to health in the clinical setting. Based on patients' responses, we make the following suggestions for changes that should occur at the AVAMC:

1. <u>Decrease waiting time:</u> Decreasing waiting time in the clinic can reduce the burden of care management felt by patients by reducing the time commitment required of patients at each appointment. This change could be accomplished through these approaches:
    a. <u>Hiring more providers</u>: Increasing the number of providers in the AVAMC not only improves the clinic's ability to satisfy the demands of the patient volume, it also allow providers to spend more time with each patient. This further addresses the juxtaposition of short interactions with clinicians after long waiting time that participants reported.
    b. <u>Increasing use of decentralized care</u>: Decreasing the need for patients to travel to the AVAMC for every treatment appointment would reduce the time burden for many patients and reduce the total volume of patients in the AVAMC. Tele medicine can provide opportunities to reduce travel and time burdens for patients with busy schedules. Down-referrals to more local physicians can benefit patients who live

    especially far from the AVAMC. Health patients could be down-referred to primary care physicians while patients with complex HIV cases or with comorbid conditions can be referred to internal medicine physicians and then follow up with the AVAMC twice annually for more focused HIV and psychosocial care.

2. <u>Improve waiting room atmosphere</u>: To an extent, waiting time are an inherent part of the clinical experience. However, some simple changes to the physical environment of the waiting area can improve the waiting experience for patients. Providing refreshments, reading materials, music, and visual media can create a more stimulating environment that patients may find more enjoyable. Reading materials and visual media also provide avenues for improving patient education about HIV treatment and the services of the AVAMC.
3. <u>Improve provider continuity</u>: Improving consistency in the clinicians that patients interact with at each appointment allows for the formation of deeper patient-provider relationships. This could improve patients' trust in their provider, which could improve their motivation to return to HIV treatment, and therefore improve their chances of reaching viral suppression. This change could be accomplished through these approaches:
    a. <u>Hiring more providers</u>: Increasing the number of providers in the AVAMC allows providers to spend more time with each patient. This provides more time to communicate with patients and ensure that their care is customized to the patients needs. Increasing the number of providers
    b. <u>Improve patient education</u>: This pertains specifically the patients' knowledge of how providers are hired and the structure of their scheduled work hours, which could help them understand how to intentionally schedule their appointments with a consistent provider. Patients should also be educated on the importance of scheduling appointments with a consistent provider.
4. <u>Improve patient provider trust</u>: Improving communication between patients and providers should occur through improving provider continuity and training providers to improve their

communication skills. Cultural sensitivity trainings can help provide clinicians with the skills to build relationships with patients, improve their "bedside manner," and deal with difficult patients.

5. <u>Improve patient knowledge of AVAMC service</u>: Only a few of participants had a full understanding of the services provided by the AVAMC to patients with HIV, and only one participant seemed to understand how to effectively use those services. Therefore, the AVAMC should look for avenues to improve patient knowledge of these services. This change could be accomplished through these approaches:
    a. <u>Materials in the waiting area</u>: Reading materials and visual media (i.e. television messages during a movie or news broadcasts) provide an avenue to passive educate patients on services at the AVAMC and the importance attending HIV treatment.
    b. <u>Case managers or education in the examination room</u>: If patients are referred to a case manager or receive care from a more consistent clinician, education about how to use the services at the AVAMC can occur in the setting of a one-on-one discussion with providers or case managers.

The research presented does not provide insight into which of these suggested changes would most effectively reduce barriers to care or change intrinsic characteristics of patients with an external locus of control in order to improve retention in HIV treatment. Implementation of any of the above changes as an intervention at the AVAMC should be accompanied by studies that examine the effectiveness of that intervention. The hypotheses raised by our research that should guide future studies on our suggested policy changes include:

1. Improvements in the clinical environment and barriers may improve attitudes and ultimately retention in care for those with external locus of control with a change in locus of control

2. Improvements in the clinical environment and barriers may improve attitudes and ultimately retention in care for those with external locus of control with no change in locus of control
3. Improvements either in the clinical environment and barriers may improve attitudes but may not affect retention in care for those with external locus of control
4. Improvements either in the clinical environment and barriers may not affect either attitudes or retention in care for those with external locus of control.

Studies that aim to answer these hypotheses should base their targeted barriers or aspects of the clinical environment on data from studies such as the one presented here. Every clinical setting is different, and the demands of the patient base at each clinic may differ based on culture, socioeconomic status, life experiences, and other characteristics. It should also be noted that factors that impact patient retention and health behaviors occur beyond the clinical setting. Therefore, studies aiming to improve patient attitudes to facilitate behavior change may need to take multi-faceted approaches, with interventions in the clinical setting occurring alongside interventions targeted at appropriate settings outside of the clinic.

Ultimately, studies that aim to answer any of the above hypotheses are attempting to accomplish two interrelated goals: (1) improve the healthcare environment and (2) improve preventive health practices at community level. Improving the healthcare environment reduces the number of barriers in the clinical setting that could inhibit the use of health services by individuals with fewer positive characteristics for behavior change. Improving preventive health practices at the community level reduces the volume of patients who are demanding health services. This reduces the strain placed on health systems and may allow them to provide higher quality care to patients with the greatest need. Improvements in preventive health practices inherently should aim to improve resilience and individuals' capacity for behavior change. In this way, interventions that occur at the community level to improve individuals' capacity for behavior change enable improvements in the health environment to have more beneficial results on improving delivery of health care.

The implications of improving individuals' capacity for resilience and behavior change are far-reaching, but some direct impacts can be identified:

1. Improvements in the management of complex, chronic conditions: preventive health measures can reduce the prevalence of chronic conditions and allow for more effective management and prevention of those conditions by primary care physicians and the patients with the conditions.
2. Improvements in the prevention of acute conditions: many acute illnesses can be easily prevented with improvements in specific preventive practices in the areas of hygiene, food preparation, etc. Self-efficacy has been shown to be more effective at improving habits if they are specific in nature (Schwarzer & Fuchs, 1995).
3. Counteract the increasing volume of individuals with access to healthcare: as more people obtain insurance and gain access to healthcare, it is becoming increasing important to find ways to maintain a healthy population that occur outside of the clinical setting.

The findings of the research presented in this thesis provide the foundation for the development of policy changes or interventions that could test the hypotheses mentioned above. The goals of these policy changes would be to ultimately improve retention in HIV treatment through reductions in clinical barriers to care, improvements in patient attitudes towards retention in HIV treatment, or improving intrinsic characteristics of patients that may facilitate better retention in HIV treatment. Successful interventions in this context could pave the way for future assessments and follow-up interventions targeting retention in HIV treatment at clinical settings in other VA locations and clinical settings in private or non-profit facilities. Improvements in retention in HIV treatment at multiple clinical settings could then have widespread positive impacts on ART adherence, viral suppression, other comorbid conditions, and ultimately quality-adjusted life years.

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APPENDIX

Figure 1- Social Determinants of Health Model

Figure A. Final form of the CSDH conceptual framework

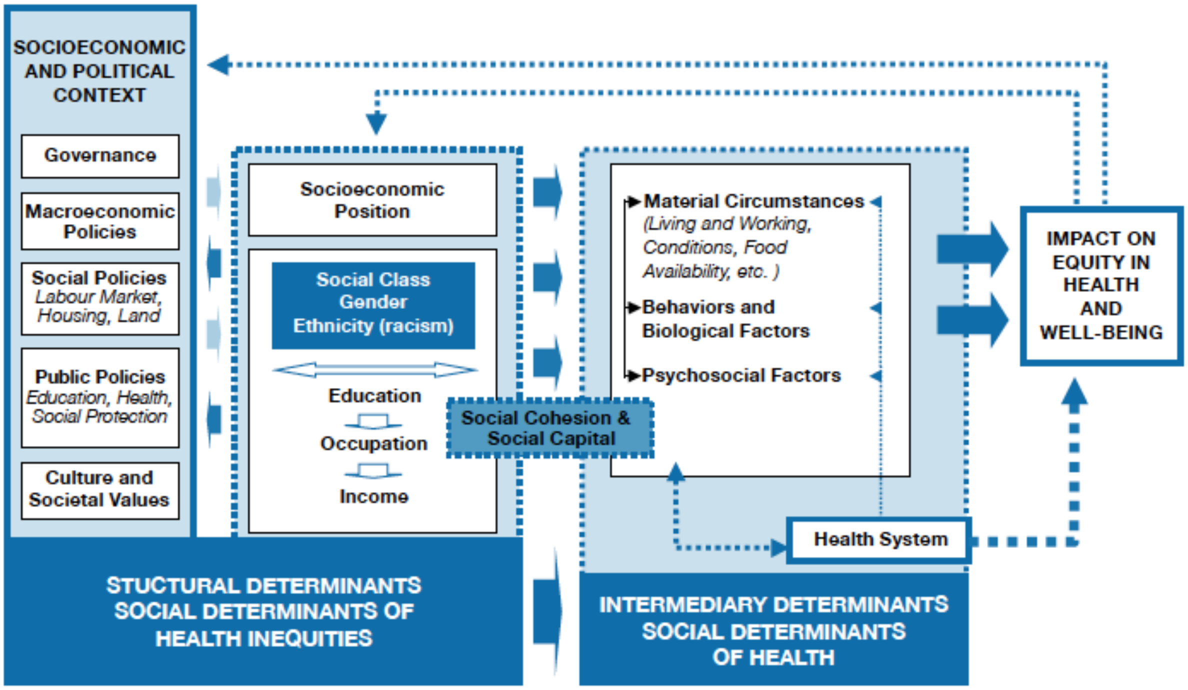

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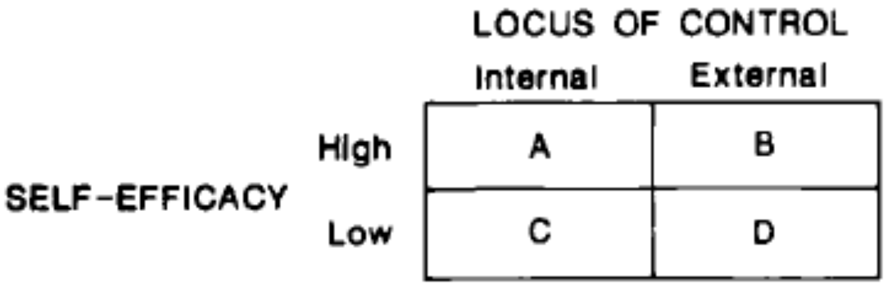
Figure 2 – Combinations of Self-Efficacy and Locus of Control



		LOCUS OF CONTROL	
		Internal	External
SELF-EFFICACY	High	A	B
	Low	C	D

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