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HIV Care Providers' Perceptions of Treatment Retention Barriers at the Atlanta Veterans Administration Medical Center

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2011

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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
2016

Abstract

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The HIV care continuum is a framework for depicting the stages of HIV treatment. Examining HIV treatment in various contexts using this framework can highlight how a particular healthcare system is functioning in regards to HIV treatment. At the Atlanta Veterans Administration Medical Center (AVAMC), retention in HIV care has the most drastic decline in proportion, despite relatively high proportions along all steps in the continuum when compared to national averages. This study aims to examine providers' perceptions of the barriers to retention in care at the AVAMC in an effort to understand causes of retention failures according to providers who have particular insight on clinic barriers. Qualitative in-depth interviews were conducted with a range of HIV care providers at the AVAMC. Results identified three perceptions held by providers about patients that vary based on whether patients are in- or out-of-care. These included views on patient psycho-social stability, motivation for treatment, and patient frustrations. These perceptions were carried throughout providers' views of retention barriers, which were categorized into three distinct groups through thematic analysis. Clinic barriers included lack of resources, scheduling, rotating providers, and wait time; the barriers within this category were largely associated with patient experiences at the clinic and the patient-provider relationship. Socioeconomic barriers included patient social network, transportation, homelessness, and financial circumstance/job status, which are not wholly addressed through veteran resources and services. Health barriers included mental health issues and substance abuse, which were associated with patients' compliance to care recommendations. Understanding

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Acknowledgements

First and foremost, I want to thank my advisors for their ongoing support and guidance through this entire process. Thank you, Dr. Monique Hennink, for your kind and comforting way of pushing me along this process; and for your patience through my learning process of collecting, analyzing and writing about qualitative data. I feel like I am still learning, but I'm very thankful to have your insights as my foundation. And thank you, Dr. Vince Marconi, for your enthusiastic and discerning advice; your timely and reliable responses to all of my questions and concerns throughout the year always put me at ease and helped me to continue moving forward. This project would not have been possible without the guidance from both of you. I am so grateful to have had the opportunity to not only work with you, but on a study that you both are involved with.

I would also like to thank Clayton Carruth for all of his help while I was working at the AVAMC. He always went above and beyond by walking me through the many aspects of coordinating a research project. Thank you for your patience, humor, and guidance through the ethics of conducting a research project.

Susan Schlueter-Wirtz was also instrumental in her assistance through the IRB process. Her knowledge of the VA RETAIN study and guidance in bringing this sub-study into fruition were invaluable. Thank you, Susan.

And additional thanks to Matthew Wessinger and Bonnie Kaiser for all of their generous assistance with a range of needs throughout this process.

To the myriad staff at the AVAMC - thank you for allowing me to work within your space. To the ID clinic staff in particular- I greatly appreciate all of the smiling faces, assistance with issues big and small, and for so warmly sharing your space with me during the summer and fall months. And especially to all of the participants from the ID clinic staff, thank you for generously sharing your time and engaging in open and honest communication with me as I was simultaneously learning and conducting this project.

I would also like to extend a thanks to the veterans of the AVAMC for sharing your space with me. And a thanks to all veterans, past and present, and current military personnel for graciously serving this country.

Finally, I want to thank my friends and family who have supported me throughout this process. I appreciate all of the advice, kind words, and commiserating you all shared with me. I am so grateful to have such an inspiring and loving community.

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Chapter I: Introduction

Introduction and Rationale

There are nearly 1.2 million Americans living with HIV, however many of these individuals are not diagnosed, do not receive treatment, or have not reached viral suppression (CDC 2015, CDC December 2014). Obtaining an HIV diagnosis is an imperative step for people living with HIV (PLWH) in order to reduce transmissions and improve health outcomes. Once individuals are diagnosed, quick and effective linkage to care is important for the individual to undergo in order to reach the goal of viral suppression. Steps prior to viral suppression include regularly seeking care from a healthcare provider and regularly taking antiretroviral therapy (ART) (AIDS.gov 2015, CDC December 2014). There are many obstacles to remaining in care that PLWH face because HIV is a chronic disease. From the perspective of an individual living with HIV, regular and ongoing treatment is necessary for improving health outcomes; viewing this issue through the lens of public health, the importance of regular and ongoing HIV treatment is vital to reducing the transmission of the virus.

The documented steps that are necessary for PLWH to achieve viral suppression are better known as the HIV care continuum. In order, the steps include: those who are diagnosed, those linked to care and/or retained in care, those prescribed ART, and those who finally achieve viral suppression (AIDS.gov 2015). These steps within the HIV care continuum are often referred to as the HIV treatment cascade because the amount of people per step steadily decreases as you move along to the final step (Giordano 2015). Within the U.S. approximately 86% of PLWH are diagnosed, 40% are engaged in HIV care, 37% are on ART, and 30% have reached viral suppression (AIDS.gov 2015, Giordano 2015). The National Strategy for HIV has a goal to increase the numbers along each step, including the number of PLWH to 90%, those linked to care to 85%, and to increase those who are virally suppressed with a focus on vulnerable populations (CDC December 2014).

Problem Statement

The VA is the largest provider to HIV positive Americans in the U.S. (Affairs 2012). The Infectious Disease Clinic (IDC) at the Atlanta Veterans Administration Medical Center (AVAMC) serves as the primary care provider for the nearly 1600 veterans living with HIV/AIDS who seek care through the AVAMC. While the numbers across the continuum are higher along each step when compared to the general population, there is still a large decrease between those who are linked to care and those who are retained in HIV treatment (Mangal, Rimland et al. 2014).

This project is a sub-study of a larger and on-going study which has examined HIV patient perceptions of barriers to treatment retention. The parent study, Retention in Care: Factors associated with failure to remain in care in the Atlanta VA HIV/AIDS clinic (VA RETAIN), largely helped inform the need and direction of new research. Examining staff perceptions within this same context was crucial for providing further insight into HIV treatment retention barriers that are specifically faced by the veteran population. The combined research efforts also allows for the development of potential interventions that may be able to be adopted by other VA IDC's nationwide.

Study Purpose

The overall purpose of this study is to understand the views of HIV care providers on patient retention in treatment at the AVAMC; and to compare these perceptions to those of patients' own motivations for treatment retention and influences on treatment 'drop-out'. It is likely the patient and provider views will share some similarities as well as differences in what is depicted as barriers to retention; likewise, the relative emphasis on certain barriers may vary. Comparing the results between the provider perceptions that are gathered in this study, and patient perceptions gathered from the parent study will help to discern any discrepancies between each group and potentially inform interventions for improving retention in AVAMC ID clinic.

Primary Research Question

The primary research question for this study is: What are HIV care providers' perceptions of the influences on patient retention in treatment at the Atlanta VA Medical Center? In-depth interviews (IDI's) with HIV care providers at the AVAMC will be collected to explore this question. The secondary research question is: What are HIV care providers' perceptions of patient characteristics at the AVAMC, which will be analyzed using data collected from the IDI's.

Significance Statement

In order to effectively target interventions toward improving treatment retention at the AVAMC it is important to understand what barriers patients are experiencing from the perspective of both the patients and providers of the IDC. Understanding the HIV care providers' perceptions on these barriers is also important to understand if there are discrepancies in what staff view as barriers, which will also help to target interventions effectively. A holistic perspective of barriers within the clinic that prevent patients from remaining in care is the first step toward improving treatment adherence. Information gathered from this study could also help target interventions at other VA and HIV clinics in the future.

Chapter II: Extended Literature Review

The HIV Care Continuum in the U.S.

The concept of the HIV treatment continuum of care has served as a formative framework in explaining how the nearly 1.2 million people living with HIV (PLWH) in the U.S. as of 2012 are diagnosed and treated (CDC 2015, Giordano 2015). The continuum of care also serves as a means for depicting the effectiveness of a particular healthcare system, based on the steps developed by Giordano which are considered necessary for successful HIV care (Giordano 2015). The steps in the treatment cascade include diagnosis of an HIV positive individual, linkage to care, receiving antiretroviral therapy (ART), and adherence to both ART and clinic visits (Giordano 2015). These steps are sometimes described as a cascade because the number of HIV positive individuals within each step decreases as the steps move closer to the overall goal- and final step- of viral suppression. For example, of the 1.2 million Americans living with HIV, approximately 86% of those individuals are diagnosed, with continual decreases in each step leading to no more than 30% achieving viral suppression (AIDS.gov 2015, Giordano 2015). The depiction of the HIV treatment cascade has raised numerous questions about potential barriers along the continuum that may be related to decreases at each step.

Frequently, the focus of the HIV care continuum lies in understanding the areas along the continuum where the prevention of further HIV transmissions can occur. Skarbinski et al. estimate that of those who are HIV infected in the US, both those that are considered undiagnosed and not retained in care are responsible for over 90% of HIV transmissions (Skarbinski, Rosenberg et al. 2015). According to the most recent estimates, nearly 50,000 Americans are newly infected with HIV each year (CDC 2015). If Skarbiski et al.'s estimates are correct, then roughly 45,000 individuals infected with HIV each year are transmitted by those individuals who are either not diagnosed or not retained in care. Of individuals who are diagnosed, according to CDC's 2014 analysis, approximately 70% of those are not virally suppressed, and of those not suppressed, 66% are not in care; this indicates that remaining in care is imperative for viral suppression (AIDS.gov 2015). It seems apparent then that it is necessary to improve the numbers along the continuum of care in order to not only bring more individuals living with HIV to viral suppression for their own well-being, but also in order to prevent transmission to others, which would bring HIV incidence down in the US.

There are goals set in place as part of the National HIV Strategy for increasing the percentages along each step of the HIV care continuum. In order for this strategy to be effective, early detection of HIV infection for all those living with HIV is considered necessary. Goals in this national strategy include increasing numbers across each step including the number of PLWH who know their status to 90%, those with a positive diagnosis linked to care to 85%, and those who achieve viral suppression with a focus on populations who are unequally affected (CDC December 2014).

The HIV Care Continuum at the VA

The Department of Veterans Affairs (VA) is the largest provider of HIV treatment in the nation. Over 25,000 HIV positive veterans receive care within the VA system as of 2011, which is a number on the rise (Affairs 2012). In addition to being the largest provider nationwide, the VA also offers a unique look at a particular healthcare system with aspects of universal healthcare and a targeted population of vulnerable users (Affairs 2011). The treatment cascade is also visible within the VA system and is reflective of national trends. However, according to a study conducted on the patient population at the Infectious Disease (ID) Clinic at the AVAMC, the numbers of those both linked to care and retained in care were higher than the general population. Increasing numbers of individuals linked and retained in care is a goal for all HIV providers because retention in care is associated with better clinical outcomes for HIV positive individuals (Mangal, Rimland et al. 2014). It is likely that within the VA system, there are effective methods to link and retain the veteran patient population in HIV care, however numbers across the continuum are still lower than the National HIV/AIDS Strategy goals (CDC December 2014).

While numbers at the AVAMC are often higher along the continuum of care than national averages, this has not been the case with the retention in care piece at the VA. In a study examining HIV care across 19 US jurisdictions, approximately 80% of participants were considered to be retained in continuous HIV care, according the definition of retention in the National HIV/AIDS strategy. Almost 74% of patients who were retained in continuous care achieved viral suppression in the year they were studied. The definition of continuous retention used in this study means patient attends 2 or more visits at least 3 months apart within the past year (Cohen, Hu et al. 2014). At the AVAMC, approximately 73% of patients are considered retained in care, which is a seven percentage point decrease from the estimated national average (Mangal, Rimland et al. 2014). Retention in HIV care is a critical component to achieving viral suppression for HIV positive individuals, and this decrease is worth exploring further.

Patients of the AVAMC face fewer healthcare-related cost barriers, and presumably fewer institutional barriers than the general population, which mitigates certain barriers to treatment retention that are faced by non-veterans (Mangal, Rimland et al. 2014). However, within this predominately male veteran population, inequities still occur as they do in the general population. For example, white race is associated with higher levels of "[antiretroviral therapy] (ART) prescription and viral suppression than black patients"(Mangal, Rimland et al. 2014). A similar trend is found among varying age groups; higher numbers of old-aged patients adhere to ART when compared to younger patients. Both of these trends are also seen among the general population (Mangal, Rimland et al. 2014). With similar retention issues as are seen in national trends, and comparatively fewer institutional and financial barriers to HIV care that veterans face, what then are the remaining barriers for HIV treatment retention for HIV positive veterans?

Barriers to HIV Treatment Retention in the U.S.

Since the modern era of ART, studies have explored the barriers to remaining in-care along the HIV care continuum. Many of these studies have qualitatively examined patient-perceived barriers to care, while others have quantitatively examined the prevalence of specific barriers, as informed by qualitative studies (Kempf, McLeod et al. 2010, Christopoulos, Massey et al. 2013, Dombrowski, Simoni et al. 2015). Common issues discussed throughout these studies have indicated insurance and cost, issues making and keeping appointments, poor relationships with doctors, depression and substance abuse, homelessness or transportation issues, and personal medical beliefs as common barriers (Dombrowski, Simoni et al. 2015). The study by Dombrowski et al. quantitatively analyzed the patient-perceived treatment barriers by assigning prevalence to common patient-perceived barriers, including each of the above barriers, in King County, WA. The most commonly reported barrier to retention in this study was lack of insurance (50%), which is the only barrier from this study that is not applicable to the VA population; however, other cost barriers, such as cost associated with transportation, are applicable to VA population. Difficulty in getting an appointment, and preference for a single provider over a team of providers were also commonly reported issues. Additionally, for those that had not initiated ART, 60% reported the primary reason for non-initiation was perceived side effects. Moving down the continuum, depression was the most commonly reported reason for discontinuing ART use (Dombrowski, Simoni et al. 2015). Although this study was based in a county of Washington state, barriers still arose that are applicable to other Americans, including veterans who receive their care through the VA.

Examining HIV barriers within the veteran population

Studies that examine PLWH in the U.S. are useful in understanding the epidemic from a national viewpoint, however, it is useful to examine specific subgroups in order to best understand barriers to treatment retention and adapt interventions most effectively. The U.S. veteran population, for instance, is a subgroup of the American population with a breadth of different characteristics that may contribute to treatment retention. Both the VA and the Department of Defense (DoD) are entities within the U.S. that have reduced barriers related to cost and insurance, in addition to having an integrated and multidisciplinary healthcare system (Guest, Weintrob et al. 2013). Within these two similar systems, the VA sees more patients with substance abuse, homelessness, and unemployment, however, clinical outcomes do not significantly differ between these two groups (Guest, Weintrob et al. 2013). Understanding the particular barriers that affect the VA population becomes increasingly significant if differences in certain patient characteristics are not able to explain clinical outcomes.

HIV barriers at the AVAMC

A recent qualitative study at the AVAMC examined patient barriers to HIV treatment retention using IDIs with both in-care and out-of-care patients. At this particular ID clinic, there are nearly 1,600 HIV positive veterans receiving their primary and HIV medical care, making it one of the largest HIV providers in the country. It is estimated that independent of an individual's status further upstream on the HIV care continuum, nearly 60% of those infected achieve viral suppression at this clinic (Mangal, Rimland et al. 2014, AIDS.gov 2015). Again, while improvements are needed, the numbers in each section of the continuum are higher within the VA system when compared to national estimates (Gardner, McLees et al. 2011, Mangal, Rimland et al. 2014, CDC 2015). For instance, the number of patients that remain in care is still lower than the National HIV Strategy goal (CDC December 2014).

This qualitative study at the AVAMC examined barriers through the framework of varying spheres of influence that impact both in- and out-of-care patients. Spheres of influence that impact poor treatment retention include wait time at the clinic, the level of confidence in physicians, and customer service. In contrast, spheres of influence that impact in-care patients include patience with structural issues (such as clinic wait times), confidence in physicians, and positive interpersonal relationships with clinic staff (Matthew Heyward Wessinger 2015). This study indicates that patients can experience perceived barriers through opposing lenses based on individualized experiences and characteristics surrounding these clinic-attributable spheres of influence. An important implication of this study is that it may be possible to diminish the negative effects of certain clinic-attributable barriers by addressing the specific issues that affect treatment retention, as reported by patients. For instance, improving the patient-physician relationship may counteract other frustrations within the system that may cause a patient to fall out of care.

Patient-provider relationships

Many studies that have focused on patient-provider relationships have indicated that improved relationships can improve clinic outcomes. For many people living with chronic diseases, the importance of forming a positive and engaging relationship with their provider is paramount. Using in-depth interviews from patient participants in primary HIV care, Mallison et al. developed a conceptual framework based on how patients describe providers (primarily physicians) as either barriers or facilitators to care. Through the researchers' grounded theory approach, themes that were associated with facilitating HIV treatment adherence for patients included the ability to establish a genuine connection with the patient, validating patients as individuals, and partnering with patients collaboratively in their care. Conversely, providers can serve as a barrier to adherence with patronizing behaviors during their interactions with patients (Mallinson, Rajabiun et al. 2007). The results from this study are significant because they present the variability in provider roles to treatment engagement, and demonstrate the ability for providers to alter their behaviors in order to play a facilitating role to treatment retention. The impact that negative provider experiences have on patients that disengage from care was studied by Magnus et al. in a clinic in Louisiana. Results from this study indicate a statistically significant association with individuals who fell out of HIV care for a year or more who report that they had providers who did not listen during interaction or who had negative views toward HIV positive individuals. Many individuals living with HIV face barriers outside the clinic related to stigma, however stigma from these relationships can carry into their provider relationships. For instance, HIV patients who score high on the Internalized Stigma Scale- which includes condescending views from society and medical professionals on HIV positive individuals- are more likely to report a break in the HIV care (Magnus, Herwehe et al. 2013).

Patient satisfaction

Patient satisfaction with HIV care has been increasingly examined as a factor contributing to treatment retention. A study conducted in Houston, Texas at a VA medical center and another Texas health center, found that patients with the highest level of self-reported highly active antiretroviral therapy (HAART) adherence scored significantly higher measures in patient satisfaction (Dang, Westbrook et al. 2013). Additionally, the idea of patient-centeredness approaches to healthcare have been associated with HAART adherence and viral suppression. A fundamental tenet of a patient-centered approach is the patient feeling that s/he is viewed as a person (Schneider, Kaplan et al. 2004, Beach, Keruly et al. 2006). These two studies demonstrate that positive patient experiences at the clinic are important for patients' medical behaviors outside of the clinic walls, such as medication habits. Many positive patient experiences are reliant on their interactions with their primary physician (Magnus, Herwehe et al. 2013).

Measuring patient satisfaction can be a difficult task, particularly when working with mental health patients. It can be difficult to quantify measures of satisfaction, even with standardized questionnaires. Many researchers of patient satisfaction believe this is why it's important to assess patient satisfaction through qualitative measures or engagement (Crawford and Kessel 1999).

Barriers to positive patient-provider relationships

Trust plays a significant role in building positive relationships between patients and providers. Patients' mistrust of their providers due to race/ethnicity and cultural differences is a key factor in the patient-provider relationship (Benkert, Peters et al. 2006, Sohler, Fitzpatrick et al. 2007, Cheatham, Barksdale et al. 2008, Saha, Jacobs et al. 2010, Saha, Sanders et al. 2011). Mistrust in physicians is frequently cited as a reason for the racial disparities seen in HIV care outcomes by African Americans (Saha, Jacobs et al. 2010). Again, black race is commonly associated with poorer adherence to ART when compared to white race; however, increasing trust among African American patients toward their physicians may help mitigate the disparities in ART adherence and viral suppression between black and white HIV positive patients (Saha, Jacobs et al. 2010, Mangal, Rimland et al. 2014). Compared to 23% of white men, 54% of black men in the South reported perceived race/ethnic discrimination as a barrier to accessing quality healthcare services (Cheatham, Barksdale et al. 2008). Within the U.S., the history of abuse and slavery along with medical misuse of African Americans are commonly cited sources of mistrust for African Americans in regard to the medical system. For example, the Tuskegee Experiment which involved a syphilis study utilizing African American men is a primary example of unethical practices engaged by the medical community in the South; not treating participants long after a known-treatment existed is a prime example of misuse and abuse by the medical community (Gaston and Alleyne-Green 2013). It is likely this this history of unethical practices and abuse has lasting impacts on African Americans' ability to trust the medical community (Katz, Green et al. 2011).

Cultural distance is also a commonly cited factor in patient-provider relationships because it is associated with decreased trust and healthcare quality ratings. Increased cultural distance between the patient and provider is negatively associated with trust, meaning that as cultural distance increases, trust decreases. Decreasing cultural distance may improve trust in physicians, but it does not mitigate racial/ethnic disparities (Saha, Sanders et al. 2011). However, in another study of African Americans at two primary care facilities, cultural mistrust and trust in the provider were mediating factors in the negative association between perceived racism and satisfaction with care. Again, racial discordance or perceived racism played a larger role in patient satisfaction with healthcare (Benkert, Peters et al. 2006).

Increasing the number of healthcare providers from minority and underserved populations is one way to decrease patient-provider discordance. Increasing providers from these populations helps to increase the amount of providers serving similar populations and helps to counter broad and historical underlying socioeconomic inequities (Sohler, Fitzpatrick et al. 2007). In Sohler et al.'s study which measured aspects of trust among concordant providers and nonwhite HIV patients, race/ethnicity concordance was associate with less mistrust of the healthcare system, however this alone did not significantly improve trust within the individual patient-provider relationship (2007).

Theories of patient-provider relationships

Exploring the interactions between patients and providers requires the use of alternative theoretical understandings different from those used in examining typical social exchanges, because patient-provider interactions are not founded on the use of common language, understanding or experience. In Talcott Parson's examination of patient-provider interactions, he reported that it is common for patients to play a more passive role in the relationship because it is more difficult for a patient to assess a proper judgment on the nature of the interaction (Roter and Hall 1991). In a contrasting theory developed by Ben-Sira, while certain judgements are not able to be made by the patient, the patient is still able to accurately assess how well the physician provided emotional support during the interaction (Roter and Hall 1991). Roter and Hall describe three levels of communication: intrinsic, conveyed, and interpreted; each of which is present in patient-provider interactions through body language, tone, words, and so on (1991).

Patient behaviors can be similarly assessed in patient-provider relationships. Many patient behaviors parallel physician behaviors in these interactions, however, distinctions between tasks and socioemotional domains may vary between the counterparts in this relationship. Ultimately, the patient decides his/her medical behavior outside of the clinic. In general, however, patients are able to distinguish between technical aspects and socioemotional aspects within their interactions with providers (Roter and Hall 1991).

A conceptual framework for patient-provider communication

Feldman-Stewart et al. developed a conceptual framework for patient-professional communication by conducting a thorough review of existing communication literature. While their framework is intended for application in the cancer context, it may also be useful in other healthcare contexts including other chronic illnesses such as HIV/AIDS. This communication framework views communication as both dynamic and multidimensional, meaning one act affects the next and both relationships and the context play a role (Feldman-Stewart, Brundage et al. 2005).

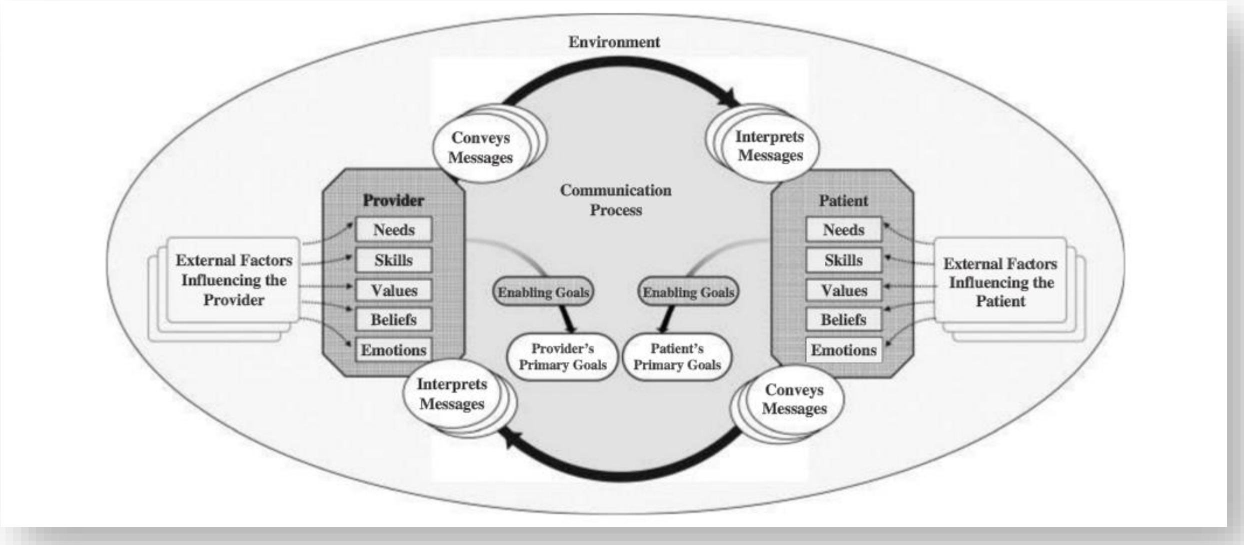
This conceptual framework (See Figure 1) focuses on one-on-one interactions between a patient and healthcare provider, and how communication happens within a specific environment to address each participant’s goals. Goals and participation are influenced by each participant’s attributes: needs, skills, values, beliefs, and emotions. Throughout the interaction messages are conveyed and received by each participant, each act influencing the next (Feldman-Stewart, Brundage et al. 2005).

Providers' perspectives

Limited research has examined perspectives of HIV treatment barriers from the perspective of healthcare providers and staff that work within clinics and healthcare systems. This group could provide valuable insight into numerous treatment retention issues including: they are often the first or only group informed of patient issues in the absence of qualitative research, they have knowledge of the healthcare system and individual clinic functions, and they may be able to provide the most feasible and fast-acting interventions in improving treatment retention. Many studies have examined factors such as patient satisfaction and the quality of the patient-provider relationship as being an important aspect in adherence to HIV Care and patient outcomes, however few studies have included staff or providers who are key informants for information on provider-patient relationships.

The purpose of this research study is to further explore this gap in the literature, by examining barriers to HIV treatment retention from healthcare staff's perspectives.

Figure 1. Patient-professional communication framework



Source: (Feldman-Stewart, Brundage et al. 2005)

Chapter III. Manuscript

HIV Care Providers' Perceptions of Treatment Retention Barriers at the Atlanta VA Medical Center

Amanda Williams, Monique Hennink, Vincent Marconi

Abstract

The HIV care continuum is a framework for depicting the stages of HIV treatment. Examining HIV treatment in various contexts using this framework can highlight how a particular healthcare system is functioning in regards to HIV treatment. At the Atlanta Veterans Administration Medical Center (AVAMC), retention in HIV care has the most drastic decline in proportion, despite relatively high proportions along all steps in the continuum when compared to national averages. This study aims to examine providers' perceptions of the barriers to retention in care at the AVAMC in an effort to understand causes of retention failures according to providers who have particular insight on clinic barriers. Qualitative in-depth interviews were conducted with a range of HIV care providers at the AVAMC. Results identified three perceptions held by providers about patients that vary based on whether patients are in- or out-of-care. These included views on patient psycho-social stability, motivation for treatment, and patient frustrations. These perceptions were carried throughout providers' views of retention barriers, which were categorized into three distinct groups through thematic analysis. Clinic barriers included lack of resources, scheduling, rotating providers, and wait time; the barriers within this category were largely associated with patient experiences at the clinic and the patient-provider relationship. Socioeconomic barriers included patient social network, transportation, homelessness, and financial circumstance/job status, which are not wholly addressed through veteran resources and services. Health barriers included mental health issues and substance abuse, which were associated with patients' compliance to care recommendations. Understanding

providers' perceptions of patients and the barriers to treatment retention garners valuable insight into barriers particularly related to the clinic due their knowledge and experience as employees.

Introduction

HIV/AIDS remains a public health issue across the globe. Worldwide, there are nearly 37 million people living with HIV/AIDS, not all of whom are aware of their status (AIDS.gov 2015). Within the U.S. there are nearly 1.2 million people living with HIV (PLWH), who fall along an HIV care continuum that stems from diagnosis to viral suppression (CDC 2015, Giordano 2015). The HIV continuum of care serves as a visual framework for how effective a particular healthcare system is, based on key steps which include diagnosis of HIV positive individuals, linkage to care, receiving antiretroviral therapy (ART), adherence to ART and clinic visits, and the final goal of viral suppression (Giordano 2015, CDC December 2014). These steps are sometimes described as a cascade because the number of HIV positive individuals within each step decreases as the steps move closer to the overall goal of viral suppression. For example, of the 1.2 million Americans living with HIV, approximately 86% of those are diagnosed, with continual decreases in each step leading to less than 30% who achievie viral suppression (AIDS.gov 2015, Giordano 2015).

Improving the prevalence of individuals in each step of the continuum is crucial in developing an HIV strategy. Within the U.S., the National Strategy for HIV has a goal to increase the prevalence within each step. This includes increasing the number of PLWH who are diagnosed to 90%, those linked to care to 85%, and to increase those who are virally suppressed overall, with a focus on vulnerable populations (CDC December 2014). This strategy was created in an effort to achieve the overall "goal of HIV treatment retention [which] is to achieve viral suppression," in order to improve individuals' health and reduce transmissions (CDC December 2014).

Background

The Department of Veterans Affairs (VA) is the largest provider of HIV treatment in the nation. Over 25,000 HIV positive veterans receive care within the VA system as of 2011, which is a number on the rise (Affairs 2012). In addition to being the largest provider nationwide, the VA is also a unique system in that it functions as a universal healthcare system and targets a population of vulnerable users (Affairs 2011). The HIV treatment continuum is also visible within the VA system and is reflective of national trends, because percentages decreases along each step. However, according to a study conducted on the patient population at the Infectious Disease (ID) Clinic at the AVAMC, the numbers of those both linked to care and retained in care are higher when compared to the general population. (Mangal, Rimland et al. 2014). It is likely that within the VA system, there are effective methods to link and retain the veteran patient population in HIV care, however numbers across the continuum are still lower than the National HIV/AIDS Strategy goals (CDC December 2014).

Although the AVAMC has higher prevalence within certain HIV care steps, this is not the case across the continuum of care. For example, approximately 73% of patients are considered retained in care at the AVAMC- a seven percentage point decrease from the estimated national average (Mangal, Rimland et al. 2014). This documented gap in HIV treatment retention at the AVAMC, indicates that this particular step in the HIV care continuum is necessary area to target for further research and future interventions.

A recent qualitative study at the Atlanta VA Medical Center AVAMC examined patient barriers to HIV treatment retention using in-depth interviews (IDIs) with both in-care and out-of-care patients. This study at the AVAMC examined barriers through the framework of varying spheres of influence that impact both in- and out-of-care patients. Spheres of influence that impact poor treatment retention include wait time at the clinic, the level of confidence in physicians, and customer service. In contrast, spheres of influence that impact in-care patients include patience with structural issues (such as clinic wait times), confidence in physicians, and positive interpersonal relationships with clinic staff (Matthew Heyward Wessinger 2015). This study indicates that patients can experience perceived barriers through opposing lenses based on individualized experiences and characteristics surrounding these clinic-attributable spheres of influence. An important implication of this study is that it may be possible to diminish the negative effects of certain clinic-attributable barriers by addressing the specific issues that affect treatment retention, as reported by patients. The following study aims to expand upon this research by exploring another perspective of HIV treatment retention barriers at the AVAMC. The primary research question for this study is: What are HIV care providers' perceptions of the influences on patient retention in treatment at the Atlanta VA Medical Center?

Methods

Study Setting

This study was conducted at the IDC at the AVAMC because it serves as the provider of about 1,600 HIV positive veterans, making it the largest HIV clinic in the VA system nationally. Data collection took place between June and December 2015, following the completion of a qualitative study, called VA RETAIN, which examined patient perceptions of barriers from both in and out of care veterans at this clinic. The results from the parent study helped to inform the study design and research questions for this study. The study was conducted at the same location as the parent study, in order to strengthen results found by including staff views with those already collected from patients of the same clinic.

Study Design

Given limited research on HIV care providers' perceptions of the influences on treatment adherence we decided to conduct a qualitative study to understand providers' own perceptions of HIV patients and their treatment barriers. Qualitative research allows researchers to "examine people's experiences in detail," through a variety of methods (Hennink 2011). By conducting IDIs, the research team was able to gather detailed data pertaining to staff views, without making prior assumptions as to what these views may be and to understand issues from the perspectives of HIV providers themselves. The lack of previous research on providers' views of treatment barriers indicated a need to fill this gap in the literature before conducting further research to develop the most effective interventions. Although the topics covered in the IDIs were not overly sensitive the researchers felt it was necessary to obtain individual perceptions through one-on-one interactions, in order to create a more comfortable setting for participants and to limit influence from peers.

Participant Recruitment

All staff of the IDC at the AVAMC who worked with HIV positive patients in the 3 months prior to the May 2015 study start were eligible for the study. Staff members included full time employees, fellows, and without compensation (WOC) employees. Fellows included physicians training in an infectious disease specialization who typically hold clinic once a week and conduct research on other days. WOC employees included physicians who volunteer their time at the AVAMC. Many of these WOC physicians are doctors will full-time jobs at the Centers for Disease Control and Prevention (CDC) who volunteer when possible by holding clinic days at the AVAMC.

Participant recruitment primarily took place through emails to clinic staff via the AVAMC secure employee-based mail server. The team purposively sought variability in participants by recruiting a range of job roles and employment status. A total of 8 participants with varying job roles were recruited for IDIs.

In-depth Interviews

The creation of the in-depth interview guide was guided by previous research. Topics were generated from results of the parent study. The guide flowed through topics starting with the participant's role at the IDC, the nature of the participant's interaction with patients, how the participant defines HIV treatment adherence, what barrier(s) the participant believes patients face, and finally what solutions in the clinic would be most beneficial in eliminating patient barriers. The IDI guide was pilot tested with a member of the research team who was familiar with the parent research project. Due to the small population size, the guide was not tested on anyone from the study population, however some questions were adapted and probes were added during data collection based on the iterative process which is inherent in qualitative research in order to produce depth to the data.

All interviews were conducted by the same interviewer and took place in a private room at the AVAMC. Participants were consented in the room prior to the interview. Interviews were recorded on a digital recorder, following verbal consent and written consent included on the informed consent form. The interviews were semi-structured and used in a flexible way whereby the interviewer could move freely between topics to follow the flow of the conversation, as well as add impromptu follow-up probes based on participants' responses to gain more depth in the data. Interviews ranged in length from 45 to 60 minutes. All participants were given $20 cash for participation, as indicated in the IRB study amendment.

Data Analysis

Recorded interviews were transcribed verbatim, and de-identified to maintain anonymity of participants throughout analysis. These transcripts were then uploaded to MAXQDA11, a qualitative analysis software package. Data were read closely and memos created to note issues, connections, further questions for exploration, and researcher's reflexivity throughout the analysis process. From the memo process, a codebook was developed with key issues and themes that were found in the data.

Once the codebook was developed, inter-coder agreement (ICA) was done to ensure consistency on data coding. Issues and inconsistencies from the ICA activity were amended by further editing and adapting the codebook to increase rigor in the coding methods. After these adjustments the remaining IDI's were coded.

Coding and close readings of the data allowed the researcher to determine a list of barriers to treatment retention that were mentioned by the participants. Comparisons were made between types of providers by each barrier to determine if different HIV care providers perceive patients barriers differently. The providers were divided into four categories: physicians, nurse, social worker, and psychologist. Thick descriptions were made of each code, and descriptions of barriers by each type participant of participant were organized in an Excel spreadsheet to better assess comparisons by provider roles.

Close readings and comparisons of codes yielded common themes surrounding participants' perceptions of barriers. Thematic analysis of the prevailing themes related to retention barriers was conducted in order to provide a "rich and detailed, yet complex account of the data" (Bazeley 2013). Overarching themes were categorized into types of barriers: clinic, socioeconomic, and health barriers. Issues within each barrier category were defined. Finally, common themes that arose within each issue were defined, which provided depth and breadth to the results. Results were validated by searching the data for contradictions and consistency.

Ethical Considerations

This study was submitted to the Emory IRB as an amendment to its parent study, the VA RETAIN. In addition to receiving IRB approval from Emory University, this study also received approval through the VA Compliance Office, as is required of any research study conducted at the VA.

The questions asked within the interviews were not considered overly sensitive, however providers were asked questions pertaining to their individual job roles, which in some cases could affect confidentiality. De-identifying answers pertaining to individuals' work while on the job were given consideration while transcribing and during the writing process to ensure confidentiality. Prior to participation, participants were reassured that their participation was completely voluntary and that participation would not affect their job in any way.

Results

The results aim to depict a broad picture of HIV care providers' perceptions of treatment retention barriers at the AVAMC. First, providers' definition of HIV treatment retention is described in order to highlight the similarities across the clinic in how providers understand and define treatment retention. Consistency in the providers' definition allows us to further explore how providers perceive retention barriers for their patient population. In describing these barriers, providers' perceptions of patients emerged. These perceptions were categorized by two broad types of patients: in-care and out-of-care patients (*See Figure1*). Providers' perceptions of these different types of patients include perceptions of patient psycho-social stability, motivation and patient frustration. These perceptions of patient characteristics help to define certain provider attitudes that are carried through to their perceptions of barriers to patient retention. Comparisons were made between provider roles, but no clear distinctions arose by provider's roles on barriers to retention. Therefore, the range of barriers presented include how all providers, regardless of role, perceived each of the barriers mentioned in the IDIs. Through thematic analysis, these barriers were categorized into three distinct groups: clinic barriers, socioeconomic barriers, and health barriers (*See Figure 2*). The barriers that comprise each category will be described in detail based on how providers described each one.

Providers' Definition of Treatment Retention

Providers who care for HIV patients at the AVAMC ID clinic are consistent in their definition of HIV treatment retention. According to providers in this clinic, HIV treatment retention involves patient compliance in attending regular clinic appointments and compliance with medication, as recommended by the physicians. While expectations and recommendations by physicians may vary from patient-to-patient based on patient-specific needs, attending clinic visits and consistent adherence to HIV medications are essential in order for a patient to be considered retained in treatment, according to HIV care providers.

Providers mentioned certain medical behaviors that would categorize patients as 'not retained' or out-of-care. Patients who regularly miss appointments or are not seen for six months or more were considered 'not retained'. Occasionally missing appointments or "stretching out" appointments did not define patients as out-of-care. Providers tended to focus on patterns of medical behaviors, such as periods of not attending appointments or periods of non-compliance with medications, as indicators for patient drop out.

Providers described some situations where patients who are not fully compliant with their medications may be considered retained. For example, there are some patients who are elite controller, meaning without medications they are maintaining low viral loads and high CD4 counts. Aside from patients without medication needs, it was described that certain patients who do not take their pills as prescribed, but maintain some regularity, make be considered compliant. In some situations, these variation in medication habits can be accepted as a success in treatment compliance. However, long periods of failing to refill medications, not taking medications, or having inconsistent laboratory results indicating medication noncompliance are considered retention failures.

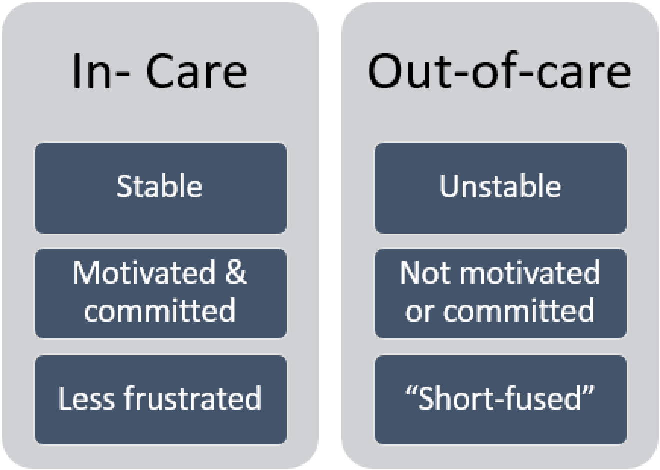
Providers stated that the purpose of HIV treatment retention is to improve the health outcomes for patients, which is the primary focus for providers during clinic visits. Patients who remain in treatment are able to achieve viral suppression to an undetectable level and maintain high CD4 counts. Many providers at the AVAMC ID clinic were aware of the larger implications for HIV treatment retention, which primarily includes reducing transmissions of HIV.

Understanding HIV care providers' definitions of HIV treatment retention and its goal at the AVAMC ID clinic is a crucial step for further exploring issues surrounding HIV treatment retention. There was a strong consistency in how providers defined treatment retention and its goals. With this basis of understanding how providers define HIV treatment retention, researchers were able to further explore issues surrounding treatment retention at the AVAMC ID clinic.

Providers' Perceptions of Patient Characteristics

In describing their perceptions of the barriers to remaining in treatment, provider attitudes of patient characteristics emerged. There was more variability in how providers discussed patient characteristics related to retention issues than in how the barriers were described. Some providers discussed how certain barriers only lead to retention failure for patients with specific characteristics. Provider attitudes of these specific characteristics of the AVAMC patient population revolved around ideas of patient psycho-social stability, patient motivation and commitment to treatment recommendations, and patient frustrations related to their care at the AVAMC ID clinic. Providers' perceptions of patients who are likely to fall out of care, indicated their perceptions of patients who remain in care by contrast *(Figure 1).*

Figure 1: *Providers' Perceptions of Patients in and out of care*



Patient Stability

The issue of patient stability emerged while providers spoke about barriers to retention. Some common themes that arose included job stability, housing stability, drug abuse and financial stability. In particular, providers perceive the AVAMC ID clinic as having a large population of homeless patients. This patient population was characterized as “transient” and therefore was perceived as leading to issues of lack of follow-through with the clinic appointments and medication behaviors. Overall, socioeconomic status and drug use were perceived as indicators for patients that are likely to fall out care. Providers mentioned that these indicators on their medical records were perceived as behavioral issues that can cause a patient to fall out of care. Providers demonstrated a way of stratifying the patient population between those patients who experience more psycho-social instability, in terms of job status, housing, and drug use, compared with patients “who are otherwise stable” (IDI1). Patients who are viewed as unstable socioeconomically or have substance abuse issues are likely to fall out of care due to these barriers. However, for patients who are stable, i.e. do not have socioeconomic or substance abuse issues, barriers to retention fall more within the clinic experience, according to providers. For example, interactions with clinic staff and providers may affect more stable patients’ choice to return to care or not, based on how positive or negative patients perceive these interactions to be.

> *“I think for the people who are otherwise stable in their life…if they have kind of a negative experience while they’re here, I think it would make it difficult for them to wanna come back and be seen regularly” (IDI1).*

Patient Motivation

Patient motivation and commitment was another theme that arose from providers’ perceptions of treatment retention. Some providers expressed that certain barriers were only issues for patients who were not motivated or committed to their HIV care. For example, one participant describes her perception of why transportation is not an issue with the veteran population at the ID clinic:

> *“I don’t think that that [distance to care] applies to the VA population, because even if they live in, I don’t know, Rome, Georgia, if they’re committed they make, the-they’ll come” (IDI2).*

Providers did perceive that patients experience challenges in receiving care from the VA, however, some providers described that with enough motivation, patients are able to overcome these challenges. It was expressed by one provider that many of the patients at the AVAMC ID clinic are healthy and have undetectable viral loads due to these patients' commitment to taking their medications and being motivated when they attend the clinic. This provider explained that the reason the AVAMC ID clinic has such a high number of patients with undetectable viral loads demonstrates that many of the patients at the clinic comply with the HIV treatment recommendations, and are motivated to do so.

Patient Frustrations

There were many barriers to retention that providers described as being frustrating for the patients. For example, difficulty parking at the AVAMC or long wait times were mentioned as barriers that are frustrating for patients to deal with. Providers' perceived that patient frustration is a characteristic of the veteran population who become easily frustrated. For instance, one physician characterized military populations as consisting of "people with very short fuses who get upset" (IDI8).

The characteristic of a "short-fused" or an easily frustrated patient population was perceived as a cause for patients who get frustrated to a point of non-compliance. For example, for patients who become easily frustrated, the challenges within the clinic can be so great that a patient may give-up and walk out of a visit, as described by one participant. Again, it was not perceived that challenges, or barriers, to receiving care at the ID clinic do not exist, but that "short-fused" patients may be less able to cope with their frustrations and more likely to walk-out, or give up on, their HIV care.

Providers' Perceptions of Barriers to Treatment Retention

All of the HIV care providers at the AVAMC indicated that there are barriers to patients remaining in HIV treatment, and overwhelming agreed on the type and nature of barriers. However, there was some variation in how certain barriers were perceived by providers, which will be addressed in the relevant sections.

As depicted in *Figure 2* the category of clinic barriers included lack of resources, scheduling, rotating providers, and wait times. Socioeconomic barriers included patients' social network, homelessness, transportation, and financial circumstance/job status. These were barriers described by participants that are beyond the scope of the clinic, but hinder retention. Finally, health barriers included mental health and substance abuse, which participants described as predominate barriers to treatment retention.

Figure2: *Providers' Perceptions of Retention Barriers*

Clinic Barriers

Clinic barriers exist due to the design of the VA system and the unique design and structure of the AVAMC ID clinic. The barriers that constitute this category include lack of resources, scheduling, rotating providers, and wait time.

Lack of Resources

Providers mentioned several factors that inhibit patient care at the AVAMC ID clinic that are related to the clinic not having adequate resources to provide patients with the quality of care as intended. For example, a common theme was the lack of personnel, particularly full time staff, at the ID clinic. It was believed that the number of full-time staff at the ID clinic was insufficient to meet the demands of the heavy patient load. Providers described this issue as a partial cause, affecting other barriers such as wait time, scheduling, and rotating providers. The limited number of providers was believed to negatively influence patients' experiences within clinic visits. For example, providers mentioned often needing more time per patient than the allotted thirty minutes, which may only be possible with fewer patients distributed among more providers. According to participants, not having enough time per patient can greatly affect whether the patient-provider interaction is perceived positively or negatively by the patient.

Another issue to providing the intended quality of care at the AVAMC ID clinic involved the clinic environment and lack of resources in providing a high quality clinic environment. Space issues and the physical environment of the clinic were common themes that arose from the data. It was mentioned that the lack of physical space was a barrier to patients in accessing all of their healthcare needs. For example, the clinic psychologist is intended to be physically embedded within the ID clinic; however, a lack of space in the clinic places the psychologist's office on another floor in the hospital. This physical distance creates a barrier between necessary communication among staff members regarding individual patient's needs, and requires patients to visit another floor on the hospital following their clinic visit. It was described that some patients will leave after their primary-care physician visit, rather than continuing to their mental health appointment. Additionally, the physical environment at the AVAMC was described by one participant as "no frills care" (IDI8), meaning that amenities present at many other healthcare facilities such as state-of-the-art design or a concierge to assist in patient navigation are absent from the AVAMC. Participants described the facilities that ID clinic inhabits as not being updated for decades.

Overall, the lack of personnel, space, and amenities in the ID clinic were described as barriers to providing quality health care as intended, potential causes for negative patient experiences, and deterrents for treatment retention.

Appointment Scheduling

The appointment scheduling system was a barrier consistently mentioned by each type of provider. Participants largely attributed this barrier to the ID clinic complying with the CDC volunteer physicians' schedules and the heavy patient load for the limited full-time physicians, as mentioned above.

Participants mentioned that twice a year, during the months of June and December, the schedule for clinic visits is "blocked" in order to accommodate the schedules of the CDC volunteer doctors. Therefore, twice a year, before the CDC doctors' schedules are set for the next 6 months, no one is able to schedule an appointment in the system. The result is that patients are unable to schedule follow-up visits at their current appointment and are asked to call back in order to schedule their next appointment. In addition to the schedule being blocked, one participant indicated that it is VA policy for patients to be required to call later for scheduling if their follow-up appointment is more than 90 days from the date of their current visit. Many HIV patients are scheduled every three to four months for follow-up visits, placing many follow-up visits outside the 90 day mark. HIV care providers described this scheduling practice as an added burden and responsibility for patients. It was felt that this tactic for scheduling makes it extremely easy for patients to leave the clinic and either never schedule a follow-up visit, or not schedule a visit within the recommended time-frame.

> *"And that puts a lot of you know responsibility on a patient to you know remember to call back and then remember when they're supposed to be seen, so I think it makes it challenging" (IDI4).*

Even during times of the year when the schedule is not blocked, providers mentioned that there is a delay in scheduling. For example, if a patient has a more immediate, but not urgent, need, it may not be possible for him/her to schedule an appointment less than a month or two from the current visit date. Therefore, active patient issues that are not considered emergent needs are more difficult to attend to in a timely manner at the clinic. Participants mentioned that sometimes these medical needs may cause patients to visit the Emergency Room, rather than waiting for the out-patient ID clinic care, or ignore health needs that are perceived as less urgent because of the difficulty in scheduling timely appointments.

Rotating Providers

Rotating, or inconsistent providers, was another barrier that was consistently described by providers. For example, providers described that patients often complain about seeing a new provider each visit, and many providers could relate to why this is frustrating for patients. One participant related this desire with her personal desire to see the same physician during her entire pregnancy, and understood why patients would want the same for their HIV care. Many participants explained that patients rotating through multiple providers was a driver for negative patient experiences at the ID clinic.

Perceived stigma and mistrust of the clinic were two sources that providers said can cause negative patient experience. For example, patients are required to retell their story multiple times to different providers. Seeing new providers each appointment and re-telling their story may propagate stigma faced by HIV patients and be a source of frustration for many patients during their appointment, as described by one provider. Providers believed that patients’ retelling their story can be traumatic and force individuals to relive stigmatizing issues. The inability for some patients to build positive relationships with consistent providers was also an example providers described for fueling mistrust of the clinic in patients eyes, particularly for those patients who tend toward paranoia. Seeing a new provider may fuel mistrust in the entire healthcare system; for instance, providers reported that some patients believe there are personal financial gains for providers who see new patients each time.

Providers indicated that provider continuity allows for the development of a positive patient-provider relationship. In short, they acknowledge that this can cultivate effective rapport between provider and patient. Providers believed that a lack of rapport becomes an issue that hinders both patients and providers who must meet with new patients each visit. For example, it was described as a difficult task to get to know a patient on their first visit, which inhibits the provider from understanding “the real issue and [how] to address it” (IDI8). This barrier can only be resolved by consistently seeing the patient each appointment. Providers believed that building rapport with the patient is essential in effectively treating the patient.

> *“And I think, again, on a single visit with a person who comes in every time, it’s really hard to get into the that kinda deep, what’s the real issue to address it, um much easier to do if you’re seeing on a regular basis” (IDI8).*

Participants stated that the source of rotating providers stemmed from the clinic’s use of CDC doctors, all of whom are working at the clinic without-compensation (WOC), or volunteer, physicians. Participants noted the benefit to the clinic utilizing having volunteer physicians, such as help accommodating the heavy patient load and free labor. However, participants also noted the barrier the use of these volunteer physicians presents to patients, and their ability to form beneficial patient-provider relationships. This stems from the fact that the CDC/WOC physicians are not present in the clinic daily, and that daily clinic physicians are inconstant, making it difficult to schedule patients with the same provider each visit. The schedules of the CDC/WOC physicians are not always consistent, as described by participants. For example, a CDC/WOC physician may aim to hold a clinic day at the VA once a month, but may be required to travel for work or other obligations which causes their schedule at the VA to become inconsistent. It was also noted that the voluntary nature of these roles means that the CDC/WOC physicians may not be held as accountable for all of their actions, such as not being reprimanded for showing up late on scheduled clinic days or leaving early. While many participants expressed appreciation for the volunteer physicians, participants recognized the larger issues this unique situation creates for their patient population by hindering the development of consistent patient-provider relationships.

Wait Time

Wait time at the clinic was perceived as both a barrier and inherent aspect of the clinic. For example, some participants mentioned wait time, including the full length of time attending clinic appointments, can easily take up about 4 hours of a patient's day. Providers perceived this as a barrier for patients who work. For example, providers described that it can be difficult for patients to take time off work in order to attend the clinic during their regular work hours. Additionally, participants noted that patients with more migratory professions, such as truck drivers and flight attendants, have schedules that often interfere with their ability to attend regular clinic appointments. Wait times at the pharmacy were also mentioned as being an issue for patients who run out medication refills. However, even for who providers who perceived wait times as a barrier, this issue was also perceived as an inherent part of the "clinic flow" that patients become frustrated with. Participants acknowledge that wait time may be caused by providers taking longer than the allotted amount of time for clinic visits, however "that's just the way it is" (IDI2). Providers believed that patients understand that they will have to wait for their appointments, because it is obvious to patients that the clinic is busy and therefore cannot immediately address all of their needs.

<u>Socioeconomic Issues</u>

Socioeconomic issues included barriers that were mentioned by participants that occur outside of the clinic walls and stem from larger social determinants of health. Participants mentioned some resources that are available for patients with these additional needs, however there was variation in the awareness of certain resources. Despite the availability of resources, issues including patient social network, transportation, homelessness, and financial circumstances/job status were still perceived as barriers.

Patient Social Network

A patient's social network outside of the clinic was mentioned several times as a barrier to care. No participants mentioned patients' social networks as a facilitator to care. However family conflict or "any psycho-social stressor" (IDI7) was perceived to be a potential barrier to care. For example, even when participants described patients who relied on individuals for places to live or rides to the clinic, this was not depicted by participants as a facilitator to treatment retention, but rather as examples of barriers patients face and the way in which they overcome these barriers. Family conflict was a predominate theme within this issue that was depicted as a barrier to care. For example, one participant mentioned that negative comments from a family member caused one of her patients to discontinue his/her medication. Additionally, family stress was depicted as a barrier to care. For example, one participant explained that some patients will chose to prioritize caring for other family members' health over their own health. However, this participant could not fully understand why family issues would cause some patients to fall out of care, because she stated that even if she had to travel to take care of family, she would still take her medications with her.

Homelessness

Each type of HIV care provider reported homelessness as a barrier to treatment retention for the veteran population at the AVAMC. The connection between homelessness and retention was not clearly depicted by participants; however, it was mentioned as an indicator for a patient who is likely to fall out of care. There was variation in the reasons that homelessness contributed to retention failure. For example, one provider mentioned that it is difficult for clinic staff to get in contact with homeless patients, while another provider said that "even homeless patients have phones" (IDI2).

Unstable housing was connected with patients' inability to keep track of their medication. For example, one participant mentioned that homeless patients are more likely to have their medication lost or stolen, particularly if living in a shelter. Additionally, homelessness was associated with transportation issues, and in particular, issues paying for transportation to and from the AVAMC.

Although participants did not always articulate exactly how homelessness is associated with retention failure, homelessness was mentioned as a barrier to medication compliance and attending the clinic were mentioned. Some believed homelessness creates issues in contacting patients, while others believed it does not.

Transportation

Transportation barriers included issues getting to the clinic and parking issues at the AVAMC. One of the most prevailing themes within this barrier includes distance to the clinic and the cost of getting to and from the clinic. Participants mentioned that many patients have to travel from areas in rural Georgia, which exceed a 40 mile radius from the clinic. Many participants believed that although patients may live far away or have transportation needs, that the VA provides transportation assistance. However, a resource-knowledgeable participant dispelled these beliefs during her interview, which indicated that many providers are not aware of the transportation resources available to veterans who face this barrier. Additionally, for programs to assist veterans that live outside a 40 mile radius of the AVAMC, there are limitations for these programs, such as the recent Choice Program which allows veterans to see be seen by a local physician for their health needs. However, while this program was designed to ameliorate barriers related to distance and transportation, its success is questionable. One participant describes the limitations of veterans being able to find a local specialist to help treat their HIV:

> *"With the Choice Program you still have to find a provider within your community that is then a Choice Provider. So if you live in a very rural town, who's to guarantee that they're gonna have*

> *the infectious disease specialist you know who's-who's not only a provider like associated with the VA you know, part of that program, but also willing to see you" (IDI4).*

For patients that were able to drive to the AVAMC, parking was an issue mentioned by participants. One participant described that patients are "frank about" (IDI8) their parking frustrations, which include trouble finding empty parking spaces in the free parking provided on the grounds of the AVAMC.

Financial Circumstances/Job Status

The financial circumstances and/or job status of patients were commonly mentioned barriers to treatment retention. Patients' inability to afford transportation to the clinic was the primary financial barrier mentioned by participants. Overall cost and ease of receiving affordable care and medications is seen as an advantage to care, rather than a barrier. In fact, many participants believed that veteran status offers many advantages to care in terms of affordability and accessibility of healthcare, when compared to the general population. However, financial issues can affect how veterans prioritize their individual needs or their ability to get to and from the clinic.

Both unemployment and work obligations were common themes within this barrier. Lack of stable employment was described as an indicator for patients that are likely to fall out of care. It was perceived that tending to other basic needs such as paying rent can supersede a patient's current health status. In many ways, providers connected economic and employment issues with patients' overall healthcare, particularly when referring to mental health issues. For example, one provider explained that with very severe mental health issues come other issues related to financial issues and difficulty maintaining stable employment. On the other hand, employment was sometimes seen as an issue because clinic hours coincide with "regular work hours" (IDI7). The issue of patients having to take off work to attend clinic appointments, as well as patients with more migratory jobs such as truck drivers or flight attendants were mentioned as barriers related to patients' employment.

> *"For patients who are just struggling financially, um, you know they are worried about how they're going to you know make the rent let alone how they're gonna get here for an appointment, you know…" (IDI4).*

Health Barriers

Health barriers, including substance abuse and mental were regularly mentioned by providers as barriers to patient retention. While these two health issues were perceived as barriers, other health issues such as hypertension or diabetes were not described as barriers to HIV care.

Mental Health

Mental health issues were described as barriers to retention by all participants. Mental health issues mentioned by providers included depression, suicidal thoughts, schizophrenia, personality disorders, anger issues, or psycho-social crises. Most participants used adjectives such as 'severe', 'substantial', or 'serious' to describe these mental health issues that serve as barriers to HIV treatment retention. For example, "severe depression would definitely be a red flag [for retention failure]" (IDI7). While not all participants were sure of making the association, some connected the veteran status of this population with having a higher prevalence of mental health issues. It was described that compared to other healthcare setting settings, there are certain mental health illnesses, such as post-traumatic stress disorder, that are found more at the AVAMC than other health institutions.

Overall, mental illness was depicted as influencing patients' compliance with their HIV treatment. Mental illnesses such as depression, anxiety or bipolar disorder were believed to affect patients' follow-up with clinic visits or medication habits. For instance, providers mentioned that apathy or depression could cause a patient to forgo their health needs related to HIV.

Trust and stigma issues were common themes within the barrier of mental illness. For example, some providers found it difficult to separate these issues from mental illness. One participant described patients with their own personal stigma who may have “a tendency to maybe be a little paranoid or whatever then it really just kind of exacerbates [their mental health issue” (IDI4). Issues such as this are connected with providers’ views that patients with mental health issues are more challenging to treat in regards to their HIV treatment. For examples, one provider mentioned that it was more challenging to “convince” (IDI6) mental health patients to take their ARVs. Communication with patients with mental health issues was more of a challenge for providers than it is with other patients. It was described by one participant that it’s important to “figure out how it is that you can make the situation better” (IDI6) by implementing individualized measures to keep a person with a mental health issue in care. For example, this provider began working with mental health providers to get one patient who was not following-up with his HIV appointments to develop the habit of visiting the ID clinic every time he attended his mental health appointments, with which he was compliant. This individualized fix for this patient was successful in the eyes of this provider.

> *“I mean initially if you see something like that [mental health, job loss] I think you have to come to-you have to figure out how it is that you can make the situation better. If it’s a mental health patient that [.] is not keepin’ appointments, then you have to figure out some kind of way to fix it, so that they keep their appointment- like the mental health person I was tellin’ you about…” (IDI6).*

Substance Abuse

Substance abuse as a barrier to retention was mentioned by nearly all participants, and often mentioned along with providers’ discussion of mental health issues. Substances that were mentioned included excessive alcohol use, cocaine, crack, and methamphetamines. Many participants indicated that substance abuse issues are indicators for retention failure. Substance abuse was seen as a barrier to compliance largely concerning medication behavior or with remembering to keep appointments.

Participants would describe substance abuse as the reason that patients would forget about the HIV treatment needs, such as causing patients to pass out and therefore forget to take their medication. However, participants also mentioned examples of patients who would remember to take their medications despite their substance use. For example, one participant mentioned, ““I'll still have patients that will like, 'Yeah, I'm still doing meth, but I'm taking my medications'” (IDI5). Many participants were not able to explain this inconsistency among their patient population.

Using substances was also described as an inhibitor to some veterans' ability for accessing other resources. For example, providers described that veteran housing may be inaccessible to some patients because it is required that active substance users must agree to undergo substance abuse treatment in order to receive housing. Participants mentioned that not all patients who are currently using substances are willing to undergo treatment to stop their substance abuse. In some ways, providers described substance use by patients as a behavioral choice.

> *“If you're actively using, it's really hard to remember to keep up with your appointments, to take your meds as prescribed, et cetera” (IDI4).*

Discussion

Through the qualitative analysis presented in this paper, we aimed to describe HIV care providers' perceptions of barriers to treatment retention at the AVAMC ID clinic. Exploring providers' views of retention barriers yielded insight into the perspectives that providers have regarding patient characteristics including patient stability, patient motivation, and patient frustrations- which are described differently between in- and out-of-care patients. Understanding provider perceptions of patient characteristics is important because these perceptions can carry through their interactions with patients and views on retention barriers.

Countertransference is a concept that has long been associated in theories of psychotherapy. Four predominate theories exist in defining countertransference, but the fundamental concept involves the physician’s conscious and unconscious reactions to the patient. These reactions can both negatively and positively affect patient-provider interactions; the effect on this relationship is why managing countertransference is often recommended in the literature (Hayes, Gelso et al. 2011). The perceptions expressed in regards to patient characteristics may be consciously or unconsciously expressed by providers in the study. However, increasing awareness in providers of how these perceptions may help mitigate any biased or stigmatizing perceptions that could impact patient-provider interactions.

With these perceptions of patient characteristics in mind, we were able to further explore providers’ perceptions of barriers that affect patients’ HIV treatment retention. Thematic analysis of this data yielded three distinct categories of providers’ perceptions of retention barriers. Clinic barriers which included lack of resources, scheduling, rotating providers, and wait time. Socioeconomic barriers which included patient social network, transportation, homelessness, and financial circumstance/job status. And the third category, health barriers, involved health issues not related to HIV infection including mental health issues and substance abuse.

Clinic barriers are largely associated with negative patient experiences. The lack of resources including a lack of providers which limits adequate time spent with patients, and the clinic’s rotating providers both inhibit positive patient-provider communication and are barriers that can greatly influence the patients experience during appointments. Because patients are more likely to play a passive role in patient-provider relationships, providers are chiefly responsible for allowing the space for patients to share their perspectives in an environment in which they are comfortable to do so. Additionally, within these interactions it is imperative address both socioemotional (social and emotional) needs and specific tasks related to the patients’ healthcare (Roter and Hall 1991). The lack of providing an adequate number of physicians to distribute patients among and creating inconsistency in patient-provider relationships inhibits the development of these necessary and positive relationships.

Patient-provider interactions are heavily influenced by the provider's style of care. For example, even with varying types of physician specialties, improved health outcomes are associated with physicians who interact with patients utilizing psychosocial aspects of care (Bertakis, Callahan et al. 1998). Part of establishing psychosocial aspects of care between patients and physicians is the physician addressing these aspects of care with patients, and the ability to build rapport with the patient. Increasing consistency in patient-provider relationships would allow physicians to incorporate psychosocial aspects of care into each of their patient interactions.

Motivational interviewing and practicing cultural sensitivity are ways of improving rapport between patients and providers, and health outcomes. Motivational interviewing (MI), for instance, has been a well-studied counseling technique for helping individuals improve lifestyle behaviors for better health out-comes, particularly surrounding addiction and diabetes management (Martins and McNeil 2009, Coyne and Correnti 2014). It is believed to be an effective technique in chronic disease management, which could indicate its usefulness in HIV care (Coyne and Correnti 2014). Providing general practitioners with the skills of MI can be a great source for addressing improvements in patients' self-care and all the requirements of managing their health issues (Martins and McNeil 2009).

In addition to improving patients' experiences through MI, practicing cultural sensitivity is an important tool within patient-provider interactions. Recent research has shown that cultural sensitivity expressed by the provider is associated with increased patient satisfaction, with trust in the provider and provider fairness as mediating factors among nearly 300 African American men who participated in the study (Tucker, Moradi et al. 2014). This indicates that through increased trust and cultural sensitivity of the provider can greatly improve patients' experiences and satisfaction with their healthcare, potentially influencing patients to remain in care.

Conclusion

Understanding providers' perceptions of barriers to treatment retention is an important step in understanding where specific interventions may be targeted. It also provides insight into variation and consistency in providers' views. Overall, providers at the AVAMC ID clinic are consistent in their perceptions of barriers affecting patients' retention; however, some variation exists within specific barriers such as transportation. Additionally, a comparison study between providers' and patients' perceptions of barriers to treatment retention can shed light on differences in perceptions between these two groups in an effort to decrease barriers and improve communication between patients and providers at the AVAMC ID clinic. Improving the communication between providers and patients during clinic visits may also mitigate negative patient experiences and improve retention.

References

Affairs, D. o. V. (2011). "Department of Veterans Affairs National HIV/AIDS Strategy Operational Plan 2011."

Affairs, D. o. V. (2012). "The State of Care for Veterans with HIV/AIDS: 2011 Summary Report ".

AIDS.gov (2015, 11/25/2015). "Global Statistics ". Retrieved March 24, 2016, from https://www.aids.gov/hiv-aids-basics/hiv-aids-101/global-statistics/.

AIDS.gov (2015). "HIV/AIDS Care Continuum ". Retrieved January 2, 2016, from https://www.aids.gov/federal-resources/policies/care-continuum/.

Bazeley, P. (2013). Qualitative Data Analysis: Practical Strategies. London, England, SAGE Publications Ltd.

Bertakis, K. D., et al. (1998). "Physician practice styles and patient outcomes: differences between family practice and general internal medicine." Med Care **36**(6): 879-891.

CDC (2015). "HIV/AIDS Statistics Overview ". Retrieved January 2, 2016, from http://www.cdc.gov/hiv/statistics/overview/.

CDC (December 2014). "Understanding the HIV Care Continuum ". from http://www.cdc.gov/hiv/pdf/dhap_continuum.pdf.

Coyne, N. and D. Correnti (2014). "Effectiveness of motivational interviewing to improve chronic condition self-management: what does the research show us?" Home Healthc Nurse **32**(1): 56-63.

Giordano, T. P. (2015). "The HIV treatment cascade--a new tool in HIV prevention." JAMA Intern Med **175**(4): 596-597.

Hayes, J. A., et al. (2011). "Managing countertransference." Psychotherapy (Chic) **48**(1): 88-97.

Mangal, J. P., et al. (2014). "The continuum of HIV care in a Veterans' Affairs clinic." AIDS Res Hum Retroviruses **30**(5): 409-415.

Martins, R. K. and D. W. McNeil (2009). "Review of Motivational Interviewing in promoting health behaviors." Clin Psychol Rev **29**(4): 283-293.

Matthew Heyward Wessinger, M. H., Vince Marconi (2015). Clinical Influences on Patient Retention in HIV Treatment at VA Medical Center. Hubert Global Health Department Emory University Rollins School of Public Health **Master of Public Health** 83.

Monique Hennink, I. H., Ajay Bailey (2011). Qualitative Research Methods. London, England SAGE Publications Ltd.

Roter, D. L. and J. A. Hall (1991). "Health education theory: an application to the process of patient-provider communication." Health Educ Res **6**(2): 185-193.

Tucker, C. M., et al. (2014). "Roles of perceived provider cultural sensitivity and health care justice in African American/Black patients' satisfaction with provider." J Clin Psychol Med Settings **21**(3): 282-290.

Chapter IV: Public Health Implications

Public Health Context

It has been well documented that in order for PLWH to have successful outcomes, it is imperative that these individuals adhere to the steps portrayed in the HIV continuum of care. These steps include diagnosis of HIV, linkage to care, retention in care, receiving an ARV prescription, and adherence to ARV therapy- all in order to ultimately achieve viral suppression (Giordano, Hartman et al. 2009, Giordano 2015, Skarbinski, Rosenberg et al. 2015, CDC December 2014). Viral suppression means that an individual has undetectable viral loads, which leads to improved health outcomes and limited risk of transmitting the virus to others. In fact, CDC published a paper indicating that along each step of the HIV care continuum, the risk of transmitting the virus to others is decreased (Mangal, Rimland et al. 2014, Skarbinski, Rosenberg et al. 2015). The need to improve prevalence of each step within the U.S. and targeted healthcare settings is demonstrated from numerous findings (CDC December 2014).

At the AVAMC, HIV diagnosis and linkage to care are high, however, retention in care is lacking. Nearly 30% of PLWH and receiving care at the AVAMC are not retained in care, indicating this area of HIV care is in need of further research within this context (Mangal, Rimland et al. 2014). A promising place to start is by understanding what barriers exist that lead to retention failure. Previous research in this patient population has indicated that patients perceive barriers through varying spheres of influence that impact both in- and out-of-care patients. Spheres of influence that impact poor treatment retention include wait time at the clinic, the level of confidence in physicians, and customer service. In contrast, spheres of influence that impact in-care patients include patience with institutional issues (such as clinic wait times), confidence in physicians, and positive interpersonal relationships with clinic staff (Matthew Heyward Wessinger 2015). Building further on this research, this particular study aimed to understand barriers to treatment retention through the perspectives of the AVAMC's HIV care providers, which may vary from patients'' perceptions.

Current controversy regarding the VA system has recently been highlighted in the media. According to a recent report by the Government Accountability Office (GAO), issues surrounding wait time for primary care and wait for linkage to care varied widely from 22 to 71 one days. Debate over the measurements used to assess wait times have also been highlighted, because schedulers often report dates based on patients' preferences rather than when these requests were first made; this has caused misinformation in terms of reporting wait times for veterans' primary care appointments (Office 2016). Many people and politicians are currently upset, believing that the VA is intentionally withholding information concerning wait times (Boyer 2016). These issues surrounding the VA system nationally, affect each VA institution in terms of appointment scheduling design and how local VA's are viewed by the public and patients. Understanding how these barriers affect patients, including patients receiving HIV care is important for health outcomes.

Public Health Implications

The research presented in this paper provides insight into the HIV care providers' perspectives on barriers to treatment retention at the AVAMC. The findings from this study demonstrate how providers perceieve certain patient characteristics as indicative of retention failure and opposing characteristics as indicative of retention success. These perceptions undoudetly influence providers' of barriers to retention at the AVAMC. Based on the findings from this study, we provide the following suggestions for mitigating barriers to retention at the AVAMC:

1. Improve continuity of care: Inconsistency in providers creates barriers to the patient-provider relationship for both patients and providers.
    a. Educate providers, patients, and schedulers to request their preferred provider while scheduling their next appointment.
    b. Hire more full-time providers: Increasing the number of full-time providers will allow providers to spend more time with patients, and limit inconsistencies in care.
    c. Require more consistency in WOC physicians schedules: Many providers site the use of CDC/WOC physicians as a primary cause for rotating providers. Creating more

    consistency in these volunteer providers’ schedules could mitigate issues in inconsistency related to the utilization of these providers.

2. Reduce scheduling and transportation issues.
    a. Utilize telehealth to alleviate some scheduling and transportation issues, while increasing visit opportunities for the patient and provider.
3. Improve the chanels between mental health and primary care: Improving communication between providers of all roles will enable the development of individualized solutions to patients with mental health issues that need to be addressed.
    a. Include the mental health practioners within the floor of the ID clinic: Embedding the mental health profiessional(s) within the ID clinic will not only improve communication among providers, but also enable patients to attend mental health appointments during their primary care appointments in the ID clinic.
4. Improve provider awareness of available resources for veterans: Inconsistencies among providers’ awareness of resources avialable for veterans would help in communicating these resources to patients.
    a. Incorporate patient/peer navigators in the clinic.
    b. Incorporate patient/peer navigators with community outreach.
5. Provide workshops to providers on evidence-based patient-provider communication methods: Workshops allow providers to all learn the same information in regard to patient-provider communication, despite varying forms of prior training received.
    a. Train providers in motivational interviews and cultural sensitivity.
    b. Encourage positive rapport between patients and providers: Providers who understand the importance of patient satisfaction and how that is often

interpretted by provider interactions and their rapport is key. Positive rapport may also improve patient activation.

   c. Work specifically with providers who receive patient complaints: No clear assesment of current providers, or protocls for providers with repetitive patient complaints was mentioned. Evauating providers' effectiveness through patient satisfaction surveys, or providing additional training to providers with multile patient complaints can benefit views of the clinic as a whole.

The suggestions listed above are not evidence-based intervetions. Nor are they based on documented effectiveness. Continued research is encouraged in order to:

1. Assess effectiveness of interventions targeting retention barriers.
2. Assess patient-provider interactions; Measuure and collect data on patient activation scores for the ID clinic.
3. Compare responses between patients and providers within this population for similarities and differences.
4. Develop a gold standard methodoly for positive patient-provider communication.
5. Develop a framework for current provider attitudes in order to assess how/if these attitudes effect patient-provider communication or perceived stigma.

Study Limitations

It is our goal to be transparent in the limitations of this study. First, due to the demanding and time-consuming work of all participants, time was the biggest limitation throughout the data collection process. Interviews were not able to exceed an hour and some ended abruptly due to the demands of participants' job roles. Second, while participants were purposively selected in order to increase variation based on job role, not all primary job roles within the clinic were represented. For instance, the clinic pharmacist who would provide the best insight into medication distribution for HIV patients was not interviewed. Additionally, a key participant, the patient services assistant, was not interveiwed. His unique relationship to the patients, and consistency for all patients, would have likely offered further depth to the data presented. Finally, due to the limited number of total HIV care providers it was difficult to recruit and eventually assure annonymity without omitting job titles.

References

Affairs, D. o. V. (2011). "Department of Veterans Affairs National HIV/AIDS Strategy Operational Plan 2011."

Affairs, D. o. V. (2012). "The State of Care for Veterans with HIV/AIDS: 2011 Summary Report ".

AIDS.gov (2015, 11/25/2015). "Global Statistics ". Retrieved March 24, 2016, from https://www.aids.gov/hiv-aids-basics/hiv-aids-101/global-statistics/.

AIDS.gov (2015). "HIV/AIDS Care Continuum ". Retrieved January 2, 2016, from https://www.aids.gov/federal-resources/policies/care-continuum/.

Bazeley, P. (2013). Qualitative Data Analysis: Practical Strategies. London, England, SAGE Publications Ltd.

Beach, M. C., et al. (2006). "Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV?" J Gen Intern Med **21**(6): 661-665.

Benkert, R., et al. (2006). "Effects of perceived racism, cultural mistrust and trust in providers on satisfaction with care." J Natl Med Assoc **98**(9): 1532-1540.

Bertakis, K. D., et al. (1998). "Physician practice styles and patient outcomes: differences between family practice and general internal medicine." Med Care **36**(6): 879-891.

Boyer, D. (2016). House chairman blasts VA for more problems with veterans' wait times The Washington Times, The Washington Times, LLC.

CDC (2015). "HIV/AIDS Statistics Overview ". Retrieved January 2, 2016, from http://www.cdc.gov/hiv/statistics/overview/.

CDC (December 2014). "Understanding the HIV Care Continuum ". from http://www.cdc.gov/hiv/pdf/dhap_continuum.pdf.

Cheatham, C. T., et al. (2008). "Barriers to health care and health-seeking behaviors faced by Black men." J Am Acad Nurse Pract **20**(11): 555-562.

Christopoulos, K. A., et al. (2013). ""Taking a half day at a time:" patient perspectives and the HIV engagement in care continuum." AIDS Patient Care STDS **27**(4): 223-230.

Cohen, S. M., et al. (2014). "HIV viral suppression among persons with varying levels of engagement in HIV medical care, 19 US jurisdictions." J Acquir Immune Defic Syndr **67**(5): 519-527.

Coyne, N. and D. Correnti (2014). "Effectiveness of motivational interviewing to improve chronic condition self-management: what does the research show us?" Home Healthc Nurse **32**(1): 56-63.

Crawford, M. J. and A. S. Kessel (1999). "Not listening to patients--the use and misuse of patient satisfaction studies." Int J Soc Psychiatry **45**(1): 1-6.

Dang, B. N., et al. (2013). "Examining the link between patient satisfaction and adherence to HIV care: a structural equation model." PLoS One **8**(1): e54729.

Dombrowski, J. C., et al. (2015). "Barriers to HIV Care and Treatment Among Participants in a Public Health HIV Care Relinkage Program." AIDS Patient Care STDS **29**(5): 279-287.

Feldman-Stewart, D., et al. (2005). "A conceptual framework for patient-professional communication: an application to the cancer context." Psychooncology **14**(10): 801-809; discussion 810-801.

Gardner, E. M., et al. (2011). "The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection." Clin Infect Dis **52**(6): 793-800.

Gaston, G. B. and B. Alleyne-Green (2013). "The impact of African Americans' beliefs about HIV medical care on treatment adherence: a systematic review and recommendations for interventions." AIDS Behav **17**(1): 31-40.

Giordano, T. P. (2015). "The HIV treatment cascade--a new tool in HIV prevention." JAMA Intern Med **175**(4): 596-597.

Giordano, T. P., et al. (2009). "Predictors of retention in HIV care among a national cohort of US veterans." HIV Clin Trials **10**(5): 299-305.

Guest, J. L., et al. (2013). "A comparison of HAART outcomes between the US military HIV Natural History Study (NHS) and HIV Atlanta Veterans Affairs Cohort Study (HAVACS)." PLoS One **8**(5): e62273.

Hayes, J. A., et al. (2011). "Managing countertransference." Psychotherapy (Chic) **48**(1): 88-97.

Hennink, M. I. H., Ajay Bailey (2011). Qualitative Research Methods. London, England SAGE Publications Ltd.

Katz, R. V., et al. (2011). "Re: Scharff DP, Matthews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D. More than Tuskegee: understanding mistrust about research participation. J Health Care Poor Underserved. 2010 Aug;21(3):879-97." J Health Care Poor Underserved **22**(1): 397-398; author reply 399-400.

Kempf, M. C., et al. (2010). "A qualitative study of the barriers and facilitators to retention-in-care among HIV-positive women in the rural southeastern United States: implications for targeted interventions." AIDS Patient Care STDS **24**(8): 515-520.

Magnus, M., et al. (2013). "Linking and retaining HIV patients in care: the importance of provider attitudes and behaviors." AIDS Patient Care STDS **27**(5): 297-303.

Mallinson, R. K., et al. (2007). "The provider role in client engagement in HIV care." AIDS Patient Care STDS **21 Suppl 1**: S77-84.

Mangal, J. P., et al. (2014). "The continuum of HIV care in a Veterans' Affairs clinic." AIDS Res Hum Retroviruses **30**(5): 409-415.

Martins, R. K. and D. W. McNeil (2009). "Review of Motivational Interviewing in promoting health behaviors." Clin Psychol Rev **29**(4): 283-293.

Matthew Heyward Wessinger, M. H., Vince Marconi (2015). Clinical Influences on Patient Retention in HIV Treatment at VA Medical Center. Hubert Global Health Department Emory University Rollins School of Public Health **Master of Public Health** 83.

Office, U. S. G. A. (2016). VA Health Care: Actions Needed to Improve Newly Enrolled Veterans' Access to Primary Care.

Roter, D. L. and J. A. Hall (1991). "Health education theory: an application to the process of patient-provider communication." Health Educ Res **6**(2): 185-193.

Saha, S., et al. (2010). "Trust in physicians and racial disparities in HIV care." AIDS Patient Care STDS **24**(7): 415-420.

Saha, S., et al. (2011). "The role of cultural distance between patient and provider in explaining racial/ethnic disparities in HIV care." Patient Educ Couns **85**(3): e278-284.

Schneider, J., et al. (2004). "Better physician-patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection." J Gen Intern Med **19**(11): 1096-1103.

Skarbinski, J., et al. (2015). "Human immunodeficiency virus transmission at each step of the care continuum in the United States." JAMA Intern Med **175**(4): 588-596.

Sohler, N. L., et al. (2007). "Does patient-provider racial/ethnic concordance influence ratings of trust in people with HIV infection?" AIDS Behav **11**(6): 884-896.

Tucker, C. M., et al. (2014). "Roles of perceived provider cultural sensitivity and health care justice in African American/Black patients' satisfaction with provider." J Clin Psychol Med Settings **21**(3): 282-290.

Appendix

IDI Guide

Introduction

Thank you again for taking the time to speak with me today. My name is Amada and I'm a public health student at Emory University. I am involved with the VA RETAIN study which examines HIV positive patient treatment retention here. Under the scope of this study, I am interviewing VA staff who work with HIV positive patients that are part of the RETAIN study to gain their perspectives of working with this group of patients. The data collected for this study will be analyzed by me and turned into a written thesis as part of my degree requirements. It will also remain part of the data collected under the umbrella of the RETAIN study for potential use for future projects or interventions.

I would like to remind you that your participation in this interview is completely voluntary. As such, you should feel free to not answer a question if you don't feel comfortable doing so, or you may ask to stop the interview at any time. Additionally, I would like to tape record our discussion today so that we can be free to talk without my constant jotting and I don't want to miss anything that we discuss. As a reminder, our discussion today is completely confidential. I will not share the recording with any other individual in the study. I plan to transcribe the interview myself, removing any identifiable data, so that no other researcher would be able to identify you to your responses. **Do I have your permission to tape record our discussion?**

I have a list of topics that I would like us to discuss, however, please feel free to bring up any other issues that you feel are relevant. The primary goal to understand your personal opinions and experiences, so please comfortable to speak freely and honestly. **Do you have any questions before we begin?**

First, let's talk about your job here at the VA..

1. When did you first start working at the VA in Atlanta?
2. What is your job title?
3. Could you please describe some of your job roles and responsibilities?
    a. Probe:
        i. Which of these roles causes you have direct interactions with the patients?

I'd now like to explore in more detail your interactions with patients…

4. Could you please describe in detail the nature of your interactions with HIV positive patients?
    a. Probe:
        i. Is most of this time face-to-face, or over the phone?
        ii. How much time do you spend interacting with patients on a daily basis?

            iii. Positive or negative?
5. How do you believe you are fulfilling patients' needs?
    a. Probe:
        i. Any gaps?
6. What do you believe is your most important role in a patient's treatment?
    a. Probe:
        i. Why?
        ii. How do you fulfill this role?
7. What does 'adhering to treatment' mean in reference to HIV treatment?
    a. Probe on:
        i. Taking medicine
        ii. Making doctor's visits
8. What is the overall goal of treatment adherence for an HIV positive individual?
9. Does treatment adherence fall mostly on the responsibility of the patient, or the provider?
    a. Probe:
        i. Actions taken by provider to ensure adherence
        ii. Actions taken by patient to ensure adherence
10. What are some of the most important duties a patient can do to remain in treatment?
    a. Probe on:
        i. Making appointments
        ii. Refilling prescriptions
        iii. Taking medication regularly
11. What do you think are some of the reasons patients fall out of treatment?
12. Do you believe the HIV positive veterans face different challenges from other HIV positive Americans?
13. Are you able to make an educated guess after your first few interactions with patients whether or not they are likely to remain in treatment?
14. Is there a 'type' or patient that is more or less likely to adhere to HIV treatment?
    a. Probe on:
        i. Positive/negative interactions with staff
        ii. Behavioral issues
        iii. Notes on patients' charts
15. What characteristics do you think make a patient more or less likely to adhere to treatment?
16. What are some of the actions taken if a patient misses a scheduled appointment?
    a. Probe on:
        i. Misses a medication refill?
17. What actions do you personally take if you notice a patient has not shown up for treatment?
18. Could you describe a time when any of these actions have helped to bring a patient back into treatment?

19. What do you see as some feasible solutions to keeping HIV positive veterans in treatment?