THE ASSOCIATION OF INTERNALIZED HIV STIGMA WITH RETENTION IN HIV CARE

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ABSTRACT

Eduardo E. Valverde: THE ASSOCIATION OF INTERNALIZED HIV STIGMA WITH
RETENTION IN HIV CARE
(Under the direction of Bryce B. Reeve)

Internalized HIV stigma should be an important construct in terms of explaining poor
retention in HIV care given that it already plays a detrimental role in several components of the
HIV medical care process such as negatively impacting access to HIV care and HIV medication
adherence, and contributing to comorbid conditions that may complicate the HIV disease
process. Yet, there is paucity on the research that explores the association of internalized HIV
stigma with retention in HIV care.

We conducted secondary data analysis of interview and medical record abstraction data
collected from a total of 188 HIV positive men and women receiving care at the University of
Miami/Jackson Memorial Hospital (UM/JHM) Special Immunology (SI) Clinics, located in
Miami, Florida. Demographic characteristics, HIV risk behaviors, HIV care related factors, as
well as psychosocial constructs were analyzed to explore the association of internalized HIV
stigma with two retention in HIV care measures: 1- number of missed clinical visits (via a
Poisson regression analysis), and 2- the proportion of appointment adherence (via a multiple
regression analysis).

Results from the analysis indicate that gender and age were significantly associated with
both retention in HIV care measures. Additionally, the Poisson regression analysis indicated that
the level of engagement with an HIV care provider moderated the relationship between
internalized HIV stigma and missed visits such that in participants with low and medium
internalized HIV stigma, better engagement with provider had a significant effect in reducing the
missed visits rate. However, for individuals experiencing high internalized HIV stigma,
engagement with provider did not have a significant effect in reducing missed visits.

Our plan for change to improve HIV retention in care rates at the UM/JHM clinics is
modelled after John Kotter's 8 Steps Leading to Organizational Change. The plan involves
lobbying the leadership of the UM/JHM clinics to implement interventions that improve
engagement with providers for patients with low and medium internalized HIV stigma, as well as
implementing interventions that reduce internalized HIV stigma, followed by intervention to
improve engagement with providers directed to patient with high internalized HIV stigma.

To the men and women affected by HIV, and to my father.

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LIST OF ABBREVIATIONS

ACA   Affordable Care Act

AIDS   Acquired Immunodeficiency Syndrome

CDC   Centers for Disease Control and Prevention

CES-D 10   Center for Epidemiological Studies - Depression 10

EMR   Electronic Medical Record

HAB   HIV/AIDS Bureau

HIPAA   Health Insurance Portability and Accountability Act

HIV   Human Immunodeficiency Virus

HRSA   Health Resources and Services Administration

IOM   Institute of Medicine

LOC   Loss of Consciousness

NHAS   National HIV/AIDS Strategy for the United States

ONAP   Office of National AIDS Policy

PCP   Primary Care Physician

SI   Special Immunology

UM/JHM   University of Miami Jackson Memorial Hospital

CHAPTER 1: INTRODUCTION

Statement of the Issue

Internalized Human Immunodeficiency Virus (HIV) stigma, defined as *the shame associated with HIV/AIDS and the fear of being discriminated against, which are both felt by persons living with HIV*, should be an important construct in terms of explaining poor retention in HIV care given that it already plays a detrimental role in several components of the HIV medical care process such as negatively impacting access to HIV care and HIV medication adherence, [1,2,3] and contributing to comorbid conditions that may complicate the HIV disease process. [3, 4] Given the detrimental impact of internalized HIV stigma on several aspects of HIV care, it is plausible to hypothesize, as Bruce Link hypothesized with mental illness [5] that it also plays an important role in shaping social interactions with medical providers that may impact retention in HIV medical care. Determining what role internalized HIV stigma plays in retention in HIV care may have important clinical and policy making (including resource allocation) implications. This can make a difference in how we train providers (i.e. trainings to minimize stigma or better engage with patients) or implement patient level interventions to reduce internalized HIV stigma in order to improve retention in care. The dissertation analysis will focus on measures of retention in care that may impact HIV clinical care and policy/administrative/resource allocation decision making in order to assist HIV care providers and public health professionals achieve the goals and objectives of the National HIV/AIDS Strategy of the United States.

Background

In 2008 the White House Office of National AIDS Policy (ONAP) was tasked with leading the effort to develop a national HIV/AIDS strategy that would address a domestic HIV epidemic that had remained stable at around 50,000 new diagnosed cases per year since the beginning of the new millennia. The resulting document, the National HIV/AIDS Strategy for the United States 2010 [6] delineates three primary goals: 1) reducing the number of people who become infected with HIV, 2) increasing access to care and optimizing health outcomes for people living with HIV, and 3) reducing HIV-related health disparities. Each of these goals has specific objectives attached to them, and each of these objectives in turn have specific strategies that, according to ONAP, will allow government agencies and their community partners to achieve all the goals and objectives of the NHAS within a 5 year period of time. Under goal number 2- increasing access to care and optimizing health outcomes for people living with HIV- one of the objectives specifically mentions the need to "**maintain people living with HIV in care.**" This focus of the NHAS on maintaining people in care (or retaining them in care) addresses a critical step necessary to ensure that all HIV infected patients are receiving the best medical care available.

The Health Resources and Services Administration (HRSA), which is the federal agency that oversees the Ryan White HIV/AIDS Program (the insurance program of last resort used by HIV infected individuals who do not have healthcare insurance or financial resources to pay for the cost of treatment services), developed the Engagement in Care Continuum (Figure 1) that allow us to visualize the different stages by which patients engage in HIV care. The HRSA Engagement in Care Continuum recognizes full engagement in HIV care as the last step

necessary in order for the patient to reap the full benefits of the clinical resources available in order to maximize health outcomes, but also identifies 2 stages (Entered HIV care but lost to follow-up & Cyclical or intermittent user of HIV care) in which patients are not fully retained in care.[7]

Figure 1. HRSA Engagement in Care Continuum

Source: HRSA. Outreach: engaging people in HIV care: summary of a HRSA/HAB 2005 consultation on linking PLWH into care. 2006

The NHAS focus on engagement in care reflected an ongoing concern among clinical practitioners from across the country that saw that a significant number of patients were accessing care but later were lost to follow-up or failed to adhere to clinical care appointments. [8, 9] These concerns were validated in 2011 when the Centers for Disease Control and Prevention (CDC) in a Mortality and Morbidity Weekly Report [10] published that of 725,302 individuals diagnosed with HIV as of 2008 who had accessed HIV care at some point after their diagnosis, 34% had not been retained in HIV care (Figure 2). These figures have been updated recently, and according to the newest estimates almost 50% of individuals diagnosed and living with HIV are not retained in care. [11] Having such a large proportion of HIV-infected individuals not retained in medical care can potentially be a serious public health problem. These individuals do not have access to HIV medications and other medical services which can prevent diseases associated with HIV infection. Those who access care again at a later stage in their disease have a higher

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probability of negative clinical outcomes including death. [12, 13] Furthermore, those who begin using HIV medications and stop due to dropping out of care can develop viral resistance, [14] which has been associated with higher mortality. [15]

In addition, little is known of the sex and drug use risk behaviors of individuals who drop out of care. Some earlier studies suggested that individuals that exhibit poor retention in care behaviors also engaged in increased HIV transmission risk behaviors. [16, 17] (Current models developed by CDC focused on estimating the rate and number of HIV transmissions from HIV-infected persons in the United States along each step of the HIV care continuum (diagnosis, retention in medical care, antiretroviral therapy, and viral suppression) show that HIV-infected undiagnosed persons and persons diagnosed with HIV but not retained in care were responsible for over 90% of HIV transmissions in 2009. [18] This information is important because population studies have shown an association between HIV treatment, lower community viral load, and lower population HIV infection rates. [19] In other words, improving access and retention in HIV care can have both clinical and prevention level benefits.

Figure 2. Number and percentage of HIV-infected persons engaged in selected stages of the continuum of HIV care — United States

Barriers to Retention in HIV Care

The Institute of Medicine (IOM) in the landmark report Access to Healthcare in America classified reasons for not accessing medical care into financial, structural, and personal (Figure 3). [20] Financial barriers according to the IOM were those that may hinder health care access via the person's eligibility/insurability, benefit coverage, and reimbursement levels of providers. Structural barriers could be envisioned as "...impediments to medical care directly related to the number, type, concentration, location, or organizational configuration of health care providers". The IOM also noted that personal barriers could be understood as demographic characteristics shared by the population such as education and income levels, or cultural traits such as attitudes towards disease. The IOM model allows us to classify the types of barriers that may impact adequate use of medical services for all types of diseases.

Figure 3. IOM Model of Access to Personal Health Care Services.

Using the IOM's classification as a framework, the literature indicates that barriers to retention in HIV care among HIV infected patients include financial level barriers such as lack of health insurance or having public health insurance; [15, 21] structural level barriers such as lack of transportation, fragmented HIV care services, and problems accessing clinical care; [22,23,24,25]

and personal level barriers such as female gender, younger age, being a racial/ethnic minority, lack of social support, multiple caregiving responsibilities, having mental health and/or substance abuse problems, being homeless, having a lower CD4 count, not having an AIDS diagnosis, having poor communication with providers, and negative perceptions of the health care system. [26-37,]

Internalized Stigma and Retention in HIV Care - Theoretical Considerations

Among personal level factors involved as a barrier to retention in HIV care, one that has not been fully explored is the role of internalized HIV stigma. Ervin Goffman defined stigma as a deeply discrediting attribute that reduces the bearer "from a whole and usual person to a tainted, discounted one with a spoiled identity." [38] He advanced the idea that individuals in society stigmatize on the basis of what they consider is a behavior outside of the norm (or a deviant behavior). According to Goffman, it is through the process of labeling, and assigning meaning to the labels, that a society makes stigmatization a reality. The social label of deviant makes others in society and the stigmatized individuals themselves view the stigmatized as "discredited or undesirable."

Link and Phelan took a similar approach as Goffman but extended their conceptualization of stigma beyond labeling. According to Link and Phelan, stigma occurs via five processes: 1- people distinguish and label human differences; 2- the dominant cultural beliefs link labeled persons to negative stereotypes; 3- labeled persons are placed in distinct categories so they can be separated; 4- labeled persons experience status loss and discrimination

that lead to unequal outcomes (including health outcomes), and finally; 5- the dominant group's power allows the stigmatization to become established in society. [39]

Link also advanced the idea that unequal outcomes (including health outcomes) among the stigmatized may occur without actual discrimination. In a "modified labeling theory" looking at the effects of stigma on people with mental illnesses [40] and developed based on the work of Scheff,[41] Link postulated the idea that individuals will develop conceptions about a particular stigmatized behavior as part of the socialization process that is constantly occurring within a culture. Once these conceptions of what it means to have a particular stigma become established as a lay theory, people will form expectations as to whether individuals possessing the stigma will be rejected by others. These expectations become particularly important for those who have or acquire the stigma because the possibility of devaluation and discrimination becomes personally relevant. As Link describes it "If one *believes* that others will devalue and reject people because they possess a particular stigma, one must now fear that this rejection applies personally." If this believe becomes part of the individual's world view, in other words, if the stigma is internalized, that perception can have serious negative consequences. Link postulated that, in the case of mental illness, patients who had been hospitalized for mental illnesses acted less confidently and more defensively, or simply avoided potentially threatening contact altogether (thus potentially avoiding mental health care) because they were expecting and fearing rejection from others in their social network including health care providers. This is turn made individuals more vulnerable to negative health outcomes or health behaviors. A description of Link's Modified Labeling Theory is presented in Figure 4.

Figure 4. Bruce Link's Labeling Theory

Modified Labeling Approach

Step 1	Step 2	Step 3	Step 4	Step 5

Societal Conceptions of What it Means to be a Mental Patient: Perceptions of Devaluation - Discrimination

Labeled: Societal conceptions become relevent to self.

Labeled Individual's Response—Eg., secrecy, withdrawal, education.

Negative consequences for self-esteem, earning power, or social network ties.

Vulnerability to new disorder or to repeat episodes of existing disorder.

Not Labeled: Societal conceptions are irrelevant to Self.

No consequences due to Labeling—Negative effects attributable to psychopathology or to social and psychological factors unrelated to labeling.

This dissertation posits that internalized HIV stigma may operate in a similar manner. Almost 30 years into the HIV epidemic individuals in our society have developed a particular conception of what it means to be HIV positive. This conception is based in large part on the association of HIV infection with behaviors such as homosexuality, intravenous drug use, and promiscuity, all behaviors that are already stigmatized in our society. In other words, a diagnosis of an HIV infection is already loaded with a number of stigmatized conceptions that together help create this "supra-conception" that defines all HIV-infected. This conception has become part of the socialization process that is constantly occurring within our culture shaping human interactions.

In addition, besides HIV affecting groups that are already stigmatized in our society, HIV infection is also perceived as a death sentence by lay persons, which adds a layer of irrational fear, shaping even more negatively how the HIV infected are perceived. This conception of what it is to be an HIV positive individual has become established as a lay theory and for many affected by the disease the possibility of devaluation and discrimination has become personally relevant. Entering HIV care has become for many a step into fully accepting this stigmatized

condition, and once the complete awareness of the new condition is internalized, individuals may respond by withdrawing from care if they expect and fear rejection from others, particularly from those that are supposed to care for them. For the HIV infected, particularly for those in care, HIV care providers are an essential component of their social network. HIV care providers make the difference between a healthy life or infirmity, or even death for those affected by HIV. Perceptions of stigmatization by health care providers and how this stigmatization has negatively impacted accessing HIV care and medication adherence, has already been reported by HIV positive individuals, [1,] so has the effect of poor patient-provider interaction on retention in care, [43, 44] therefore it is plausible to hypothesize that patient-provider interaction may moderate the relationship between internalized HIV stigma and retention in care. An adaptation of Link's modified labeling theory applied to the association of internalized HIV stigma with retention in HIV care and the potential moderating effect of provider interaction is described in Figure 5.

Figure 5. Labeling Theory Modeling the Association of Internalized HIV Stigma with Retention in HIV Care

Step1

Societal perception of what it means to be HIV infected

Perceptions of Devaluation - Discrimination

Step 2

Labeled– HIV Positive

Societal conceptions become relevant to self once individual enrolls in HIV care.

Step 3

Internalized HIV Stigma may produce:

Withdrawal and isolation fearing rejection

Step 4

Impact of Social Networks

Patient-Provider relationship

Step5

Impact on HIV care behaviors/ outcomes

Retention in Care

Not Labeled

Not in care
Societal Conceptions are irrelevant to self

No Consequences due to Labeling

Negative health outcomes attributable to natural disease progression

Modeling the Association of Internalized HIV Stigma with Retention in HIV Care

In our conceptual theoretical model, we see how societal perception of what it means to be HIV infected become internalized by individuals in our society who perceive those infected by HIV as devalued human beings who may be discriminated against because of their HIV infection. Societal conceptions of what it means to be HIV-positive (the label of HIV-infected) become relevant to the individual once he/she enrolls in HIV care. Once enrolled in care, the expectation and fear of rejection, may lead the individual to withdraw himself/herself or avoid potentially threatening social interactions (interactions where the stigmatized condition is or may be revealed). The patient –provider interaction, a critical social interaction for the HIV positive individual in care, may be affected by the degree in which the HIV stigma is internalized leading to impacting HIV care behaviors or outcomes, in this case, retention in HIV care. Internalized HIV stigma may operate in a direct way so that it impacts on retention in care without the need of being shaped by the patient-provider interaction, or the patient-provider interaction may moderate the relationship between internalized HIV stigma and poor retention in care. Testing this conceptual model should help us understand if (and how) internalized HIV stigma impacts retention in HIV care.

Measuring Retention in HIV Care

One of the challenges in studying retention in HIV care relates to measurement. Researchers have used many different criteria for measuring retention in care, which has created some confusion on what exactly is being measured and for what purpose. Recently, Mugavero and colleagues in an effort to standardize the measurement of retention in HIV care synthesized

all the published literature on retention in HIV care and described five different methods in

which retention in HIV care could be measured depending on the objective of the analysis.[45]

According to Mugavero the simplest and most widely used way of measuring retention in

care is by counting Missed Visits, regardless of how many visits have been scheduled. Another

way of measuring retention in care is by measuring appointment adherence during an

observation period of interest as a proportion that captures the number of completed visits in the

numerator and the number of total scheduled visits in the denominator. A third way of measuring

retention in care is by calculating the Visit constancy, which evaluates the proportion of time

intervals (typically 3-6 months when looking at HIV care) with at least 1 completed clinic visit

during an observation period of interest. Gaps in care, the 4th way of measuring retention in care,

calculates the time interval between completed clinic visits in a typical time interval ranging

from 3 and 12 months. The final measure is the one used by HRSA called the HRSA HIV/AIDS

Bureau (HAB) Medical Visits Performance Measure. The HRSA HAB measure captures

whether a patient had 2 or more completed clinic visits separated by 3 or more months in time

during a 12-month observation period.[45]

Retention in Care for Improving Clinical Care and Policy Decision Making

Mugavero and colleagues examined how retention in care measures could be utilized to

improve the HIV care and treatment system. Two areas that were examined in which these

measures could have an impact included improving the clinical care of HIV patients, and as a

tool for clinic administrators and policy makers to improve administrative & policy decision

making activities.[45]

Retention in Care Measures and Clinical Care

The relationship between retention in HIV care and several HIV biomarkers as well as HIV clinical outcomes has been well described in the literature. From failure to suppress viral load, developing clinically significant drug resistance, poor adherence to antiretroviral therapy, predicting the presence of an AIDS-defining CD4 cell count (independent of Highly Active Antiretroviral Therapy use), and higher mortality rates, retention in care seems to be a critical aspect to consider when trying to improve the clinical care of patients. [46, 47, 48, 49, 50]

Mugavero noted that for clinicians, the missed visits measure could be the most useful to incorporate in their routine patient care activities. This measure could be a way to identify at the clinic level patients that need additional help to keep their appointments, or patients that need additional help because of potentially unmet needs. Mugavero's own analysis of how this measure has been used found it associated with patient outcomes including higher mortality. [45]

Retention in Care Measures and Administrative/Policy Decision Making

Another important area in which these measures can be used is as administrative/policy tools. The appointment adherence measure for example can be used to track retention in care longitudinally as well as to compare appointment adherence between units within clinics. Clinic administrators from individual hospitals/clinics can use this information in order to improve optimal clinic scheduling including optimal staffing and health care resource needs. For policy planning and/or evaluation, program administrators of agencies like HRSA, which as previously mentioned funds the Ryan White program, can look at retention in care rates across clinics

nationwide and use this information to plan regional and national resource allocation needs in collaboration with State or County health agencies.

Some of these activities may include policy advocacy in certain States or Counties where retention in care rates are poor and changes in legislation are required to shift funds to retention in care practices. Likewise, policy actions at the national level may require that federal insurance programs such as Medicaid and Medicare (which combined fund 40% of all HIV care in the U.S) require public and private healthcare providers who receive funds from these program to demonstrate improvement in HIV retention in care rates as a way to demonstrate improvements in care coordination, and population and public health.

These requirements are more likely now that a key provision of the American Recovery and Reinvestment Act of 2009, the adoption and demonstrated "meaningful use" of electronic medical records (EMR), has gone into effect as of January 2014. Improving care coordination as well as population and public health are examples of "meaningful use" of EMRs, as defined by HealthIT.gov, which also includes improving quality, safety, and efficiency of care; reducing health disparities; and engaging patients and family in the care process. Retaining HIV-infected patients has the potential to also help in a long term goal of health policy planners: to help contain health care costs. Several researchers have noted that this can be achieved by improving HIV-specific health outcomes and reducing emergency department visits and hospitalizations.[51,52]

Research Purpose and Specific Aims

This dissertation will be used to address this question: To what extent does internalized HIV stigma relate with retention in care among HIV positive individuals accessing HIV care? The dissertation aims are to:

(1) Assess the extent to which internalized HIV stigma is associated with retention in HIV care.

(2) Assess whether engagement with provider moderates the relationship between HIV stigma and retention in HIV care.

CHAPTER 2: REVIEW OF THE LITERATURE

Context of Search

The field of retention in HIV care is relatively new and so is exploring the barriers and facilitators that impact retention in HIV care. This growing field has become more prominent given the focus of the federal government through the National HIV/AIDS Strategy (NHAS) in increasing the number of HIV infected retained in HIV medical care, and the increasing federal funds that are being allocated for this objective. The number of studies describing barriers and facilitators to retention in HIV care has increased significantly over the last 10 years.

The field of internalized HIV stigma is also relatively new. Although efforts to minimize stigma related to HIV have been on the forefront of HIV prevention strategies around the world since the beginning of the epidemic, most work on stigma has been focused on enacted stigma (or the act of stigmatizing) and how to reduce the stigmatization that HIV infected individuals face every day by members of their society. The research on the impact of internalized HIV stigma on health outcomes and risk behaviors is a recent phenomenon of the last 10 years. This systematic review of the literature on the relationship of stigma and its impact on retention in HIV care is intended to shed light on the literature that explores a phenomenon that is more than likely occurring in almost every HIV clinical setting but that has not been systematically evaluated. Because both of these fields are relatively new it is important to have clear definitions of the concepts.

Definitions

Human Immunodeficiency Syndrome (HIV) - Human immunodeficiency virus; a retrovirus that causes AIDS by infecting CD4 cells of the immune system. The most common serotype, HIV-1, is distributed worldwide, while HIV-2 is primarily confined to West Africa. Also called AIDS virus, human T-cell leukemia virus type III, human T-cell lymphotrophic virus type III, lymphadenopathy-associated virus. HIV uses CD4 cells to replicate, later destroying them, thus debilitating the human immune system.

Acquired Immunodeficiency Syndrome - a syndrome involving a defect in cell-mediated immunity that has a long incubation period, follows a protracted and debilitating course, is manifested by various opportunistic diseases or AIDS defining conditions. Without treatment has a poor prognosis.

HIV Infected - having a positive reaction on a test for the human immunodeficiency virus; used to indicate that an individual has been infected with the human immunodeficiency virus.

CD4+ lymphocyte cell test - Tests for CD4 cells monitor disease progression in HIV infection. The CD4 lymphocyte count is used to track the progression of HIV infection and disease.

Viral Load - the amount of HIV in a sample of blood.

Viral Load count - A blood test that measures the quantity of active virus in the blood. Results are expressed as the number of copies per milliliter of blood plasma. Viral load testing is used to determine when to initiate and/or change HIV medication regimens.

HIV Antiretroviral medication - Drugs that inhibit the reproduction of HIV, human immunodeficiency virus, the causative agent of AIDS. The goal of the medication is to move the viral load down, ideally to undetectable levels.

Undetectable Viral Load - Viral load count that it is below what a laboratory test can find. In general, the viral load will be declared "undetectable" if it is under 40 to 75 copies in a sample of blood. The exact number depends on the laboratory that analyzes the test. The patient still has HIV and needs to stay on ART to remain healthy.

Retention in HIV medical care - Continuous engagement in appropriate medical care. Multiple ways have been used to measure retention in HIV care. The five methods most widely used have been: Missed Visits, appointment adherence, Visit Constancy, Gaps in Care, and the HRSA HIV/AIDS Bureau medical visits performance measure.

Barriers to HIV care - Financial, structural, and personal reasons for not accessing HIV care.

Stigma - The holding of derogatory social attitudes or cognitive beliefs, a powerful and discrediting social label that radically changes the way individuals view themselves or the way they are viewed by others.

Internalized HIV Stigma - The shame associated with HIV/AIDS and the fear of being discriminated against, which are both felt by persons living with HIV. Internalized stigma causes refusal or reluctance to disclose one's HIV status, or denial of one's HIV/AIDS.

Enacted Stigma – Involves the process of dehumanizing and sometimes the depersonalization of others into stereotypic caricatures.

Layered Stigma - Also known as intersecting stigma, or compound stigma, refers to the multiple stigmas that individuals may face, particularly marginalized individuals.

Discrimination - Refers to any form of arbitrary distinction, exclusion, or restriction affecting a person, usually but not only by virtue of an inherent personal characteristic or perceived belonging to a particular group—in the case of HIV and AIDS, a person's confirmed or suspected HIV-positive status.

Social support - The perception and actuality that one is cared for, has assistance available from other people, and that one is part of a supportive social network.

Social Network - Interactive field of persons made up of a set of actors (such as individuals or organizations) and a complex set of the dyadic ties between these actors.

Self-efficacy - Refers to an individual's belief in his or her capacity to execute behaviors necessary to produce specific performance attainments. Self-efficacy reflects confidence in the ability to exert control over one's own motivation, behavior, and social environment.

Selection of the Literature

The literature was searched for empirical studies correlating sigma with retention in HIV care. Even though the field of "retention in HIV care" is relatively new, meaning that most of the publications will probably have been published in the last 10 years, individuals have been diagnosed and have accessed HIV care for the past 30 years. Taking this into consideration I decided to include all empirical studies that have been published since 1985 when the first HIV screening test was available in the United States. It was also decided that because the term "retention in HIV care" has just been recently used by researchers and policy makers, we were going to examine studies and reports that assessed access to HIV care to broaden the initial search but later focus on studies that examined instances of assessing retention in HIV care. In terms of internalized stigma, it was decided that because researchers are using several variations

of this term to measure the same construct (internalized stigma, felt stigma or just stigma) the all-encompassing term "stigma" was going to be used to broaden the search. Findings related to stigma and retention in HIV care referenced in book chapters, dissertations, and non-peer-reviewed journals were also omitted. Finally, for expediency, the decision was made to focus the search on articles published in peer-reviewed, English-language journal s even though relevant studies could have been published in other languages.

A systematic search was performed using PubMed which accesses MEDLINE, and Sociological Abstracts using the same search terms for both search engines). Bibliographies of relevant articles, and related citations in PubMed and Sociological Abstracts were also searched as part of a technique called "snowballing" to identify additional applicable studies. Searches were limited to publication dates of 01/01/1985 – 1/15/2015.

Table 1. Literature Search Strategy

ALL Searches were limited to English, Publication date of 01/01/1985 – 1/15/2015 and INCLUDE:	
Concept	**Key words, search terms**
Stigma	"social stigma"[MeSH Terms] OR ("social"[All Fields] AND "stigma"[All Fields]) OR "social stigma"[All Fields] OR "stigma"[All Fields])
AND	
Access	"access[All Fields]
Retention	"retention (psychology)"[MeSH Terms] OR ("retention"[All Fields] AND "(psychology)"[All Fields]) OR "retention (psychology)"[All Fields] OR "retention"[All Fields])
AND	
HIV Care	Hiv"[MeSH Terms] OR "hiv"[All Fields]) AND care[All Fields]

Inclusion/exclusion criteria

Selection criteria

Besides the language and publications dates the inclusion criteria previously mentioned, two other inclusion criteria were used for this review. First, the study had to focus on

internalized stigma in relation to retention in HIV care, not care for other type of disease or conditions (ex. substance abuse treatment). Second, the study had to focus on internalized stigma as a barrier or facilitator of retaining HIV individuals in clinical care. Articles or reports were excluded if they assessed the correlation of internalized stigma with accessing HIV care for the first time.

All abstracts identified through the electronic searches were screened for the inclusion and exclusion criteria. The background, methods, and results sections of all abstracts or reports were examined for any mention of internalized stigma in relation to retention in HIV care. If the abstract and report mentioned internalized stigma (or felt stigma) in relation to retention in HIV care, the full text of the article was examined. Additional criteria for article selection included:

1. Study Design - Observational studies, randomized control trials conducted worldwide, written in English and published since 1/1/1985 were included.

2. Types of participants - HIV diagnosed individuals who have accessed HIV medical care.

3. Internalized Stigma and Retention in Care Measures - Studies were analyzed and the Internalized Stigma and Retention in Care measures were described.

Process for reviewing articles

Abstracts or reports that referenced internalized stigma in terms of retention in HIV care were examined to determine if the relationship existed or not and/or if it was mediated or moderated by another construct. All relevant articles and reports were recorded on a summary sheet that included authors, year it was published, characteristics of the target population (gender, race, sexual orientation, etc.), and major findings of the article or report.

Literature Review Results

Initial search using the terms "stigma," "access," and "HIV Care" yielded at total of 369 articles in PubMed and 87 articles in Sociological Abstracts. From the 456 articles, 441 were excluded after review of the title for any mention of one of the exclusion criteria and/or cursory examination of the background, methods and results sections of the abstracts (355 in PubMed, 86 in Sociological Abstracts). A second search using the terms "stigma," "retention," and "HIV care" yielded a total of 56 articles in PubMed and 5 articles in Sociological Abstracts. From the 61 articles, 47 were excluded after review of the title for any mention of one of the exclusion criteria and/or cursive examination of the background, methods and results sections of the abstracts (44 in PubMed, 3 in Sociological Abstracts). The total initial search included 517 studies of which 488 were excluded for not meeting the eligibility criteria after a cursory examination of the background, methods and results sections of the abstracts. Out of the remaining 29 articles, 3 articles were duplicated in PubMed and Sociological Abstracts. After full review of the remaining 26 manuscripts 13 were removed for not meeting the eligibility criteria, leaving a total of 13 articles. Examinations of the references (snowballing) of the final 13 studies yielded an additional 3 studies that met the eligibility criteria bringing the final total of studies included in the review to 17. A visual description of this process is reflected in Figure 6.

Full examination of the final 17 studies/reports indicated that the majority of studies and reports were published in the United States (11 out 17). Among the studies, 2 were longitudinal studies, 5 were cross sectional studies, two utilized mixed methods, and 8 were qualitative studies. Fifteen of the seventeen studies (88%) had been published in the last 5 years with the oldest one published eight years ago in 2007. All were published in peer reviewed journals.

Seven studies measured retention in care via medical record. [54, 55, 56, 57, 58, 59] Four studies

measured retention in care using a visit constancy measure - three of the four focused on at least

1 completed visit within a 6 month interval period over a 1 year period of time, [56, 57, 59] while the

fourth one measured retention in care as 2 or more visits within a 1 year period of time

(irrespective of interval).[55]

Figure 6. Flowchart of literature search of empirical studies correlating internalized stigma with retention in HIV care.

Empirical Studies

	PubMed – 425 **Sociological Abstracts - 92**
Total initial search	**517 studies**
Initially excluded for not meeting eligibility criteria	**488 studies**
Before DE duplication	**29 studies**
After DE duplication	**26 studies**
Excluded after full review	**13 studies**
Final from original search	**13 studies**
Snowball	**4 studies**
Total publications for analysis	**17 studies**

Wolf and colleagues defined not retained in care as patients who had no contact with the clinic for four months or more during the year before the initiation of project activities,[54] Dietz et al measured retention in care via appointment adherence (proportion of appointments kept of all appointments scheduled).[58] Finally Earnshaw and colleagues measured retention in care using the definition in place at the clinic from which participants were recruited, which recommended that HIV patients have a care visit at least once every 3 months. Participants were considered to have had a gap in care if they had not had an HIV medical visit in a 3 month period.[56] Five studies used validated stigma scales. [44, 54, 56, 57,]

All the studies except two reported a relationship between internalized stigma and retention in HIV care. Naar-King and colleagues did not find a significant association between internalized stigma and retention in care, but they did note that patients who reported high levels of stigma at baseline and continued to do so at follow-up had less than adequate retention in care.[59]

Several authors found that in conjunction with stigma, HIV care related factors such as patient-provider interactions, [41, 44, 53, 60, 61, 62, 63] problems with the clinic, such as appointment scheduling, [22, 41, 62, 63, 64, 65,] and problems taking the HIV medications, [22, 60, 64, 65] where negatively correlated with retention in HIV care.

Others researchers reported patient level factors associated with retention in care such as poverty, [41, 64]marihuana use, [58] lack of social support, [60, 61, 65] high risk behaviors such as alcohol

and drug use, [60, 61, 63 65] mental health issues such as depression, [61, 65] and the stigma associated

with being a man who has sex with other men. [57]

Table 2. Characteristics of studies assessing the relationship of internalized HIV stigma and retention in HIV care

Author and Year	Country	Study Design Methods	Sample	Major Findings	Internalized Stigma And Retention In Care Measures
Wolf et al., 2014	Kenya	Qualitative	27 HIV positive youths	HIV-related stigma was the overarching factor to poor retention in care among HIV + youth. Stigma operated on multiple levels to influence retention, including in the home/family, at school, and at the clinic. In all three settings, participants' fear of stigma due to disclosure of their HIV status contributed to poor retention.	Internalized Stigma measure: Self report Retention in HIV care measure: Medical record review
Valenzuela et al., 2014	Peru	Cross Sectional	176 HIV infected individuals (66 out of care, 110 in care)	Stigma scores were higher for the out of-care compared to the in-care patients.	Internalized Stigma measure: Modified scale based on the Berger scale [66] Retention in HIV care: Medical record review
Layer et al., 2014	Tanzania	Mixed-methods	48 HIV positive individuals in care	Key barriers included the reluctance to engage in HIV services while healthy, rigid clinic policies, disrespectful treatment from service	Internalized Stigma measure: Self report Retention in HIV care: Self report

				providers, stock-outs of supplies, stigma and discrimination, alternate healing systems, and distance to health facilities and poverty.	
Tomori et al., 2014	Tanzania	Qualitative	14 HIV diagnosed individuals in care	Participants reported significant barriers to retention, including, persistent stigmatization, and frequent reliance on alternative healing systems instead of biomedical treatment	Internalized Stigma measure: Self-report Retention in HIV care: Self-report
Magnus et al., 2013	USA	Cross sectional	479 HIV diagnosed individuals in care	A break in care was associated with perceiving that the doctor or health professionals do not listen carefully most or all of the time, having an elevated stigma score, and indicating that providers dislike caring for HIV-infected people. Women were more likely to have an elevated stigma score than men, as were participants over 30; those with a gay/bisexual orientation were less likely to have an elevated stigma score.	Internalized Stigma measure: For this study they used a subset (14 items) of Sayles et al.28-item Internalized Stigma Scale. [67] Retention in HIV care measure: Self report
Earnshaw et al., 2013	USA	Cross sectional	95 HIV diagnosed individuals in care	Internalized stigma was significantly associated with days in medical care gaps and ARV non-adherence.	Internalized Stigma measure: Modified scale based on the Berger scale [66] Retention in HIV care measure: Medical record review

Pecoraro et al., 2013	USA	Qualitative	41 HIV diagnosed individuals in care	Dropping out of care was associated with drug/alcohol use, unstable housing/homelessness, psychiatric disorders, incarceration, problems with HIV medications, inability to accept the diagnosis, relocation, stigma, problems with the clinic, and forgetfulness.	Internalized Stigma measure: Self-report on reasons for leaving and returning to HIV treatment
					Retention in HIV care measure: Medical records review and self-report
Lifson et al., 2013	Ethiopia	Qualitative	21 HIV diagnosed individuals in care	Respondents reported multiple barriers in attending clinic appointments, including stigma and discrimination and lack of support.	Internalized Stigma measure: Self-report (question assessing barriers to HIV care)"
					Retention in HIV care measure: Self report
Dasgupta et al., 2013	India	Cross sectional	198 HIV diagnosed women in care.	Higher levels of stigma were associated with lower CD4 count upon entry into care. Stigma was not associated with having missed scheduled HIV care appointments.	Internalized Stigma measure: Modified scale based on the Berger scale[66]
					Retention in HIV care measure: Medical record review
Smith et al., 2012	USA	Mixed Methods	20 HIV diagnosed individuals in care	Factors influencing retention in HIV care were related to stigma associated with comorbidities such as substance use and depression. Such	Internalized Stigma measure: Self-report (question assessing barriers to HIV care)

				experiences (e.g., shame, anticipated judgment from providers, viewing care attendance as incompatible with drug use), when identified by participants, significantly impacted their attitudes toward engaging in care. In particular, internalized stigma emerged as a critical barrier to care in this population.	Retention in HIV care measure: Self report
Russ et al., 2012	USA	Qualitative	17 HIV diagnosed in care	Clients acknowledged that stigma is a severe barrier to access to care.	Internalized Stigma measure: Self-report (question assessing barriers to HIV care)
					Retention in HIV care measure: Self-report
Wohl et al., 2011	USA	Cross Sectional	398 HIV diagnosed individuals in care	The major predictor of retention in HIV care was disclosure of HIV status to more social network members. More MSM-stigma was associated with poorer retention for Latino MSM.	Internalized Stigma measure: Validated Internalized HIV stigma scale [68]
					Retention in HIV care measure: Medical record review
Williams et al. 2011	USA	Qualitative	25 HIV diagnosed individuals in care.	Five themes emerged for barriers to remaining engaged in care once initiated: (a) the impact of competing demands, (b) aspects of the system of care, (c) the influence of stigma, (d) the experience of negative affect, and (e) various beliefs about the need	Internalized Stigma measure: Self report (based on questions identifying the main facilitators and barriers to remaining in HIV care once initiated.)

				for or role of HIV treatment.	Retention in HIV care measure: Self report
Kempf et al., 2010	USA	Qualitative	45 HIV diagnosed individuals in care residing in rural counties in Alabama.	Factors that impacted participants' ability to maintain clinic visit appointments included personal, contextual, and community/environmental factors that included: patient/provider relationships, family support, access to transportation, organizational infrastructure of the health care facility visited and perceived HIV stigma within their communities.	Internalized Stigma measure: Self-report. Retention in HIV care measure: Self-report
Dietz et al., 2010	USA	Longitudinal	178 HIV-infected female adolescents aged 13–24	Controlling for ART status and CD4 counts, participant's age, and number of scheduled appointments, marijuana use remained significant in multivariate analyses. HIV stigma subscales were not significantly associated with the outcome of interest.	Internalized Stigma measure: Modified scale based on the Berger scale Retention in HIV care measure: Medical record reviews
Rajabuin et al. 2007	USA	Qualitative	76 HIV diagnosed individuals in care in six cities.	Findings indicated that participants cycled in and out of care, a process that was influenced by (1) their level of acceptance of being diagnosed with HIV, (2) their ability to cope with substance use, mental illness, and stigma, (3) their health care provider relationships, (4) the presence of external	Internalized Stigma measure: Self report (based on participant's past experience with HIV medical care; current HIV medical care and barriers facilitators to retention in care)

				support systems, and (5) their ability to overcome practical barriers to care.	Retention in HIV care measure: Self-report
Naar-King et al., 2007	USA	Longitudinal	104 newly diagnosed Persons Living with HIV/AIDS	Improvements in mental health status and the elimination of stigma as a barrier were not associated with retention, but those who reported stigma as a barrier at baseline and continued to report stigma at 6 months had less than adequate retention.	Internalized Stigma measure: Single item question assessing perception of HIV stigma as a barrier to care
					Retention in HIV care measure: Medical record review

Discussion

We were not able to find a substantial number of studies that focused on the relationship between internalized stigma and retention in HIV care. The majority of the studies have been published in the last 5 years with 9 of the 17 studies published in the last 2 years, indicating how new this area of HIV research is, and how important it is becoming. The fact that the majority of the studies have a qualitative design also indicates that research in this area is in the exploratory phase.

Themes

From all the studies reviewed a majority (15 of the 17 studies) concluded that internalized stigma was a barrier to retention in care. Of the two studies that did not find an association between internalized HIV stigma and retention in HIV care one was conducted among HIV

positive women in India,[55] while the second study was conducted among adolescent women receiving HIV care in adolescent HIV clinics.[58]

A recurrent theme that emerged from the literature review was that internalized HIV stigma is not associated with retention in care in isolation. Clinical care factors such as patient-provider interactions, clinic and treatment related issues, as well a patient level factors such a high risk behaviors, lack of social support and mental health issues are also important to consider when exploring the association of internalized stigma with retention in HIV care.

Strengths and Weaknesses of Reports

All of the studies in our analysis were based on sound qualitative or quantitative methodology. Five studies utilized validated internalized stigma scales, and seven studies assessed retention in care using medical record abstractions which are considered the gold standard for measuring retention in care. Only three studies in the United States, one focusing on men who have sex with men,[57] a second one focusing on adolescent women,[58] and the third among a sample of only 95 HIV positive patients,[56] measured retention in care via medical records and utilized a validated stigma scale. The majority of the studies that measured retention in care via medical record abstraction used visit constancy to assess retention in care, which according to Mugavero and colleagues is not the ideal measure of retention in care from a clinical or policy/administrative perspective.[45]

Limitations of the Review Process

Our search of potential studies to include in this review was purposefully wide. We knew going into the search that the field was new and that all researchers might not be using the same terminology to describe their studies. This is clear when one examines the titles of the studies that ultimately were included in the review. As such, there was no narrower set of "key" words that would have identified all the reports in our analysis so our initial decision to be as broad as possible seems to have been the correct one. Having said that, additional searches using different combinations of words identified in the titles of the studies that ultimately were used in the analysis might have produced additional studies to include, so we can't say that the studies in this review are the only ones assessing our outcome of interest. The use of snowballing (which identified 4 additional studies), mitigates in some way this weakness of the review process.

Implications and Future Research

The existing literature on the association of internalized HIV stigma with retention in HIV care is scant. Most of the articles have been published recently and are qualitative in nature; having said that, the evidence from this systematic review points to a relationship between internalized HIV stigma and retention in HIV care. The majority of the studies conducted in the United States with different patient populations and utilizing different methodologies reached the same preliminary conclusion. Still, more work needs to be done to clarify this relationship. Future studies need to use valid retention in care measures that will help us understand what role internalized HIV stigma plays in clinical management as well for policy making and resource allocation decision. Likewise, future studies should use validated internalized HIV stigma scales and include larger and more heterogeneous samples. Finally, HIV care and patient level factors

negatively correlated with retention in HIV care such as patient-provider interactions, problems with the clinic (such as appointment scheduling), problems taking HIV medications, poverty, drug use, lack of social support, high risk behaviors (such as alcohol and drug use), mental health issues (such as depression), and other stigmatizing conditions should also be assessed to determine how they impact the relationship between internalized HIV stigma and retention in HIV care .

This dissertation, therefore, proposes to test the hypothesis that internalized HIV stigma is significantly associated with poor retention in HIV care among a diverse sample of HIV positive individuals. The study will also explore whether Internalized HIV stigma operates directly on retention in HIV care or if there are other covariates that moderate the relationship between internalized HIV stigma and retention in care. Ultimately, study findings will serve to inform HIV prevention and care policy in order to improve the lives of those affected by this disease.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

Study hypotheses were tested in an observational, cross-sectional study, via secondary data analysis of interview and medical record abstraction data collected from a total of 194 HIV positive men and women who received care at the University of Miami/Jackson Memorial Hospital Special Immunology Clinics. Data was collected from August 2009 to May 2011 as part of a R21 study (Health Literacy, Cognitive & Social Determinants of HIV Appointment Attendance - R21 MH084814) funded by the National Institute of Mental Health (NIMH) that sought to explain the effect of low reading literacy for health-related information and neurocognitive impairment on poor adherence to appointments for HIV care.

Description of the *Health Literacy, Cognitive & Social Determinants of HIV Appointment Attendance* Study

Study Participants

All participants were in HIV care with the University of Miami Jackson Memorial Hospital (UM/JMH) Special Immunology (SI) clinics at the time of enrollment. The UM/JMH is the largest medical provider in the area and serves the indigent and non-insured population of South Florida. At the time of the study the UM/JMH Infectious Diseases Clinic database characterized the patient population as follows: There were a total of 2559 unduplicated clients served in the SI clinics from 01/01/01 to 12/31/06. They represented a total of 8,855 total visits with an average of 700 visits per month to the clinic. Of those, 342 individuals were new to the

clinic. Gender characteristics of clinic patients included 62% men, 37% women, and 1% transgender. Racial/ethnic breakdown for clinic population included 58% Black, 29% Hispanic, 7% Haitian, 8% White, and 1% other. Age distribution of clinic population included 1% ages 18-24, 40% ages 25-44, 52% ages 45-64, and 6% age 65 & older.

The research team had conducted studies with patients from this clinic for a number of years. Researchers had obtained excellent cooperation from clinic staff and strong interest in the studies from clinic patients in the past. No exclusions were made on the basis of antiretroviral use since the number of routine scheduled appointments was the same for those taking and not taking antiretrovirals. Researchers collected detailed locator information and participant's permission during the informed consent process to continue to follow them during the 7 month study period. Those participants who relocated to another HIV care clinic during the course of the study remained eligible and were asked to provide written permission to contact their new HIV care provider in order to verify appointment adherence.

Inclusion/exclusion criteria in this study included:

1. Participation in a clinical trial- Patients from the UM/JMH SI clinics enrolled in a clinical trial were excluded. Clinical trial patients' appointment-making and reminder procedures were different from routine clinic patients, thus limiting generalizability of findings.

2. Major Psychiatric Illness - During screening, participants were asked questions from the Schizophrenia and Other Psychotic Disorders section of the Interview Guide for Evaluating DSM-IV Psychiatric Disorders and the Mental Status Examination to rule out a psychotic illness.[69] The interview consisted of 12 questions related to delusions and hallucinations. Those

who respond yes to any of the questions, indicating the existence of a psychotic symptom, were excluded.

3. Below 21 years of age – Participants had to be 21 years old and older (there is no upper age limit). The nature of cognitive functioning is different between children and adults and many of the tests used in this study were not appropriate for individuals under the age of 21.

4. History of head trauma with loss of consciousness (LOC) > 15 minutes or other history of significant pre-existing brain disease. Participants who reported ever having head trauma with LOC > 15 minutes were excluded due to the potential confounding cognitive effects of head injury. This exclusion criterion also excluded participants with a history of neurological disease resulting from or independent of HIV infection, which can also effect cognitive functioning.

5. Inability to communicate comfortably in English - Approximately 29% of patients at the UM/JMH Infectious Diseases Clinic are Hispanic and 7% are of Haitian descent. However, the neuropsychological tests, psychosocial measures and normative data required for interpretation of the tests are limited for those who speak only Spanish and virtually non-existent for speakers of Creole. Therefore, all participants in this study had to communicate comfortably in English.

Anticipated Number of Patient Appointments

Procedures for routine HIV care at the UM/JMH SI clinics followed recommended guidelines during the study period.[70] Patients are routinely seen every 3 months for laboratory assessments (e.g., HIV viral load, CD4 cell count) and for regular medical appointments with their physician. Those just establishing HIV care are seen 4 to 6 weeks after their initial visit. Those who are sicker are seen more often. The number of scheduled visits is the same whether or not the patient is taking antiretroviral medications. It was anticipated based on historical clinic

information that patients would attend an average of 4 visits per year. At the Infectious Diseases Clinics, appointments are written on an appointment card at the time of discharge from the current appointment. A mailed reminder is also usually given. Patients who miss appointments are not contacted and the patient is responsible for rescheduling a missed appointment.

Recruitment

Members of the medical teams within the Infectious Diseases Clinic (i.e., attending physicians, nurse practitioners, and physician assistants) who were involved in patient care approached patients in the clinics and determined their interest in learning more about the study. In addition, flyers describing general study information were posted in the clinic with contact information for the study recruiter. If members of the medical team determined that a particular patient was interested in learning more about the study, that patient was referred to the study recruiter who arranged to meet with the patient to discuss the study further. Clinic team members either brought the patient to the study recruiter for a brief pre-screening interview or they contacted her via cell phone and she conducted the pre-screening interview over the phone. All recruitment procedures were in compliance with HIPAA regulations. During the pre-screening interview, the patient was asked questions to determine if s/he met basic inclusion and exclusion criteria. For potential participants for whom English is a second language, researchers incorporated a simple assessment of English communication into the screening process to ensure that potential participants were able to communicate in English and comprehend the study's evaluations.

Study Procedures

Participants completed the baseline (T0) study procedures in one session. After obtaining informed consent, participants completed demographics information, a neuropsychological evaluation and psychosocial measures including those to assess social support and patient-provider communication (all assessments are described in detail below). Researchers also obtained permission from participants to access their medical records in order to obtain verification of their attendance at scheduled HIV clinic appointments. Participants were compensated $40 upon completion of baseline procedures.

Participants were then asked to complete a 2nd and final study session 7 months after completion of their baseline assessment. This 7-month follow-up assessment (T1) was to assess through self-report, attendance at HIV care appointments. Researchers also verified the self-report through medical record abstraction. Participants were paid $40 upon completion of the T1 visit. Researchers allowed a window period of +/- 2 weeks to complete the T1 study visit. The timeline of activities for the Health Literacy, Cognitive & Social Determinants of HIV Appointment Attendance study is reflected in Figure 7.

A total of 325 individuals were screened for the study. The most common reasons for ineligibility were active psychiatric illness (hallucinations or delusions) or hospitalization due to head injury. A total of 8 individuals who were eligible for the study no-showed for their consent and baseline appointment and 15 were uninterested in participating after screening eligible.

Final Enrollment and Follow-up

A total of 210 HIV positive persons meeting eligibility criteria and willing to participate in the study were consented prior to baseline study procedures. Since researchers anticipated many in the sample to be low literate or cognitively impaired, they included a post-test consent to verify comprehension of study procedures, risks, benefits, and other pertinent information. Only 1 individual was unable to complete the consent post-test and ultimately denied eligibility for the study.

Table 3. Timeline of R21 Study Activities								
May-June 2009	July – Sept 2009	Oct – Dec 2009	Jan – Mar 2010	Apr – June 2010	July- Sept 2010	Oct – Dec 2010	Jan – Mar 2011	Apr 2011
Start-up activities	T0	T0	T0	T0	T0			
			T1	T1	T1	T1	T1	
	EMR audit T0 visits	EMR audit T0 visits	EMR audit T0 visits & EMR audit T1 visits	EMR audit T0 visits & EMR audit T1 visits	EMR audit T0 visits & EMR audit T1 visits	EMR audit T1 visits	EMR audit T1 visits	Close out Data Analysis
Note: This study was funded under the NIH R21 mechanism which provides two years of funding. NIH project start date was 5/6/2009 and NIH project end date was 4/30/2011. T0 is the baseline interview, the point at which participants were enrolled. T1 is the follow-up interview that occurred 7 months post-baseline. Medical Chart abstraction was conducted retrospectively – only after enrollment into the study and was conducted for each participant at completion of T0 and again at completion of T1.								

As previously mentioned, participants who completed the baseline interview and assessment were scheduled for a follow-up appointment 28 weeks later. So as to not influence clinic appointment behavior, participants were not contacted until 24-hours prior to their follow-up appointment. If they did not attend their follow-up they were mailed a reminder letter and attempts to contact the person by phone were made for up to two weeks. If after this time,

researchers were unable to reach a participant he or she was considered lost to follow-up. Of the 210 individuals enrolled at baseline, 194 completed follow-up interviews 28-weeks later. This reflected a 94% retention rate**.**

Dissertation Approach and Design

As described in Figure 7, for the purposes of the secondary data analysis conducted in this observational, cross-sectional study, de-identified interview data from the 194 participants who completed the follow-up data point (T1) will be used to describe the characteristics of the patient population including demographics, clinical care experiences, internalized stigma, social support, alcohol and drug use, and depression (see below for a more detailed explanation of potential independent variables). Moreover, de-identified medical record abstraction data will be used to describe clinic attendance patterns over the 14 month period of time preceding the interview.

Figure 7. Data Collection timeline

MONTHS OF RETROSPECTIVE CHART ABSTRACTION							T0	MONTHS OF PROSPECTIVE CHART ABSTRACTION							T1
-7	-6	-5	-4	-3	-2	-1		1	2	3	4	5	6	7	

- T0 is the baseline interview, the point at which participants were enrolled. T1 is the follow-up interview that occurred 7 months post-baseline
- Medical Chart abstraction was conducted retrospectively (7 months prior to T0) and prospectively (7 months post T0)
- The proposed study will test study hypotheses using a retrospective analysis of interview data collected at T1 and medical chart abstracted data collected from months -7 to 7.

Data Management and Analysis

Dependent variable measures

In order to measure retention in care for both clinical and policy/administrative purposes, we propose to use two constructs recommended by Mugavero and colleagues; one construct that reflects retention in care for clinical purposes and the other construct that reflects retention in care for policy/administrative purposes.[45]

To assess retention in care for clinical purposes we propose to use missed visits, which is a simple count of the number of scheduled visits that were missed (or "no-shows"), irrespective of the number of visits that were scheduled. We will measure this construct as a count or the total number of scheduled visits that were missed. This variable was named "missed visits."

To assess retention in care for policy/administrative purposes we propose to use the appointment adherence measure calculated as the percentage of total scheduled medical appointments at the outpatient SI clinics that were kept during the 14-month period. This variable will be named "appointment adherence" and will be reported as a continuous variable (0%-100%).

As stated above, patients at the UM/JMH clinics were scheduled for a minimum of one regular physician appointment every 3 months (+/- 2 weeks). In the electronic patient medical record, each patient's appointments were coded as "no-show", "cancelled", "rescheduled" or "checked-out" (indicating that the patient attended the visit). Visits classified as "no-show" were used for the missed visits construct measure, while appointments classified as "checked out"

were used for the appointment adherence construct measure (with the denominator being the total number of appointments scheduled that were not cancelled or rescheduled). Visits that were "cancelled" or "rescheduled" (either by the patient or the clinic) were not included in the two dependent variable measures.

Independent Variable

Internalized HIV stigma: The 13-item HIV Stigma Scale was developed by Sowell et al. [71] and further validated by Emlet for use in older adults living with HIV/AIDS.[68] During the initial development study, content validity was addressed by the active involvement of the target population during focus group discussions concerning item generation selection, and ease of item understanding.[71] During the further validation study, the factor structure of the scale was defined and Cronbach's alphas calculated for the overall 13-item scale (Cronbach's alpha = 0.86). Construct validity was addressed and the correlations were as expected with higher scores representing higher levels of stigma.

Covariates

Social Support: We assessed available social support using a subscale from the Social Support Questionnaire developed by Zich and Temoshok.[72] This scale consists of eight items that assess four types of support one may have received since becoming HIV positive. For each category of support, the person states how (1) desirable you believe this type of help/support would be for you at this time in your life, (2) how available this type of help/support would be if you wanted it, (3) how often you have experienced this type of help/support since you were diagnosed HIV?, and how useful this type of help/support has been when you did receive it.

Items are rated from 1 "not at all" to 5 "very much, constantly". For this analysis, only the subscale that assessed "how often you have experienced this type of help/support since you were diagnosed HIV?" (#3 above) was used.

Since depression has been consistently associated with medication adherence in HIV, the Center for Epidemiological Studies - Depression 10 (CES-D10) [73] was used to measure current depressive symptomatology. Item responses are rated using a Likert scale ranging from 0 (none of the time) to 3 (all of the time). Scores range from 0 to 30, a score of ≥ 10 is indicative of significant depressive symptoms. The CES-D has very high internal consistency, adequate test-retest reliability ($r = 0.71$) and well established validity across a wide variety of populations.

Patient-Provider Relationship: The association of patient-provider relationship with retention in care was measured through the perceived quality of the relationship with providers. The quality of patient-provider communication will be assessed with the Engagement with Healthcare Provider Scale, a 13-item scale. Patients rate the nature of their interactions with providers on a scale where 1 = always true and 4 = never true. The scale was developed for use with HIV positive patients and shows good reliability.[74]

Demographic and other patient characteristics: Study findings will be adjusted for demographic (e.g., gender, race/ethnicity, age, education, marital status) and other patient characteristics that may be associated with retention in HIV care. For example, we assessed sexual orientation, injection drug use (ever), time in HIV care, whether participant is currently taking ART, and time to travel to the clinic.

Power calculation

Estimates of the prevalence of internalized stigma among HIV infected persons suggest that nearly 50% of these individuals report at least moderate levels of internalized stigma and about 25% report high to very high levels.[68] Post hoc power analyses were conducted based on the sample size of 194 participants who completed follow-up activities in the study. First, power analysis was performed using GPower for a multiple linear regression on modeling the percentage of missed appointments in terms of the primary covariate of interest, HIV stigma score, and other 5 covariates from those listed above (time in care, # scheduled visits, age, marital status, time to travel to clinic) selected because of their association with retention in HIV care in previously published studies from this dataset. [75](Waldrop-Valverde et al., 2014). We considered three effect sizes for this assessment: small ($f^2=0.02$), moderate ($f^2=0.15$), and large ($f^2=0.35$) where f^2 represents Cohen's f .[76] The alpha level was pre-specified at 0.05 (2-sided). The post hoc power analysis indicates that the statistical power for the detection of a moderate to large effect exceeded .99, and was 0.50 for detecting a small effect of 0.02. The multiple linear regression had 0.80 power for detection f^2 as large as 0.04.   Power analysis was then performed for a Poisson regression on modeling the probability of having missed visits in terms of the primary covariate of interest, HIV stigma score, and other covariates using the Power Analysis Sample Size (PASS) software. Based on the data, the probability of having missing appointments at the mean of HIV stigma score was set at 0.80. We considered three effect sizes for this assessment: small (Odds ratio=1.5), moderate (Odds ratio=2), and large (Odds ratio=3), where the odds ratio correspond to the increase in the odds of having missing appointments when the HIV stigma score is increased to one standard deviation above the mean. The post hoc power analysis indicates that the statistical power for the detection of small,

moderate and large effects were 0.6, 0.97, >0.99, respectively, at the alpha level of 0.05 (2-sided).

Analysis

Univariate analyses (ex. frequency, range, mean, standard deviation) will be conducted for all variables. The internal consistency of the HIV internalized stigma, social support, CES-D scale and other scales will be reported. Bivariate analyses will be conducted in order to examine factors related to each of the retention in HIV care outcome variables (Number of Missed Visits and appointment adherence). Given the categorical and count nature of some variables in this analysis associations between the retention in HIV care variables and independent variables was assessed using Spearman rank correlation. The statistical software (SAS) used to calculate the Spearman rank correlation automatically rank orders the data within variables. Multivariable models included all independent variables identified in the Spearman rank correlation to be associated at $p<.10$ with the two dependent variables. Given that the Number of Missed Visits variable is a count of the total number of scheduled visits that were missed, it will be examined in a multivariate Poisson Regression model. Multivariable linear regression (MLR) will be used to assess the association of internalized HIV stigma with retention in HIV care measured by the appointment adherence variable. After testing the association of internalized HIV stigma with retention in HIV care, and based on our theoretical postulation that internalized stigma may be negatively associated with patients' perceptions of social interactions, including provider interactions, increasing vulnerability to poor health behaviors such as missing medical visits, we will test the engagement with provider construct as a moderator of the relationship between internalized HIV stigma and the two retention in care dependent variables. Overall statistical

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significance for the two final models was set at $p<.05$. All statistical analyses were conducted using SAS 9.3.

IRB Approval

Ethics approval for the proposed research study was obtained through the Institutional Review Board at the University of North Carolina at Chapel Hill.

CHAPTER 4: RESULTS

Sample Characteristics

From the 194 participants that completed the follow-up interview six participants were removed for having missing data for at least one of the variables needed to calculate appointment adherence. Results from the analysis of the cross-sectional data indicate that fifty-four percent of the participants were female and forty six percent were male. The majority of the participants were forty five years or older. Fifty-five percent of the participants had never married and were currently single while thirty-one percent were divorced/separated/widowed. Only fourteen percent of participant were currently married or living with a partner. The majority of participants (83%) were African American, ten percent were Hispanic, five percent were white and three percent were of other racial/ethnic groups. Forty-eight percent of participants had less than a high school degree, thirty-four had a high school degree, and eighteen percent had some college education. The majority of participants (84%) considered themselves heterosexual while sixteen percent considered themselves homosexual or bisexual. Five percent of participants had been admitted to mental health care in past 14 months. Eighteen percent of participants had ever injected drugs, while fifty-five percent of participants had used alcohol or non-injection drug use in the past 14 months.

In terms of characteristics related to participants' HIV diagnosis and care, mean time of having been diagnosed with HIV was 12.6 years (standard deviation [SD] 7.4 years) with a range

of less than 1 year (some participants were recently diagnosed) to 37 years. Participants took an

average of 43.9 minutes (SD 30.6) to travel to the clinic for their HIV medical appointments

(although some participants reported up to 2 hours to get to the clinic). Ninety-five percent of

participants reported taking antiretroviral medications. Because one fourth of viral load

observations were missing, the possible effects of missing observations for viral load were

evaluated by sensitivity analysis that compared the results of the model using all available data

and using data that included imputed values for missing viral loads (derived using next-and-last

imputation methods with viral load data gathered from participants' longitudinal medical

records). Imputed values were used in all analyses. Sixty percent of participants had undetectable

viral load. Of the 188 participants, twenty-six participants or 14% of participants did not miss a

medical care appointment during the study period. Mean number of missed appointments was

3.7 (SD 3.4, range 1-16), while mean appointment adherence was 55% (SD 28%, range 2%-

100%).

The 13-item HIV Stigma Scale used to assess internalized HIV stigma in our study had a

good internal consistency reliability (Cronbach's alpha = 0.880). Mean internalized HIV stigma

score was 21.1 (SD 7.8). Only sixteen percent of the sample reported experiencing no stigma at

all, while thirty-five percent of the sample scored higher than the mean. Mean social support

score for the sample was 32.3 (SD 7.0) with a range from 11 to 40. The Social Support

Questionnaire scale showed good reliability in the current sample (Cronbach's alpha = 0.887).

The Center for Epidemiological Studies - Depression 10 scale, which was used to measure

current depressive symptomatology in our sample had a good internal consistency reliability

(Cronbach's alpha = 0.827). Mean depression score for the sample was 10.1(SD 6.2). As

previously noted a score of ≥10 is indicative of clinically significant depressive symptoms.

Based on this cutoff half of the sample had clinically significant depressive symptoms. Average

score on the Engagement with Healthcare Provider Scale was 16.2 (out of a range of 13 to 44).

Since lower scores reflect better engagement, overall this sample was quite engaged with their

provider. In this sample, the Cronbach's coefficient alpha for the Engagement with Healthcare

Provider scale was good at 0.77.

Table 4. Demographic and clinical characteristics for study participants (N=188)

Characteristic (variable name)	Frequency	Percent (%)	Range	Mean (SD)
Gender				
Male	86	46.0	------	------
Female	102	54.0	-----	------
Age			24-70	47 (7.4)
18-44	49	26.5	-----	------
45 and above	139	73.5	-----	------
Marital Status				
Never married/single	102	54.5	----	----
Married/living with partner	27	14.3	----	----
Divorced/separated/widow/widower	59	31.2	----	----
Race/Ethnicity				
White	9	4.8	----	----
Black	156	82.5	----	----
Hispanic	18	10.1	----	----
Other	5	2.7	----	----
Education				
Grades 1-8	20	10.6	----	----
Grades 9-11	70	37.5	----	----
12 or GED	65	34.0	----	----
Any college	33	17.5	----	----
Sexual Orientation				
Gay/Bisexual	30	16.0	----	----
Heterosexual	158	84.0	----	----
Admitted to mental health care	9	4.8	----	----
Yes	179	95.2	----	----
No				

Injection drug use ever				
Yes	33	18.0	----	----
No	155	82.0	----	----
Alcohol/non-injection drug use past 14 months				
Yes	103	54.5	----	----
No	85	45.5	----	----
Depression past 30 days	----	----	0-25	10.1(6.2)
Available Social Support	----	----	11-40	32.3(7.0)
Engagement with Healthcare Provider Scale	----	----	13-44	16.2(5.4)
Internalized HIV Stigma	----	----	13-46	21.1 (7.8)
Time since diagnosis (days)	----	----	0-37	12.6 (7.4)
Currently taking ART				
Yes	179	95.2	----	----
No	9	4.8	----	----
Time to travel to the clinic (minutes)	----	----	3-120	43.9(30.6)
Viral Load				
Suppressed	113	60.3	----	----
Not Suppressed	75	39.6	----	----
Number of Missed Visits	----	----	0-16	3.6 (3.4)
Appointment adherence (percent)	----	----	2-100	55 (28)

Results of the Bivariate Analysis

Results from the Spearman correlation analysis indicated that number of missed visits was correlated at p<0.10 with gender and age, while appointment adherence was correlated at p<0.10 with, gender, age and engagement with Provider.

Table 5. Spearman Correlation Matrix for Characteristics Associated with Retention in HIV Care Measures

NAME	Number Missed Visits	Appt Adh	Gender	Age	Marital	Race_ethni	Edu	Sex_orient	Mental Health	IDU ever	Non-inject	Depres	Available SocSup	Eng Provider	HIV_Stigma	Time_since_dx	ART_tx_	Mins_clinic	VL
Number Missed Visits	1.000	0.886**	0.240**	-0.176**	0.018	-0.094	-0.107	0.067	0.064	-0.017	0.094	0.104	-0.010	0.087	-0.051	-0.048	-0.082	-0.114	0.075
Appt. Adh	-0.886**	1.000	-0.159**	0.191**	0.016	0.082	0.049	0.000	-0.083	0.087	-0.091	-0.111	0.091	-0.127*	0.005	0.073	0.113	0.092	-0.056
Gender	0.240**	-0.159**	1.000	-0.038	0.056	-0.097	0.018	0.081	-0.096	0.053	-0.146**	-0.055	0.132*	-0.039	-0.120	0.161**	-0.053	0.094	-0.102
Age	-0.176**	0.191**	-0.038	1.000	0.188**	-0.030	0.080	0.034	0.078	0.281**	0.006	-0.017	0.026	0.116	-0.023	0.178**	-0.134*	0.032	-0.046
Marital	0.018	0.016	0.056	0.188**	1.000	-0.089	0.026	0.103	-0.054	-0.034	0.071	-0.087	0.032	-0.045	-0.088	-0.040	-0.089	-0.134*	0.041
Race_ethni	-0.094	0.082	-0.097	-0.030	-0.089	1.000	-0.021	0.047	0.017	0.045	-0.001	0.139*	-0.155**	0.054	0.104	-0.154**	-0.143*	0.051	0.013
Edu	-0.107	0.049	0.018	0.080	0.026	-0.021	1.000	-0.026	0.113	-0.087	-0.019	-0.052	-0.134*	-0.080	-0.050	-0.198**	-0.068	0.065	-0.031
Sex_orient	0.067	0.000	0.081	0.034	0.103	0.047	-0.026	1.000	-0.038	0.087	-0.016	-0.063	-0.058	0.019	-0.108	-0.023	0.038	0.077	-0.024
Mental Health	0.064	-0.083	-0.096	0.078	-0.054	0.017	0.113	-0.038	1.000	0.025	0.005	0.239**	-0.178**	0.138*	0.062	0.007	0.050	0.020	-0.005
IDU Ever	-0.017	0.087	0.053	0.281**	-0.034	0.045	-0.087	0.087	0.025	1.000	-0.015	-0.011	0.067	0.050	-0.116	0.174**	-0.025	0.039	0.040
Non-inject	0.094	-0.091	-0.146**	0.006	0.071	-0.001	-0.019	-0.016	0.005	-0.015	1.000	0.108	-0.125	0.161**	0.101	-0.051	-0.055	-0.003	0.133
Depres	0.104	-0.111	-0.055	-0.017	-0.087	0.139*	-0.052	-0.063	0.239**	-0.011	0.108	1.000	-0.353**	0.251**	0.458**	-0.135*	0.011	0.124*	0.018
Available SocSup	-0.010	0.091	0.132*	0.026	0.032	-0.155**	-0.134*	-0.058	-0.178**	0.067	-0.125*	-0.353**	1.000	-0.377**	-0.357**	0.122*	-0.002	-0.084	0.016
Eng Provider	0.087	-0.127*	-0.039	0.116	-0.045	0.054	-0.080	0.019	0.138*	0.050	0.161**	0.251**	-0.377**	1.000	0.253**	-0.053	0.015	-0.028	-0.091
HIV_Stigma1	-0.051	0.005	-0.120	-0.023	-0.088	0.104	-0.050	-0.108	0.062	-0.116	0.101	0.458**	-0.357**	0.253**	1.000	-0.072	0.050	0.031	0.018
Time_since_dx	-0.048	0.073	0.161**	0.178**	-0.040	-0.154**	-0.198**	-0.023	0.007	0.174**	-0.051	-0.135*	0.122*	-0.053	-0.072	1.000	0.155**	0.020	0.167**
ART_tx	-0.082	0.113	-0.053	-0.134*	-0.089	-0.143*	-0.068	0.038	0.050	-0.025	-0.055	0.011	-0.002	0.015	0.050	0.155**	1.000	0.017	0.215**
Mins_clinic	-0.114	0.092	0.094	0.032	-0.134*	0.051	0.065	0.077	0.020	0.039	-0.003	0.124*	-0.084	-0.028	0.031	0.020	0.017	1.000	0.184**
VL	0.075	-0.056	-0.102	-0.046	0.041	0.013	-0.031	-0.024	-0.005	0.040	0.133	0.018	0.016	-0.091	0.018	-0.167**	-0.215**	0.184**	1.000

Note: **indicates $p < 0.05$; *indicates $p < 0.10$

Results of the Multivariable Analysis

Results from the multivariable regression analysis model indicate that the overall regression model was significant at $p < 0.01$. The linear model explained a significant amount of variance in appointment adherence ($R^2 = .09$, $p = 0.005$) although the amount of variance explained (9%) was small. In adjusted analyses, gender was significantly associated with appointment adherence in the model ($p = 0.019$) with women attending significantly fewer scheduled medical appointments than men. Also, age was significantly related to appointment adherence ($p = 0.006$); participants 45 years and older attended a greater number of scheduled medical appointments than those younger than 45 years. Engagement with provider was not significantly associated with appointment adherence ($p=0.254$). In this model, internalized HIV stigma was not significantly associated with appointment adherence ($p=0.915$) neither was the interaction variable that explored whether engagement with provider moderated the relationship between internalized HIV stigma and appointment adherence ($p= 0.102$).

Results from the Poisson regression analysis on missing visits count indicate that model explained a significant amount of variance in missed visits ($R^2 = .15$, $p <0.001$) although the amount of variance explained (15%) was also small. The Poisson regression analysis on missing visits count indicate that the adjusted incidence rate ratio for gender ($=1.749$) is 74.9% higher for females than for males. Likewise the adjusted incidence rate ratio for individuals 18-44 years of age ($=1.383$) suggests that missing visits count is 38.3% higher for 18-44 year olds than for individuals 44 years and older.

Table 6. Linear Regression Model Assessing Factors Associated with appointment adherence

Characteristics	Univariate Model		Multivariate Model	
	Mean Diff (95% CI)	p value	β (95% CI)	p value
Gender		0.0213*		0.019*
Female vs Male	-0.094 (-0.173, -0.014)		-0.095 (-0.176, -0.015)	
Age		0.0056*		0.006*
18-44 vs 45 and above	-0.126 (-0.215, -0.037)		-0.125(-0.214, -0.034)	
Engagement with Provider		0.4828		0.254
per score increase	-0.003 (-0.010, 0.005)		-0.025 (-0.052,0.001)	
Internalized HIV Stigma		0.9290		0.915
per score increase	0.001 (-0.005-0.005)		-0.015 (-0.034, 0.004)	
HIV Internalized Stigma x Engagement with Provider				0.102
(per stigma score increase)			0.001 (-0.001, 0.002)	

Note: Variables associated with appointment adherence and Number of Missed Visits at p<.10 in the Spearman Correlation analysis are included in the model as well as Engagement with Provider.

Additionally, the relationship of internalized HIV Stigma and Missed Visits is moderated by engagement with provider (p=0.003). Results of this moderating effect are shown for pre-specified values that present scenarios when internalized HIV stigma is equal to the first, second or third quartiles. For subjects with low HIV stigma, the effect of engagement with provider is as follows: every one-unit increase in the engagement score (meaning lower engagement with the provider) is associated with 3.3% increase in missed visits incidence rate. For subjects with median HIV stigma, the effect of engagement with provider is as follows: every one-unit increase in the engagement score (meaning lower engagement with the provider) is associated with 1.8%

increase in missing visits incidence rate. For subjects with high HIV stigma, engagement with

provider is not significantly associated with Missed Visits.

Table 7. Multivariate Poisson Regression Model Assessing Factors Associated with Number of Missed Visits

Characteristics	aIRR	95% CI	p value
Gender			<0.0001
Male	Ref	Ref	
Female	1.739	1.480-2.045	
Age			<0.0001
18-44	1.388	1.185-1.626	
45 and above	Ref	Ref	
Internalized HIV Stigma	1.053	1.012-1.096	0.009
Engagement with Provider	1.090	1.033-1.150	0.001
Internalized HIV Stigma * Engagement with Provider	0.996	0.994-0.999	0.004
Engagement with Provider:			
Low Internalized HIV Stigma	1.033	1.013-1.053	0.001
Medium Internalized HIV Stigma	1.018	1.004-1.032	0.010
High Internalized HIV Stigma	0.9969	0.980-1.014	0.724

Note: Variables associated with appointment adherence and Number of Missed Visits at p<.10 in the Spearman Correlation analysis are included in the model as well as Engagement with Provider. aIRR: adjusted Incidence Rate Ratios

CHAPTER 5: DISCUSSION

Addressing Central Questions

In order to address its central question of how internalized HIV stigma affects retention in HIV care, this study examined two key Aims:

(1)   Assess the association of internalized HIV stigma with retention in HIV care measured for clinical (missed visits), and policy making (adherence).

(2)   Assess whether engagement with provider or other construct moderates this association.

In terms of the first Aim we utilized two retention-in care measures that have been recommended for use in clinical and policy making decisions. One of the variables assessed retention in care via missed visits while the other assessed retention in care from the opposite perspective of appointment adherence (or appointments kept). Although we found that both retention in care measures were significantly correlated to variables such as age and gender, our findings from the bivariate and multivariable analysis indicate that there is not a direct association between internalized HIV stigma and either of the retention in HIV care measures assessed in this study, which rejects one of the hypothesis of our study.

In terms of the second question, the multivariable analysis indicated that engagement with provider moderated the association between internalized HIV stigma with retention in HIV care. Engagement with provider was also hypothesized to serve as a moderator between internalized HIV stigma and retention in HIV care, according to our Labeling Theory Modeling

the Association of Internalized HIV Stigma with Retention in HIV Care. As conceptualized, the expectation and fear of rejection, which is a product of the internalized HIV stigma, would lead the individual to withdraw or avoid potentially threatening social interactions (interactions where the stigmatized condition is revealed). Because the patient–provider social interaction is an unavoidable step that every HIV infected individual has to go through, the perceived quality of the relationship with providers was hypothesized to moderate the degree in which internalized HIV stigma affects HIV care behaviors that promote or hinder retention in HIV care. Results from our analysis looking at missed medical appointment visits confirmed that engagement with provider moderates the relationship between internalized HIV stigma and retention in care. Our findings indicate that engagement with provider is associated with reducing missed visits in patients reporting low to medium levels of HIV stigma. However, for participants with high HIV stigma, the perceived quality of the relationship with providers is not associated with reductions in missed visits. To our knowledge, this is the first time that such a finding has been reported in the literature of retention in care and has important implications in terms of patient care.

Although not related to retention in HIV care, a similar finding was reported by Katz and colleagues in their meta-analysis that assessed the impact of HIV-related stigma on antiretroviral treatment (ART) adherence.[77] Not only did the results of the meta-analysis confirm that HIV-related stigma negatively impacted participants' abilities to successfully adhere to ART, but it also identified several intrapersonal, interpersonal and structural levels in which this happened. One of the main themes from their analysis identified different aspects of the health system (both interpersonal and structural) as potentially moderating the impact of HIV-related stigma on ART adherence. One of these aspects referred to the nature of interpersonal relationships between

patients and providers and how these relationships could foster better treatment adherence. Their qualitative findings in this area focused on the concept of "compassionate human capital elements," which includes having doctors and nurses engaged in patient-centered care in order to establish bonds of trust and empower patients to overcome the stigma associated with taking medications. Katz and colleagues referred specifically to the perceived quality of the relationship with providers as key to foster better treatment adherence.[77]

Findings from this dissertation, like those by Katz and colleagues, indicate the importance of developing interventions that strengthen interpersonal patient - provider relationships in order to moderate the association of low to moderate levels of HIV internalized stigma on retention in HIV care. However, for patients experiencing high levels of internalized HIV stigma, provider relations may not moderate missed visits. For these patients the challenge is to reduce internalized HIV stigma to low/moderate levels so that better provider relations can help to decrease missed visits.

Of note, this was a cross-sectional observational study and the sample was comprised of an older population with a higher proportion of women and African-Americans than either the clinic caseload or the total U.S. HIV patient population. This limits the generalizability of these findings to other HIV infected patient populations beyond those showing the characteristics of our sample. On the other hand, our analysis indicated that 86% of participants in our sample reported missing one or more scheduled medical appointments. As previously noted, these scheduled appointments did not include those that were re-scheduled or cancelled; such a large proportion of missed scheduled visits is problematic from a clinical perspective. Other studies

have noted rates of 60% - 68% missed visits,[15,48] suggesting that missed visits rates among our

sample were higher than among other patient populations. Furthermore, a recent national

analysis reporting levels of HIV infected patients engaged in care, prescribed antiretroviral

treatment (ART), and virally suppressed reported that 82% of those prescribed ART were virally

suppressed.[78] However, only 60% of participants in our sample prescribed ART were virally

suppressed, this implies that patients in our sample were less virally suppressed compared to the

national estimates. Both of these findings indicate that our sample was comprised of individuals

with poorer retention in care practices and poorer clinical outcomes than other patient

populations, precisely the type of patient population that would benefit from interventions to

improve retention in care.

Our findings suggest that for a patient population that reflects the characteristics of our

sample (i.e. with poor retention in care practices, and poor clinical outcomes), implementing

interventions that improve engagement with providers may be a good approach for those with

low and medium internalized HIV stigma, but interventions to reduce internalized HIV stigma

also need to be considered for those experiencing high levels of internalized HIV stigma.

Improving Engagement with Provider

Research in the area of improving patients' engagement with and trust in doctors or a

group of doctors has been going on in different disciplines for many years and has taken different

forms. Rolfe and colleagues examined in a Cochrane Review ten randomized controlled trial

interventions that focused on physician training, education for patients and interventions were

patients were provided additional information about doctors in terms of financial incentives or

consulting style, all aiming at improving patients' relationships with their medical providers.[79]

Among all the interventions assessed only 3 (one provider focused and two patient focused)

proved to be effective. In project SCOPE, Tulsky and colleagues evaluated whether oncologists

who received a CD-ROM training program on communication skills, that had examples of their

own audio-recorded clinic visits would improve the providers' ability to empathize with negative

emotions expressed by cancer patients.[80] The hypothesis was that improvements in

communication skills would also result in increased trust.

Findings showed that patients whose oncologists were in the intervention group reported

higher trust in their oncologists than patients whose oncologists did not receive the CD-ROM

training (p = 0.036). Patients in the intervention group also reported significantly greater

perceived empathy and a greater sense that their medical provider understood them in a holistic

manner. Tulsky also reported that providers in the intervention group used significantly more

empathic statements and were significantly more likely to respond to negative emotions

empathically than the providers in the control group.[80]

Clancy and colleagues evaluated the effects of Managed Care, in the form of group

educational visits, on underinsured or uninsured patients with type 2 diabetes.[81] The intervention,

delivered by a physician and a nurse practitioner focused on a monthly 2 hour group session

where presentations related to health-related topics, prevention activities, and one-on-one

consultations took place. The authors found that overall there was a significant increase in the

total trust score for the patients who attended the group visits compared to those who received

usual care. The authors also stated that significant positive increases occurred in the patients'

perception of coordination of care, community orientation and cultural competency.

Finally, in Patient Choice, Hsu and colleagues matched patients seeking a new primary

care provider (PCP) and practitioners based on beliefs about care.[82] The investigators either gave

patients the option to choose a provider or assigned a provider based on patient and provider

preferences for shared decision making. The study also explored the effect of the intervention on

patient satisfaction and patients' perception of the process. Findings demonstrated that

intervention subjects were more likely to retain their primary care provider at 1 year, and to

report greater overall satisfaction with the PCP, compared to control subjects who were assigned

to a PCP. The intervention subjects also reported greater trust in their PCP on most measures and

reported a significantly increased perception that their clinician knew them well.

Reducing Internalized HIV Stigma

Our findings indicate that for patients experiencing high levels of internalized HIV

stigma improving patient provider relationships might not be enough to reduce missed visits. For

these individuals the best approach would be to reduce the high levels of internalized HIV stigma

to medium or low levels so that interventions that improve patient provider engagement may

work to improve retention in HIV care. In order to identify interventions that reduce internalized

HIV stigma, we conducted a literature search of evidence based interventions that have been

found to reduce internalized HIV stigma. Our search found 3 interventions that have been tested

in the last few years that targeted specific groups and that have reported positive outcomes in

terms of reducing internalized HIV stigma. Barroso and colleagues, developed an intervention

targeting minority women in the Southeastern United States that included a 45-min video titled, ''Maybe Someday: Voices of HIV-Positive Women'' based on a protocol for the systematic integration of findings of qualitative studies conducted with HIV-infected women in the United States.[83] The main points of the intervention were to "include the experience of being an HIV-infected women; the fear of the negative social effects that come with telling other people about one's HIV status; women's tremendous struggle about whether or not to tell their children; the importance of communicating with nurses, doctors, and those family members and friends whom they trust; the positive effects of disclosure; the extra stigma and discrimination connected with being a woman, being a minority woman, and being a mother; and ambivalence about disclosing one's HIV status to potential and actual sex partners." Finding from their randomized controlled trial indicated that the intervention was successful in improving self-esteem and decreasing internalized stigma, as well as improving coping self-efficacy.

A second intervention, also targeting minority women, developed by Rao and Colleagues [84] modified the HIV Stigma Toolkit developed by the International Center for Research on Women (ICRW), the Academy for Educational Development, and the International AIDS Alliance, [85] to reduce public stigma in global settings. The toolkit which includes modules that provide individuals infected with HIV the skills to cope with internalized HIV stigma was modified to be applicable to African American women living with HIV infection in the United States and pilot tested during a workshop where the researchers measured changes in internalized stigma before and after workshop participation. Results of their pilot intervention showed that the intervention was feasible, and led to statistically significant reductions in internalized stigma from the start of the workshop to the end.

Finally, the intervention developed by Harper and colleagues focused on adolescents and young adults newly diagnosed with HIV and sought to reduce four dimensions of HIV-related stigma—personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes about people with HIV.[86] The intervention, tested in a pilot study, was based on the Disability- Stress-Coping model, [87] which theorizes that that risk and resistance factors work together to impact how adolescent's adapt to chronic illness and/or disability. Risk factors included in the model focus on disease/disability parameters, functional independence, and psychosocial stress, while resistance factors fall into intra-personal, socioecological, and stress-processing. Findings from this pilot study revealed overall reductions in stigma in three dimensions: personalized stigma, disclosure concerns, and negative self-image although results varied by gender; with males showing long term (3 month) decreases among all dimensions, while females only showed a post-intervention decrease for personalized stigma.

Improving Retention in HIV Care

In addition to interventions that increase patient – provider engagement and to reduce internalized HIV stigma, it is also important to focus on interventions that increase retention in care, as a way to address the fact that for patients reporting high levels of stigma the engagement with provider interventions and/or the interventions to reduce internalized HIV stigma might not work as effectively. Gardner and colleagues recently published the results of a multi-site randomized controlled trial that sought to determine whether enhanced personal contact with HIV infected patients across time improves retention in care.[88] Their findings indicate that their intervention, which focuses on having a dedicated staff that is trained in case management techniques and maintains personal contact with patients with a history of missed visits, improves

retention in HIV primary care. This important finding coupled with findings from a meta-analysis conducted by Higa and colleagues where the authors concluded that other low cost evidence-informed strategies such as displaying posters and brochures in waiting rooms, and having medical providers present brief messages to patients are also effective in retaining patients in care; [89] provide a wide array of alternatives to strengthen efforts to maintain UM/JHM patients engaged in care. These low cost interventions were even found to be cost effective generating a net-positive effect on clinic revenue of +$24,000/year for an average-size clinic (7400 scheduled visits/year).[90]

Limitations

The findings from the present cross-sectional observational study are subject to several limitations. First, study participants were a convenience sample recruited from the University of Miami Jackson Memorial Special Immunology clinics located in Miami, Florida therefore they are not representative of the larger population of HIV/AIDS patients at the UM/JHM clinics, Florida or the rest of the United States. At best our sample may reflect experiences of HIV infected individuals attending publicly funded health facilities who have similar characteristics. Second, our analysis focused mostly on patient-level predictors of visit adherence and missed visits. Potentially important health care structural-related characteristics that may also impact scheduled appointments were not assessed. Some important individual level characteristics such as self- efficacy were not assessed in this study even though these constructs have been related to retention in care in previous work.[91] The potential effect of self-efficacy as a moderating construct between internalized HIV stigma and retention in care should be further explored. Findings from the missed visits and appointment adherence models indicated that although the

variables included in the models significantly explained 15% and 9%, respectively, of the variance of these retention in care measures, the variance was small signifying that other constructs need to be assessed to fully understand what impacts retention in HIV care. This study only included patients who were currently receiving HIV care; there may be a significant proportion of individuals with HIV who have high internalized HIV stigma who may have entered care at the UM/JHM clinic at some point but were lost to follow-up (never returned for appointments). As described in Link's Labeling Theory and our own Modified Labeling Theory (3rd step on both), these individuals are those with internalized HIV stigma whose coping response is to go in "secrecy" or "withdrawal". These findings would not be applicable to this group of individuals. Finally, some data for HIV viral load was imputed due to missing data. This may have underestimated a possible relationship with the retention in care variables and/or overestimated levels of viral load suppression.

CHAPTER 6: PLAN FOR CHANGE

Organizational and Policy Changes

This dissertation explored the mechanisms by which internalized HIV stigma is associated with retention in HIV care in order to develop interventions that ultimately would contribute to achieve one of the objectives of the National HIV/AIDS Strategy, i.e. maintaining HIV infected individuals in care. Internalized HIV stigma is one of several factors that contributes to poor retention in care, but as we tried to assert in this dissertation, we believe as Bruce Link and others believe, that understanding the mechanism by which internalized HIV stigma is associated with poor health outcomes is important in order to improve those health outcomes. Findings from this dissertation of how 1- internalized HIV stigma doesn't impact directly on retention in HIV care, 2- that the patient - provider relationship moderates the association of low to moderate levels of HIV internalized stigma on retention in HIV care, and 3- that for patients experiencing high levels of internalized HIV stigma, the patient - provider relationship may not moderate missed visits, provide important information on the mechanism by which internalized HIV stigma is associated with poor retention HIV in care. The expectation is that these findings will contribute to address retention in HIV care among the patient population of the Special Immunology Outpatient Clinics at Jackson Memorial Hospital, one of the largest clinics treating HIV patients in the southeast of the United States. The clinic is located in Miami, Florida which in 2013 ranked number 1 in the nation in terms of the rate (per 100,000 population) of reported HIV diagnosed cases.[92]

Based on the findings and limitations of our analysis, the literature regarding improving engagement with provider, reducing internalized HIV stigma, and improving retention in care, and the feedback from my Dissertation Committee members, I decided to focus the activities in the plan for change on a three-prong approach.

First, in an effort to address those individuals most affected by retention in care issues and considering that average appointment adherence was 55% in our sample (i.e. patients in our sample attended on average 55% of their scheduled appointments) to recommend that all patients who miss 50% or more visits in the past 12 months be screened for internalized HIV stigma. We prefer to use this measure for screening purposes given that it takes into consideration both the number of visits scheduled and missed, since concerns that a person who misses his/her only scheduled visit and the person who misses 1 of 4 visits would have the same number of missing visits (1) despite being different situations (with 0% attendance vs. 75% attendance). This will also help to identify among the UM/JHM clinic patient population individuals that may have retention rates similar to those in our sample that could benefit most from the proposed interventions.

Second, after screening and identifying individuals with low, moderate and high internalized HIV stigma levels, we will recommend offering a patient focused patient-provider engagement intervention to those clinic patients reporting low to moderate levels of internalized HIV stigma to potentially improve retention in care rates among this group as our findings indicate. We will also recommend offering an internalized HIV stigma intervention to reduce internalized HIV stigma to clinic patients reporting high levels of internalized HIV stigma. Once

the internalized HIV stigma levels are reduced to medium or low levels among these patients, these patients will also be offered the patient focused patient-provider engagement intervention to potentially improve their retention in care rates. Although, the success of this approach will need to be evaluated.

Finally, Gardner's low cost retention in care intervention Stay Connected, which has been found to improve clinic attendance will also be recommended.[90] Although this intervention has not been tested in terms of its effect on individuals reporting low, medium or high levels of internalized HIV stigma, the intervention focuses on repeated messages coming from different sources (doctors, nurses, posters in clinics, brochures, etc.) regarding the importance of maintaining medical appointments. This intervention has been proven to be effective, especially for patients that at some point withdrew from care. Given that the models tested in this study explained little of retention in care, it is recognized that other factors remain to be identified. Broad-based interventions that have been shown to improve clinic attendance are also important to include. Moreover, this low cost intervention has also proven to be cost effective,[93] which may serve to offset the costs of the engagement with provider interventions in the long run.   The success of this and other interventions will have to be evaluated.

Strategy to Achieve Organizational and Policy Change

Part of our strategy to promote the organizational changes described above is to use John Kotter's 8 Steps Leading to Organizational Change.[94] Kotter's model visualized in Figure 9 emphasizes 8 sequential steps that leaders need to implement to achieve changes in organizations.

Figure 8. Kotter's Eight Step Change Model

Eight Steps To Successful Change - John Kotter

Institutionalise the change
Consolidate & build on the gains
Create short term wins
Empower people to act on the vision
Communicate the vision
Develop a clear shared vision
Create a guiding coalition
Establish a sense of urgency

The first step in Kotter's process is to "establish as sense of urgency". In order to establish a sense of urgency at the UM/JMH clinics we will present the findings of this dissertation to all the staff at the SI clinics. The objective of the presentation will be not only to present the data regarding the high proportion of missed visits and the findings of how internalized HIV stigma affects retention in care when it is moderated by provider engagement, but also to open an honest and convincing dialogue about what's happening at the SI clinics, including possible solutions to the problem. The purpose as described by Kotter is to have the staff at the SI clinics to start talking about the proposed changes so that the urgency can build and feed on itself. Final decision on what strategies/interventions to be used in our efforts to reduce internalized HIV stigma and improve retention in care among UM/JHM clinic patients will be made after presentation of our findings to UM/JHM clinic staff, and consultations with the UM/JHM clinic leadership, patient advocates, and members of the guiding coalition.

The second step according to Kotter is to "create a guiding coalition". Our efforts here will be to focus on recruiting leaders at the UM/JMH clinics, but given the importance that the UM/JHM clinics have in terms of patient care (and potentially prevention activities) at the county level, we will also try to recruit selected HIV prevention and care leaders in Miami-Dade County.

One of the dissertation committee members is Dr. Allan Rodriguez who is the Operational Director of the Special Immunology Outpatient Clinics at JMH and the Director of the Behavioral/Social Science & Community Outreach Core of the Miami CFAR. We will ask Dr. Rodriguez to champion the organizational change at the UM/JMH SI clinics. His leadership and support will be essential to promote the changes that will improve retention in care at the UM/JMH SI clinics.

A second member from the UM/JHM leadership that will be tapped with Dr. Rodriguez' help is Dr. Michael Kolber who is the Director of the Comprehensive AIDS Program, Clinical Director of the Adult HIV Section for Infectious Diseases and Professor of Medicine at the University of Miami Miller School of Medicine. As Director of the Comprehensive AIDS Program, Dr. Kolber interfaces directly with both community and state services and entities that provide or support HIV-related activities. He established the Infectious Diseases Research Unit and has oversight for HIV inpatient and outpatient clinical functions.

A third individual who will be tapped to become a member of the guiding coalition is Ms. Villamizar who is the Director of the HIV/AIDS Program of the Miami-Dade County Health Department (MDCHD). I have worked with Ms. Villamizar for many years and we are close

friends. The prevention aspects of improving retention in care in Miami-Dade County is something that her office will strongly support. I have no doubt that she will support our plan and become an active member of our guiding coalition. We will ask Ms. Villamizar to set a meeting with Ms. Michelle Wyatt, who is the current Chair of the Miami-Dade HIV/AIDS Partnership (The Partnership). The Partnership is the official county planning board for HIV/AIDS care services. It obtains input on community needs, sets priorities and allocates funds for Ryan White Part A/MAI, and makes recommendations for Ryan White Part B, General Revenue and Housing Opportunities for People with AIDS. In addition, it serves as an advisory board to the Miami-Dade County Mayor and Board of County Commissioners. The UM/JHM Clinics is one of the largest recipients of Ryan White funds in Miami-Dade County. Dr. Wyatt's role as a leader in HIV care and treatment issues in Miami-Dade County will make her a valuable member of the guiding coalition.

These four members of the guiding coalition will also be key to refine the plan for change, including the selection of the patient-provider and internalized HIV stigma interventions so that the plan for change better reflects the needs in terms of retention in care of the UM/JHM clinic patient population.

The third step in Kotter's process is to "create a vision for change". All the members of the guiding coalition are familiar with the stakes. As previously described, the problem of failing to retain individuals in consistent HIV care has negative prevention and clinical consequences. How to address the problem regarding retention in care has proven to be more elusive. Our vision for change involves mitigating the impact of internalized HIV stigma on retention in care

by reducing high levels of internalized HIV stigma, and partnering patients and providers to address the problem, utilizing proven interventions that work at different levels. The vision will be synthesized in succinct messaging that captures what the guiding coalition sees as the future of the HIV prevention and care activities in Miami-Dade County: *The burden of HIV in Miami-Dade County is significant and making sure that patients receive timely treatment is a priority to improve clinical outcomes, prevent new infections, and minimize the impact of HIV in our community. The best way to achieve this goal is to reduce stigma and for patients and providers to work together.*

The next step according to Kotter is to "communicate the vision." In addition to creating and posting messages within the UM/JMH SI clinics, and seeking every opportunity to present the dissertation findings and plan of action at the UM/JHM clinics (ex. medical rounds, SI clinic staff meetings, etc.), the plan will be communicated at a larger scale. With assistance of Ms. Villamizar we will reach County Commissioner and Chairman Jean Monestime from District 6. Commissioner Monestime has previously supported HIV/AIDS prevention and education initiatives in his district and has been the sponsor of several presentations of HIV prevention and care experts in front of the Miami-Dade County Commission in efforts to keep the County Commissioners updated on HIV care and prevention issues impacting citizens of Miami-Dade County. The Miami-Dade County Commission oversees the County's Ryan White program so making them aware of our findings at one of the largest funded Ryan White clinics in the county is important.

In addition, to ensure a wide dissemination of our proposed plan to increase the rate of patients that keep their medical appointments at the UM/JHM clinics we will seek the support of media health reporters. The Miami Herald (MH), which is the newspaper that has the largest circulation in the Miami area, has a strong health reporting section led by Ms. Amy Driscoll who has been very active in reporting health issues in South Florida. We will meet with her and her staff to present them with the same information that we presented to the UM/JHM clinic leadership and solicit their support by writing a piece on the high burden of HIV in Miami-Dade County and the negative impact of low retention rates on patients' health.

The fifth step on Kotter's model is to "empower people to act on the vision". Our selection of change leaders will assure that we have a broad coalition that allows us to put in place the vision for change, and continually check for gains and barriers to achieving the desired vision. Part of our activities to empower leaders to act on the vision is to allow them to address potential obstacles and make sure that they address any resistance in a quick manner. For example, although some providers might at first oppose to patient-provider engagement intervention, with the assistance of Dr. Rodriguez we will educate the providers of why improving patient-provider relations will improve job satisfaction and achieve better health outcomes for their patients. Other activities to empower individuals include selecting key members of the guiding coalition to be spokespersons of the plan for change. For example, members of the guiding coalition will present our strategy for reducing internalized HIV stigma and improve retention in care rates at the UM/JMH SI clinics at various community settings that are served by UM/JHM hospital. Finally, with the assistance of the members of the guiding coalition at the UM/JMH clinics other individuals within the UM/JMH clinics will be selected to

serve as additional champions so that activities to promote change are disseminated at several layers of the organization.

The sixth step of Kotter's model is to "create short-term wins." Our first priority will be to get the patient-provider engagement intervention up and running at the UM/JHM clinics. Implementation of this intervention will signal that the combined patient-provider partnership to improve the retention in HIV care in Miami-Dade County has commenced. Even though the benefits won't be seen for a while, the beginning of this patient-provider partnership will be seen as a symbolic step, galvanizing those affected by HIV (patients and providers) in order to work together to address stigma, strengthen patient-provider relationships, retain patient in care, improve patient outcomes, and minimize the impact of HIV across Miami-Dade County. The target is to have this intervention up and running within 6 months after the plan has been approved by the UM/JHM clinic leadership and members of the guiding coalition.

The seventh step according to Kotter is to "build on the change." In order to build on the change we need to conduct a thorough process evaluation to understand how intervention activities are being implemented and if they are achieving the desired outcomes. The evaluation will allow us to identify what processes are working and which ones are not, providing timely information to continuously improve processes.

Given the three-prong approach (screening for internalized HIV stigma, interventions to reduce internalized stigma and improve patient and provider engagement, and structural retention in care intervention) the expectation is that even those patients reporting high levels of

internalized HIV stigma will benefit by seeing their stigma levels reduced which should facilitate the effect of the patient-provider engagement interventions to improve retention in care, but if that is not the case, the next level of evaluation will be to assess factors that potentially moderate the relationship between those individuals reporting high levels of internalized HIV stigma and missed visits. For this analysis, I looked at social support as a potential moderator (data not shown), hypothesizing that social support might better moderate the relationship between internalized HIV stigma and missed visits, but I found no significant relationship between social support and missed visits. Other constructs, such as self-efficacy would need to be explored.

Finally, if the interventions at the UM/JHM clinics produce the desired effect, full implementation of these interventions county-wide might be warranted. We will work with the Partnership to identify Ryan White clinics with poor retention in care rates (and similar patient characteristics) where interventions as the ones proposed at the UM/JMH SI clinics might help in improving retention in care rates.

The eight and last step according to Kotter is to "institutionalize the change." As Kotter describes it, to make the changes permanent they must become a core part of the organization (or the system). To accomplish this we will disseminate widely the progress in mitigating the impact of internalized HIV stigma on retention in care by reducing high levels of internalized stigma and forging strong patient – provider partnerships, and how these partnerships are allowing to improve retention in care rates at UM/JHM clinics. This progress will be touted to UM/JHM and Partnership leaders as well as County Commissioners so they continue to support the change.

Every effort will be made to publicly recognize key members of the change coalition, and make sure that the rest of the staff remembers their contributions.

A summary of the plan for action that includes the Change Step, Recommended Actions, Goal (s), Specific Actions, and Measures is presented in Table 8.

Dissemination of Dissertation Findings

Besides directly promoting organizational and policy changes, findings from this dissertation will be widely disseminated to encourage further studies and evaluations that may promote organizational and policy changes at the national level. Finding will be presented at key conferences and meetings (e.g., American Public Health Association (APHA), United States Conference on AIDS (USCA), International AIDS Conference, International Conference on HIV Treatment and Prevention Adherence, etc.) coupled with the submission of papers to leading peer reviewed journals for publication in journals such as the American Journal of Public Health, AIDS Care, AIDS Health and Behavior, and the Journal of the Association of Nurses in AIDS Care.

Findings will also be presented to the HRSA HIV/AIDS Bureau staff that oversees the use of Ryan White funds across clinics in the United States and to the staff of the Centers for Disease Control and Prevention that are working in collaboration with State Health Departments to improve outcomes along each step of the HIV care continuum (diagnosis, retention in medical care, antiretroviral therapy, and viral suppression). Although findings from a small study like this might not produce organizational and policy changes across clinics in the United States, it will

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promote further research that may lead to nationwide changes in how internalized HIV stigma is addressed to improve retention in HIV care among HIV- infected individuals.

Table 8. Summary of Plan for Change

Change Step	Recommended Actions	Goal (s)	Specific Actions	Measures
1. Establishing a sense of urgency	• Identify audiences • Frame messaging to reflect urgency of the situation	• Develop open discussion among all Stakeholders • Refine Plan for Change	• Present findings to staff at UM/JHM Clinics • Meet with UM/JHM leadership	• Presentations conducted where study findings have been disseminated • Actions taken by leadership of organization
2. Creating a guiding coalition	• Identify members of the guiding coalition	• Have leaders among all major stakeholders that can advocate for change	• Meet individually with selected leaders involved in HIV/AIDS prevention and care activities in Miami-Dade County	• Number of leaders participating in the guiding coalition
3. Developing a clear shared vision	• Work with members of the guiding coalition to refine vision	• Have a unified vision that promotes the importance of reducing internalized HIV stigma and improving patient-	• Develop clear messaging the conveys the vision	• Vision accepted by all stakeholders

			provider partnerships		
4. Communicating the vision	• Identify different venues where the vision can be shared with all the community	• Have a wider dissemination of the vision	• Present findings and plan for change to UM/JMH staff • Present findings and plan for change to Miami-Dade County commission • Enlist help from experts to communicate health related information to the wider public	• Number of presentations conducted to key audiences • Number of newspaper articles describing the vision	
5. Empower People to Act on the Vision	• Identify areas in which members of the guiding coalition (and other identified by them) can take leading roles	• Ensure that activities to promote change are widespread and buy-in occurs at different levels of the organization	• Meet with members of the guiding coalition to identify areas in which they or other assigned by them can take leading roles	• Number of members of the guiding coalition and others recruited by them that are actively promoting change	
6. Create short term wins	• Identify areas where short term wins can be obtained	• Motivate individuals to continue with the change activity and address	• Meet with members of the guiding coalition to identify areas where short term wins can	• Number of interventions implemented within 6 months of the plan acceptance by	

		concerns from potential naysayers	be obtained interventions that is low cost	the UM/JHM leadership
7. Consolidate & build on the gains	• Assess processes and actions to determine what is/is not working and if there are ways to improve these processes/actions. • Identify gaps to achieve vision of activities that minimizes internalized HIV stigma, strengthens patient-provider partnerships and improve retention in care	• To ensure that vision is fulfilled	• Conduct a thorough process and outcome evaluation • Identify gaps not covered by the plan for change and include new activities interventions as part of the long term plan for change	• Number of processes or activities that are meeting/failing expected outcomes • Number of actions implemented to improve and/or correct processes and/or activities • Number of gaps identified and addressed within 12 months of initiation of plan for change
8. Institutionalize the change	• Disseminate widely the progress • Publicly recognize key members of the change coalition	• To make the changes permanent they must become a core part of the organization	• Identify venues where progress can be disseminated • Identify venues/events where members of	• Number of venues where progress was promoted • Number of venues/events where members of the guiding

	• Recruit new members of the guiding coalition	(or the system)	the guiding coalition can be recognized • Work with existing members of the guiding coalition to recruit new cadre of members	coalition where recognized • Number of new members of the guiding coalition recruited

[To be read aloud by interviewer]: I am going to ask you some questions that will help me to know more about you. There are no right or wrong answers and we do not prefer one response over another. Giving us honest answers to these questions will help us to help others like you who need care for HIV infection.

DEMOGRAPHICS

D1. What is your date of birth? __ __/ __ __/ __ __ __ __   *[dob]*
                              MM / DD / YYYY

D2. So you are how old?   _____   *[age]*

D3. Do you consider yourself to be male, female, or transgender? *[CHECK ONLY ONE.]*
        [gender]
        Male.. ☐ 1
        Female .... ☐ 2
        Transgender .... ☐ 3
        Refused to answer .... ☐ 77☐☐
        Don't know.. ☐ 88

D4. What is your marital status? *[marital_status]*
        Never married/single .... ☐1
        Married .... ☐2
        Divorced/Separated .... ☐3
        Widow/Widower .... ☐ 4
        Living with partner/significant other................................... ☐5
        Other *(Specify:*_____*)*..... ☐6
        Refused to answer .... ☐ 77
        Don't know.. ☐ 88

D5. How many children do you have?   _____ ➡ if zero, skip to
D6*[children]*

D5a. What is the HIV serostatus of your child(ren)? *[hiv_children]*
        HIV negative .... ☐ 0
        HIV positive .... ☐ 1
        Refused to answer .... ☐ 77☐☐
        Don't know... ☐ 88

D6. Who do you live with right now? [*CHECK ONLY ONE*] *[live_with]*
        Single.. ☐1
        Spouse .... ☐2 ➡ if yes, ask D6a
        Significant other/partner... ☐3 ➡ if yes, ask D6a

Parents .... ☐ 4
Other extended family .... ☐5
Children .... ☐6
Children and Partner Alone... ☐7
Friends .... ☐8
Other *(Specify:_____)* ..... ☐9
Refused to answer .... ☐ 77
Don't know.. ☐ 88

D6a. What is the HIV serostatus of your *[SAY RESPONSE TO D6]*? *[hiv_status_live]*
HIV negative .... ☐ 0
HIV positive .... ☐ 1
Refused to answer .... ☐ 77☐☐

Don't know.. ☐ 88

D7. Do you consider yourself to be Hispanic or Latino? *[hispanic]*
No .... ☐ 0
Yes.. ☐ 1
Refused to answer .... ☐ 77☐☐

Don't know.. ☐ 88

D7a. Which of the following best describes your ethnic background? *[ethnic_bkgrnd]*

     Spaniard, from Spain .... ☐1
     Mexican .... ☐2
     Central American .... ☐3
     South American .... ☐ 4
     Puerto Rican .... ☐5
     Cuban .... ☐6
     Dominican .... ☐ 7
     Other *(Specify:_____)* .... ☐9
     Refused to answer .... ☐ 77
     Don't know .... ☐ 88

D8. How would you describe your race/ethnicity? *[race_ethni]*

     White/Non-Hispanic .... ☐1
     Hispanic .... ☐2
     Black or African American .... ☐3
     American Indian/Alaska Native .... ☐ 4
     Native Hawaiian/Other Pacific Islander .... ☐5
     Other *(Specify:_____)* ..... ☐6
     Refused to answer .... ☐ 77
     Don't know .... ☐ 88

D9. Do you think of yourself as: *[READ CHOICES. CHECK ONLY ONE.]* *[sex_orient]*

     Homosexual, gay, or lesbian .... ☐ 1
     Heterosexual or straight .... ☐ 2
     Bisexual .... ☐ 3
     Other *(Specify:_____)* .... ☐ 4
     Refused to answer .... ☐ 77☐☐
     Don't know .... ☐ 88

D10. How do you think you were infected with HIV?

Homosexual sex .... ☐ 1*[inf_w_hiv.1]*
Heterosexual sex.. ☐ 2*[inf_w_hiv.2]*
Drug use/sharing needles.. ☐ 3*[inf_w_hiv.3]*
Blood transfusion .... ☐ 4*[inf_w_hiv.4]*
Multiple Risks (*Specify_____*) .... ☐ 5*[inf_w_hiv.5]*
Refused to answer .... ☐ 77☐☐
Don't know... ☐ 88

D11. How many years of school have you completed? _____*[yrs_sch]*

D12. What is the highest level of education you completed? *[CHECK ONLY ONE RESPONSE. DON'T READ CHOICES.]* *[lvl_of_sch]*

Never attended school .... ☐ 1
Grades 1 through 8 .... ☐ 2
Grades 9 through 11 .... ☐ 3
Grade 12 or GED.. ☐ 4
Some college, associate's degree, or technical degree.......... ☐ 5
Bachelor's degree .... ☐ 6
Any post-graduate studies .... ☐ 7
Refused to answer .... ☐ 77
Don't know.. ☐ 88

D13. Are you currently employed? *[employed]*

No .... ☐ 0
Yes.. ☐ 1
Refused to answer .... ☐ 77☐☐
Don't know... ☐ 88

D14. Do you have a regular place where you stay? *[place_to_stay]*

No .... ☐ 0
Yes.. ☐ 1
Refused to answer .... ☐ 77☐☐
Don't know... ☐ 88

D15. Where do you currently live? *[CHECK ONLY ONE RESPONSE. DON'T READ CHOICES.] [curnt_res]*

    Your own or partner's household/apartment.........................□ 1
    Someone else's household/apartment ....□ 2
    Street..□ 3
    Treatment facility/halfway house ....□ 4
    Single room, rented room, motel, etc ....□ 5
    Homeless shelter..□ 6
    Other 1 *(Specify:_____)* ....□ 7
    Refused to answer ....□ 77
    Don't know...□ 88

D16. In the **past 7 months**, have you been homeless at any time? By homeless, I mean you were living on the street, in a shelter, a Single Room Occupancy (SRO) hotel, temporarily staying with friends/family, or living in a car. *[homeless_7months]*
    No ....□ 0
    Yes...□ 1
    Refused to answer ....□ 77□□
    Don't know...□ 88

D17. In the **past 7 months,** have you been arrested and put in jail, detention, or prison for longer than 24 hours? *[jail_7months]*
    No ....□ 0
    Yes...□ 1
    Refused to answer ....□ 77□□
    Don't know...□ 88

D18. In the **past 7 months**, have you had any kind of health insurance or coverage? I am not referring to coverage for medicines only. *[insur_7months]*
    No ....□ 0 ⟶ *Skip to D19*
    Yes...□ 1
    Refused to answer ....□ 77□□   *Skip to D19*
    Don't know...□ 88

D18a. What are all the kinds of health insurance or coverage you have had in the **past 7 months**? *[CHECK ALL THAT APPLY. DON'T READ CHOICES.]*

Private health insurance or HMO .... ☐ 1
Medicaid .... ☐ 2
Medicare .... ☐ 3
Ryan White .... ☐ 4
Tricare/Champus .... ☐ 5
Veterans Administration coverage .... ☐ 6
Other 1 *(Specify:_____)* .... ☐ 7
Refused to answer .... ☐ 77
Don't know .... ☐ 88

D19. Was there a time in the **past 7 months** when you had **no** insurance coverage?
[no_insur_7months]

No .... ☐ 0
Yes .... ☐ 1
Refused to answer .... ☐ 77☐☐
Don't know .... ☐ 88

D20. In the **past 7 months**, where did most of your money or financial support come from?
[CHECK ONLY ONE RESPONSE. DON'T READ CHOICES.] *[money_7months]*

Salary or wages .... ☐1
Savings/investments .... ☐2
Pension/retirement fund .... ☐3
Supplemental Security Income (SSI) or Social Security
     Disability Insurance (SSDI) .... ☐ 4
Public assistance ("welfare") .... ☐5
Spouse, partner or family .... ☐6
Friends .... ☐ 7
No income/financial support .... ☐ 8
Other *(Specify:_____)* ..... ☐9
Refused to answer .... ☐ 77
Don't know .... ☐ 88

D21. What is your average monthly income? Remember, this information will be kept
confidential. _____*[month_income]*

D22. Do you own your own car? *[own_car]*
    No .... ☐ 0
    Yes... ☐ 1
    Refused to answer .... ☐ 77☐☐
    Don't know... ☐ 88

D23. Do you have a working telephone? [*either "land" or cellular*] *[telephone]*
    No .... ☐ 0
    Yes... ☐ 1
    Refused to answer .... ☐ 77☐☐
    Don't know... ☐ 88

HEALTH CARE HISTORY

[INTERVIEWER: Read to participant] **I am going to ask you some questions about your
experiences with your health care, particularly as they relate to your HIV. I would like you to
think back to the time when you first were tested for HIV.**

A1.   When did you **first** test positive for HIV?

    __ __ / __ __ __ __
    (M M / Y   Y   Y   Y)   *[Month: 77 = Refused to answer, 88= Don't know;*
                         Year: 7777 = Refused to answer, 8888 = Don't know]

*Inconsistency check: A1 (date first tested positive for HIV) must match date given on
screener interview.*

A2.   So when you tested positive for HIV, where were you tested? *[CHECK ONLY ONE
RESPONSE. DON'T READ CHOICES.]*
    Community health center/primary care clinic/health
        department general medical clinic (public source)........... ☐ 1
    Hospital .... ☐ 2
    Private physician/HMO/primary care clinic (private source) ☐ 3
    HIV counseling and testing site.. ☐ 4
    STD clinic.. ☐ 5
    AIDS/infectious disease clinic .... ☐ 6

    Mobile test site (health department van, needle
        exchange, etc.).. ☐ 7
    Correctional facility (jail/prison)... ☐ 8

Emergency room .... ☐ 9
Blood bank .... ☐ 10
Prenatal/obstetrics clinic.. ☐ 11
Family planning clinic.. ☐ 12
Drug treatment clinic... ☐ 13
Military facility... ☐ 14
Insurance clinic/employee clinic .... ☐ 15
Other*(Specify:_____)* ☐ 16

A2a.   What was the **main reason** you were tested? *[CHECK ONLY ONE RESPONSE. DON'T READ CHOICES.]*
Illness (pneumonia, weight loss, etc.) .... ☐ 1
I'm an IDU……. .... ☐ 2
I'm a MSM .... ☐ 3
I had high-risk sexual behavior .... ☐ 4
Sex partner is IDU or MSM .... ☐ 5
Sex partner is HIV positive .... ☐ 6
Sex partner was worried I might have HIV............................. ☐ 7
Needle sharing partner is HIV positive .... ☐ 8
Surgery (pre-op) .... ☐ 9
Needle stick follow-up/ occupational exposure .... ☐ 10

Health department informed me of possible exposure to
    HIV (partner notification) .... ☐ 11
Blood donor... ☐ 12

Offered as a screening test at a clinic (STD, family
    planning clinic, etc.) .... ☐ 13

Started new relationship/wanted to stop using condoms
    with partner... ☐ 14
Pregnancy/prenatal visit .... ☐ 15
Routine check-up/physical exam... ☐ 16
I just wanted to know/was curious .... ☐ 17
Other *(Specify_____)* .... ☐ 18

A3.   When did you **first** go to a health care provider for HIV care after learning you had HIV?

__ __/ __ __ __ __
(M M / Y Y Y Y)   *[Month: 77 = Refused to answer, 88= Don't know;*
                        Year: 7777 = Refused to answer, 8888 = Don't know]

A4.   When did you **last** go to a health care provider for HIV care?*]*

$\frac{\_\_\ \_\_}{(M\ M}\ /\ \frac{\_\_\ \_\_\ \_\_\ \_\_}{Y\ \ Y\ \ Y\ \ Y\ )}$ *[Month: 77 = Refused to answer, 88= Don't know;*
                                                       Year: 7777 = Refused to answer, 8888 = Don't know]

Interviewer instructions: If A4 (date last went to health care provider) is more than 6 months prior to interview date, go to A5a; otherwise, skip to A6.

A5a.   What were the reasons you didn't go to a health care provider for HIV care during the past **6** months? *[CHECK ALL THAT APPLY. DON'T READ CHOICES. MAY NEED TO PROMPT WITH "IS THERE ANY OTHER REASON?"]*

Felt good, didn't need to go .... ☐ 1
Forgot to go .... ☐ 2
Missed my appointment(s) .... ☐ 3
Too busy to go .... ☐ 4
Moved or out of town .... ☐ 5
Don't want to think about being HIV positive .... ☐ 6
Didn't believe test result .... ☐ 7
Unable to get transportation .... ☐ 8
Unable to get childcare .... ☐ 9
Inconvenient (location, hours, time, etc.) .... ☐ 10
Didn't know where to go .... ☐ 11
Hard to find the right doctor or a good doctor for me .... ☐ 12
CD4 count and viral load were good .... ☐ 13
Drinking or using drugs .... ☐ 14
Living on the street .... ☐ 15
Didn't have money .... ☐ 16
Didn't have insurance .... ☐ 17
Unable to get earlier appointment .... ☐ 18
Incarcerated .... ☐ 19
Other 1 *(Specify:_____)* .... ☐ 20
Other 2 *(Specify:_____)* .... ☐ 21
Other 3 *(Specify:_____)* .... ☐ 22
Other 4 *(Specify:_____)* .... ☐ 23
Refused to answer .... ☐ 77
Don't know .... ☐ 88

A5b.   What was the **main reason** you didn't go to a health care provider for HIV care during the past **6** months? I am going to read a list of the reasons you just gave me. Please tell me which of these was your main reason. *[CHECK ONLY ONE RESPONSE. READ RESPONSES GIVEN in A7a.]*

Felt good, didn't need to go .... ☐ 1
Forgot to go .... ☐ 2 *[RNOCRL2]*
Missed my appointment(s) .... ☐ 3 *[RNOCRL3]*
Too busy to go .... ☐ 4 *[RNOCRL4]*
Moved or out of town .... ☐ 5 *[RNOCRL5]*
Don't want to think about being HIV positive .... ☐ 6 *[RNOCRL6]*
Didn't believe test result .... ☐ 7 *[RNOCRL7]*

Unable to get transportation .... ☐ 8 *[RNOCRL8]*
Unable to get childcare... ☐ 9 *[RNOCRL9]*
Inconvenient (location, hours, time, etc.).............................. ☐ 10 *[RNOCRL10]*
Didn't know where to go... ☐ 11 *[RNOCRL11]*
Hard to find the right doctor or a good doctor for me .... ☐ 12 *[RNOCRL12]*
CD4 count and viral load were good..................................... ☐ 13 *[RNOCRL13]*
Drinking or using drugs.. ☐ 14 *[RNOCRL14]*
Living on the street... ☐ 15 *[RNOCRL15]*
Didn't have money .... ☐ 16 *[RNOCRL16]*
Didn't have insurance... ☐ 17 *[RNOCRL17]*
Unable to get earlier appointment .... ☐ 18 *[RNOCRL18]*
Incarcerated .... ☐ 19 *[RNOCRL19]*
Other 1 *(Specify:_____)*.............. ☐ 20 *[RNOCRL20]*
Other 2 *(Specify:_____)*.............. ☐ 21 *[RNOCRL21]*
Other 3 *(Specify:_____)*.............. ☐ 22 *[RNOCRL22]*
Other 4 *(Specify:_____)*.............. ☐ 23 *[RNOCRL23]*
Refused to answer .... ☐ 77
Don't know.. ☐ 88

A6. Has a doctor or health care provider ever told you that you had AIDS?   *[DRAIDS]*
No .... ☐ 0
Yes.. ☐ 1
Refused to answer .... ☐ 7☐☐
Don't know.. ☐ 8

---

*SAY: "*Now, I'm going to ask you some questions about your CD4 counts, also called T cell counts."

A7. Have you **ever** had a lab test called a T-cell or CD4 count? *[CD4_DONE* *Skip to Say*
box before A9
No .... ☐ 0 ➡
Yes.. ☐ 1
Refused to answer .... ☐ 7☐☐   *Skip to Say box*
Don't know.. ☐ 8   }   *before A9*

A7a. When was your **last** T-cell (CD4) count given to you? *[LASTCD4]*

__ __/ __ __ __ __   *[Month: 77 = Refused to answer, 88= Don't know;*
(M M / Y Y Y Y)   *Year: 7777 = Refused to answer, 8888 = Don't know]*

A7b. What was your last T-cell (or CD4) count?
[USE RESPONSE CARD A.] [CDLWST]
0-49... ☐ 1
50-99... ☐ 2
100-199... ☐ 3
200-349... ☐ 4

350-499 .... ☐ 5
500 or more .... ☐ 6
Refused to answer .... ☐ 7
Don't know... ☐ 8

SAY: "Now I'm going to ask you some questions about your viral load tests."

A8. Have you **ever** had a viral load test (to measure the amount of HIV in your blood)?
[VL_DONE]   *Skip to next section, Usual care*

 No .... ☐ 0 ➡
Yes... ☐ 1
Refused to answer .... ☐ 77☐☐   *Skip to next section, Usual care*
Don't know... ☐ 88

A8a. When was your **last** HIV viral load count given to you? *[LASTVL]*

__ __ / __ __ __ __
(M M / Y Y Y Y)   *[Month: 77 = Refused to answer, 88= Don't know; Year: 7777 = Refused to answer, 8888 = Don't know]*

A8b. What was your **last** viral load count?
[USE RESPONSE CARD B.]
Below the level of detection, undetectable........................... ☐ 1
Detectable but less than 5,000 viral copies/ml .... ☐ 2
5,000 to 100,000 viral copies/ml .... ☐ 3
Greater than 100,000 viral copies/ml .... ☐ 4
Refused to answer .... ☐ 77
Don't know... ☐ 88

USUAL SOURCE OF HIV CARE

SAY: "Now I'm going to ask you some questions about the places where you get medical care for HIV. If you don't remember everything, that's okay. Tell me what you remember."

A9.   In the **past 7 months**, is there one place in particular, like a doctor's office or clinic where you **usually** go for most of your HIV care? HIV care may include T-cell tests, viral load tests, or prescriptions for HIV medicines? *[PLCARE]*
No .... ☐ 0   *Ask A.11, then skip to A14*
Yes... ☐ 1
Refused to answer .... ☐ 7
Don't know... ☐ 8   *Skip to A14*

A10. What is the name of this place? Remember, this information will be kept confidential.
Jackson Memorial SI Clinic .... ☐ 1

Jackson Memorial OB/Gyn clinic .... ☐ 2
PHT/North Dade Health Center .... ☐ 3
P.E.T. Center .... ☐ 4
Other 1 *(Specify:*_____)...... ☐ 5
Refused to answer .... ☐ 77
Don't know... ☐ 88

A10a. Did you get any sort of care at *[USE FACILITY NAME IN A12]* between *[USE TODAY'S DATE]* and *[USE TODAY'S DATE AND 7 MONTHS EARLIER]*? *[CAREPER1]*
No .... ☐ 0
Yes.. ☐ 1
Refused to answer .... ☐ 77
Don't know... ☐ 88

A10b. Between *[USE TODAY'S DATE]* and *[USE TODAY'S DATE AND 7 MONTHS EARLIER]*, how many times did you go to *[USE FACILITY NAME IN A12]* for any sort of care? *[TIMECAR]*

___ ___ ___   *[777 = Refused to answer, 888 = Don't know]*

A10c. Is your HIV provider the same race/ethnicity as you?
No .... ☐ 0
Yes.. ☐ 1

A10d. How long (in minutes) does it take you to arrive at the HIV clinic from where you stay?
___ ___ ___ *[777 = Refused to answer, 888 = Don't know]*

A11. In the **past 7 months**, have you been to any other doctor's office or clinic for your HIV care? If you were in jail or prison this includes any visits with doctors or nurses while you were there. *[OHEPRO]*
No .... ☐ 0 ➡ *Skip to A14*
Yes... ☐ 1
Refused to answer .... ☐ 7
Don't know... ☐ 8 } *Skip to A14*

A11a. What is the name of this place? _____

A11b. Between *[USE TODAY'S DATE]* and *[USE TODAY'S DATE AND 7 MONTHS EARLIER]*, how many times had you been to *[USE FACILITY NAME FROM A11a]* for any sort of care? *[TIMECAR]*
___ ___ ___ *[777 = Refused to answer, 888 = Don't know]*

A12. During the **past 7 months**, how many times did you go to an emergency room for care? (This would be visits made to the ER for care that did not lead to a hospital admission. Please don't include visits related to injuries such as accidents or other types of injuries.) *[ERVIS]*
___ ___ *[77=Refused to answer, 88=Don't know]*

A12a. What for?
_____

A13. During the **past 7 months**, how many times did you go to an urgent care center for care? (This would
be visits made to the urgent care center that did not lead to a hospital admission. Please don't include
visits related to injuries such as accidents or other types of injuries.) *[URCARVIS]*
___ ___ *[77=Refused to answer, 88=Don't know]*

A13a. What for?
_____

A14. During the **past 7 months**, how many times were you admitted to a hospital? (Please don't include
visits that were made only to the emergency room.)
[IF ZERO, SKIP TO A17] *[HOSP]*
___ ___ *[77=Refused to answer, 88=Don't know]*

A14a. What for?
_____

A15.   During the **past 7 months**, how many days total did you spend in a hospital?
___ ___   *[77=Refused to answer, 88=Don't know]*

A16.   During the **past 7 months**, were you admitted to a mental health facility?
No .... ☐ 0
Yes.. ☐ 1
Refused to answer .... ☐ 77
Don't know.. ☐ **88**

A17.   How many times have you been treated for any psychological or emotional problems?

A17a.   In a hospital   _____

A17b.   As an Outpatient or Private patient   _____

A18.   Do you receive a pension for a psychiatric disability?

0 - No

1 – Yes

A19.   Have you had a significant period, (that was not a direct result of drug/alcohol use), in which you have:

(Code: 0 – No, 1 – Yes for each of the following.)

		PAST 30 DAYS	IN YOUR LIFE
A19a.	Experienced serious depression		
A19b.	Experienced serious anxiety or tension		
A19c	Experienced hallucinations		
A19d.	Experienced trouble understanding, concentrating or remembering		
A19e.	Experienced trouble controlling violent behavior		
A19f.	Experienced serious thoughts of suicide		
A19g.	Attempted suicide		
A19h.	Been prescribed medication for any psychological emotional problem		

A20.   How many days in the past 30 have you experienced these psychological or emotional problems?   _____

A21. How much have you been troubled or bothered by these psychological or emotional problems in the past 30 days?

Not at all .... ☐ 0
Slightly .... ☐ 1
Moderately.. ☐ 2
Considerably... ☐ 3
Extremely .... ☐ 4
Refused to answer .... ☐ 7
Don't know... ☐ 8

A21. How important to you now is treatment for these psychological problems?

Not at all .... ☐ 0
Slightly .... ☐ 1
Moderately.. ☐ 2
Considerably... ☐ 3
Extremely .... ☐ 4
Refused to answer .... ☐ 7
Don't know... ☐ 8

A22. During the **past 7 months**, were you admitted to an inpatient drug or alcohol treatment facility? *[ADDRAL]*

No .... ☐ 0
Yes.. ☐ 1
Refused to answer .... ☐ 77
Don't know... ☐ 88

ANTIRETROVIRAL TREATMENT

SAY: "Next I would like to ask you some questions about medicines you may take to treat HIV infection.

A23. Have you **ever** taken any antiretroviral medicines to treat your HIV? These medicines are also known as ART, HAART, or the AIDS cocktail. Other pills to treat infections, such as Bactrim, are not antiretroviral medicines. *[ANTIRET]*

No……………………………………………….…… .... ☐ 0   ➤ ***Skip to A26***
Yes…………………………………….……….…...................... ☐ 1
Refused to answer…………………………….… .... ☐ 77   *Skip to A26*
Don't know…... ☐ 88

A24. Are you currently taking antiretroviral therapy (HIV medications)?

No .... ☐ 0   ➤ ***Skip to A27***
Yes.. ☐ 1
Refused to answer .... ☐ 77 ☐☐   *Skip to A27*
Don't know.. ☐ 88

A24a. How long have you been taking your current regimen? (*record responses in months*)

_____

A25. What are the **main ways** your prescription medicines for HIV and related illnesses were paid for in the **past 7 months**? *[CHECK ALL THAT APPLY. DON'T READ CHOICES.]*

Private health care coverage .... ☐ 1
I got my HIV medicines at a public clinic............................. ☐ 2
I paid for my HIV medicines myself ("out of pocket") .... ☐ 3
AIDS Drug Assistance Program (ADAP) .... ☐ 4
I participated in a clinical research trial or drug study that
    provided my medicines .... ☐ 5
An AIDS service organization provided me my medicines .. ☐ 6
Medicaid/Medicare... ☐ 7
Other 1 (*Specify:* _____) .... ☐ 8
Refused to answer .... ☐ 77
Don't know.. ☐ 88

> ***ONLY ASK THE FOLLOWING QUESTIONS IF PERSON HAS NEVER TAKEN ANTIRETROVIRAL MEDICATIONS***

A26. What are the reasons you have never taken any antiretroviral medicines?
[CHECK ALL THAT APPLY. DON'T READ CHOICES.]

Doctor advised to delay treatment.. ☐ 1
Participant believed he/she didn't need medications because

94

felt healthy or believed HIV laboratory results were good .. ☐ 2
Due to side Associations of medication .... ☐ 3
Felt depressed or overwhelmed .... ☐ 4
Didn't want to think about being HIV positive .... ☐ 5
Worried about ability to adhere .... ☐ 6
Drinking or using drugs .... ☐ 7
Money or insurance issues .... ☐ 8
Homeless .... ☐ 9
Taking alternative or complementary medicines .... ☐ 10 *[*
Other 1 *(Specify:*_____) ...... ☐ 11
Refused to answer .... ☐ 77
Don't know .... ☐ 88

A26a. What is the **main reason** you have never taken any antiretroviral medicines? I am going to read a list of the reasons you just gave me. Please tell me which of these was your main reason. *[CHECK ONLY ONE RESPONSE. READ RESPONSES GIVEN IN A26.]* *[MNANT8]*

Doctor advised to delay treatment .... ☐ 1
Participant believed he/she didn't need medications because
felt healthy or believed HIV laboratory results were good ... ☐ 2
Due to side Associations of medication .... ☐ 3
Felt depressed or overwhelmed .... ☐ 4
Didn't want to think about being HIV positive .... ☐ 5
Worried about ability to adhere .... ☐ 6
Drinking or using drugs .... ☐ 7
Money or insurance issues .... ☐ 8
Homeless .... ☐ 9
Taking alternative or complementary medicines .... ☐ 10
Other 1 (*Specify:*_____)...... ☐ 11 *[SMNANT81]*
Refused to answer .... ☐ 77
Don't know .... ☐ 88

A27. What are the reasons you aren't **currently** taking any antiretroviral medicines?
[CHECK ALL THAT APPLY. DON'T READ CHOICES.]

Doctor advised to delay or stop treatment .... ☐ 1   *[NANT8CA]*
Participant believed he/she didn't need medications because
felt healthy or believed HIV laboratory results were good ... ☐ 2   *[NANT8CB]*
Due to side Associations of medications .... ☐ 3   *[NANT8CC]*
Felt depressed or overwhelmed .... ☐ 4   *[NANT8CD]*
Didn't want to think about being HIV positive .... ☐ 5   *[NANT8CE]*
Worried about ability to adhere .... ☐ 6   *[NANT8CF]*
Drinking or using drugs .... ☐ 7   *[NANT8CG]*
Money or insurance issues .... ☐ 8   *[NANT8CH]*
Homeless .... ☐ 9   *[NANT8CI]*
Taking alternative or complementary medicines .... ☐ 10   *[NANT8CJ]*
Other 1 *(Specify:_____)* .... ☐ 11   *[NANT8CK]*
Refused to answer .... ☐ 77
Don't know .... ☐ 88

A27a. What is the **main reason** you aren't currently taking any antiretroviral medicines?
I am going to read a list of the reasons you just gave me. Please tell me which of these was your main reason. *[CHECK ONLY ONE RESPONSE. READ RESPONSES GIVEN IN A27.] [MNANT8C]*

Doctor advised to delay or stop treatment .... ☐ 1
Participant believed he/she didn't need medications because
  felt healthy or believed HIV laboratory results were good ☐ 2
Due to side Associations of medications .... ☐ 3
Felt depressed or overwhelmed .... ☐ 4
Didn't want to think about being HIV positive .... ☐ 5
Worried about ability to adhere .... ☐ 6
Drinking or using drugs .... ☐ 7
Money or insurance issues .... ☐ 8
Homeless .... ☐ 9
Taking alternative or complementary medicines .... ☐ 10
Other 1 (*Specify:*_____) .... ☐ 11 *[SMNAN8C1]*
Refused to answer .... ☐ 77
Don't know .... ☐ 88

UNMET NEEDS

> **SAY**: *"Now I am going to ask you some questions about your need for services related to HIV."*

In the **past 7 months**, have you needed any of these services: *[SHOW RESPONSE CARD D.]*

> *Interviewer instructions: If response to N1a is "No," "Refused to answer," or "Don't know", skip to N2a; otherwise, go to N1b. If response to N1b is "Yes," "Refused to answer," or "Don't know," skip to N2a; otherwise, go to N1c. Follow the same pattern for N1-N14.*

		[Needed this service in the past 7 months?]	If "Yes" in N1a-N14a, ask: Have you been able to get the service in the past 7 months?	If "No" in N1b-N14b, ask: What was the main reason you haven't been able to get this service?
		CODE: No = 0, Yes = 1, Refused to answer = 7, Don't know = 8	*CODE: No = 0, Yes = 1, Refused to answer = 7, Don't know = 8*	*CODE: SEE CODE LIST BELOW FOR RESPONSE [CHECK ONLY ONE. DON'T READ CHOICES.]*
N1.	HIV case management services *[HIVCMS][HIVCMS12][HIVCMSRS]*	a. [_____]	b. [_____]	c. [_____]
N2.	Mental health counseling *[MENCON][MENCON12][MENCONRS]*	a. [_____]	b. [_____]	c. [_____]
N3.	Social services, such as insurance assistance or financial counseling *[SOCSER][SOCSER12][SOCSERRS]*	a. [_____]	b. [_____]	c. [_____]
N4.	Assistance in finding a doctor for ongoing medical services *[DOCASS][ASSDOC12][ASSDOCRS]*	a. [_____]	b. [_____]	c. [_____]
N5.	Assistance in finding dental services *[DENSER][DENSER12][DENSERRS]*	a. [_____]	b. [_____]	c. [_____]
N6.	Adherence support services – Help managing medications *[ASS][ASS12][ASSRS]*	a. [_____]	b. [_____]	c. [_____]

		[Needed this service in the past 7 months?]	If "Yes" in N1a-N14a, ask: Have you be able to get th service in the past 7 months?	If "No" in N1b-N14b, ask: What was th main reason you haven't been able to get this service?
		CODE: No = 0, Yes = 1, Refused to answer = 7, Don't know =	CODE: No = 0, Yes = 1, Refused to answer = 7, Don't know = 8	CODE: SEE CODE LIST BELO FOR RESPONSE [CHECK ONLY ONE. DON'T REA CHOICES.]
N7.	Home health services, such as home nursing care or assistance [HHSASS][HHSASS12][HHSSERRS]	a. [_____]	b. [_____]	c. [_____
N8.	Chore or homemaker services (paid or volunteer) [HOMSER][HOMSER12][HOMSERRS]	a. [_____]	b. [_____]	c. [_____
N9.	Assistance in finding shelter or housing [SHLTER][SHLTER12][SHLTRRS]	a. [_____]	b. [_____]	c. [_____
N10.	Assistance with finding meals or food [MLSFOD][MLSFOD12][MLSFODRS]	a. [_____]	b. [_____]	c. [_____
N11.	Transportation assistance [TRSASS][TRSASS12][TRSSERRS]	a. [_____]	b. [_____]	c. [_____
N12.	Childcare services [CHLDCR][CHLDCR12][CHDCARRS]	a. [_____]	b. [_____]	c. [_____
N13.	Education or information on HIV risk reducti [HIVEDU][HIVEDU12][HIVEDURS]	a. [_____]	b. [_____]	c. [_____
N14.	Other (Specify:_____) [OTHSERNM][OTHSER12][OTHSERRS]	a. [_____]	b. [_____]	c. [_____

Interviewer instructions: For N1c-N14c: [ENTER ONLY ONE RESPONSE. DON'T READ CHOICES.]

1	I don't know where to go or who to call	8	Transportation problems
2	Didn't complete application process	9	Language barrier
3	The system is too confusing	10	Not eligible / denied services
4	The waiting list is too long	11	I'm too sick to get out
5	It isn't available in my area	12	Other (*Specify:* _____)

DRUG AND ALCOHOL USE HISTORY

INJECTION DRUG USE

> **SAY***:* "The next questions are about drug and alcohol use. Please remember your answers will be kept confidential and that you can refuse to answer any question you are not comfortable with. First I'm going to ask you about injection drug use. This means injecting drugs yourself and/or having someone who isn't a health care provider inject you."

U1.   Have you ever shot up or injected any drugs that weren't prescribed for you? By shooting up, I mean anytime you might have used drugs with a needle, either by mainlining, skin popping or muscling. *[EVERINJ]*

No .... ☐ 0   ➡ *Skip to Say box before U8*
Yes... ☐ 1
Refused to answer .... ☐ 7 ☐☐   *Skip to Say box before U8*
Don't know.. ☐ 8

U2.   When was the last time you shot up or injected any drugs (that weren't used for medical purposes)? *[LASTINJ]*

__ __ / __ __ __ __
(M M / Y Y Y Y)   *[Month: 77 = Refused to answer, 88= Don't know;*
                         Year: 7777 = Refused to answer, 8888 = Don't know]

> *Interviewer instructions: If date in U2 is greater than 7 months from the interview date, skip to Say box before U8; otherwise, go to Say box before U3.*

U3.How often did you inject: *[CHECK ONLY ONE RESPONSE PER TYPE OF DRUG. USE RESPONSE CARD E. READ EACH DRUG CHOICE.]*

	Didn't use	More than once a day	More than Once a day	More than Once a week	once a week	More than Once a month	Once a month	Less than once a month	Once a month	Ref Don't Know
a. Heroin and cocaine together (speedballs) **[HERCOC]**	□1	□2	□3	□4	□5	□6	□7	□8	□77	□88
b. Heroin alone………. **[HEROIN]**	□1	□2	□3	□4	□5	□6	□7	□8	□77	□88
c. Cocaine alone………**[COCAINE]**	□1	□2	□3	□4	□5	□6	□7	□8	□77	□88
d. Crack……………….**[CRACK]**	□1	□2	□3	□4	□5	□6	□7	□8	□77	□88
e. Methamphetamines (crystal, meth, tina, crank, ice) **[CRAMTCI]**	□□1	□2	□3	□4	□5	□6	□7	□8	□77	□88
f. Other amphetamines **[AMPHETA]**	□1	□2	□3	□4	□5	□6	□7	□8	□77	□88
g. Oxycontin………..…**[OXYCON]**	□1	□2	□3	□4	□5	□6	□7	□8	□77	□88
h. Steroids/hormones… **[STRHRM]**	□1	□2	□3	□4	□5	□6	□7	□8	□77	□88
i. Other injected drug.… **[OINJDRY]**	□1	□2	□3	□4	□5	□6	□7	□8	□77	□88

   (Specify: _____) [OINJDR]

> **SAY***:* **"**Now I'm going to ask you about alcohol and drugs that you may have used <u>but did not inject</u>. I will refer to these as non-injection drugs. This includes drugs like marijuana, crystal, cocaine, crack, club drugs, painkillers, or poppers. Again, we are interested in drugs that were no prescribed for you."

U4.   In the **past 7 months**, have you used alcohol or any non-injection drugs? *[ANID12]*

No .... ☐ 0

Yes .... ☐ 1 ➡ ***Skip to Say box before U5***

Refused to answer .... ☐ 7☐☐

Don't know .... ☐ 8

> *SAY:* The next few questions ask about the past 30 days, rather than the **past 7 months**.

U5.   During the **past 30 days**, on how many days did you have a drink containing alcohol? *[DRINK]*

___ ___   *[Refused to answer = 77, Don't know = 88]*

> *Inconsistency check: U5 (number of days the respondent had an alcoholic drink during the past 30 days) cannot be greater than 30.*

> *Interviewer instructions: If U5 is "0," "Refused to answer," "Don't know," skip to Say box before U9.*

U6.   During the **past 30 days**, how many drinks did you have on a **typical** day when you were drinking? By a drink I mean a can of beer, a glass of wine or a shot of hard liquor. *[NDRINK]*

___ ___   *[Refused to answer = 77, Don't know = 88]*

> *Inconsistency check: U6 (number of drinks on a typical day during the past 30 days) cannot greater than 30.*

> *Interviewer instructions: If DEMOGRAPHICS D3 (gender) is "Female" skip to U8.*

U7. On how many days in the **past 30 days** did you have 5 or more drinks? *[DRINK5]*
___ ___   *[Refused to answer = 77, Don't know = 88]*

> *Inconsistency check: U7 (number of days the respondent had 5 or more drinks during the past 30 days) cannot be greater than 30.*

> *Interviewer instructions: After recording response, skip to Say box before U9.*

U8. On how many days in the **past 30 days** did you have 4 or more drinks? *[DRINK4]*

___ ___   *[Refused to answer = 77, Don't know = 88]*

> *Inconsistency check: U8 (number of days the respondent had 4 or more drinks during the past 30 days) cannot be <u>greater</u> than 30.*

> **SAY***:* "I'm going to read you a list of drugs, including alcohol. For each one I mention, please tell me how often you used it in the **past 7 months**. **Don't** include drugs you injected or drugs that were used for medical purposes."

U9. How often did you use: *[CHECK ONLY ONE RESPONSE PER TYPE OF DRUG. USE RESPONSE CARD E. READ EACH DRUG CHOICE.]*

	Didn't use	More than once a day	More than Once a day	More than once a week	More than once a week	Once a month	Less than once a month	Once a month	Ref Don't once a Know

a. Alcohol…………….………☐1 .... ☐2...... ☐3 ...... ☐4 ...... ☐5 .... ☐6 ...... ☐7 ...... ☐8 ...... ☐77 ☐88
[ALCOHOL]

> *Inconsistency check: U9 cannot be "didn't use alcohol" if U5 is "1" or greater than 1.*

b. Methamphetamines (crystal,
meth, tina, crank, ice)……☐☐1☐2.. ☐3 ...... ☐4 ...... ☐5 ...... ☐6 .... ☐7 ...... ☐8 ...... ☐77 .... ☐88
[CRYMTCI]

c. Other amphetamines…..……☐1☐2........ ☐3 ...... ☐4 ...... ☐5 .... ☐6 ...... ☐7 ...... ☐8 ...... ☐77 ☐88
[AMPHETA1]

d. Crack …………….…………☐1☐2......... ☐3 ...... ☐4 ...... ☐5 .... ☐6 ...... ☐7 ...... ☐8 ...... ☐77 ☐88
[CRACK1]

e. Cocaine that is smoked
   or snorted…………….…....☐1☐2........ ☐3 ...... ☐4 ...... ☐5 .... ☐6 ...... ☐7 ...... ☐8 ...... ☐77 ☐88
[COCSMO]

f. Downers such as Valium,
   Ativan, or Xanax…………..☐1☐2.......... ☐3 ...... ☐4 ...... ☐5 .... ☐6 ...... ☐7 ...... ☐8 ...... ☐77 ☐88
[DOWNERS]

g. Painkillers such as Oxycontin,

Vicodin, or Percocet...…… ☐1☐2.......... ☐3...... ☐4...... ☐5........... ☐6...... ☐7...... ☐8...... ☐77 ☐88

[PAINKILL]

h. Hallucinogens such as LSD
  or mushrooms……….…… ☐1☐2.......... ☐3...... ☐4...... ☐5........... ☐6...... ☐7...... ☐8 ☐77.... ☐88

[HALLUC]

i. X or Ecstasy……………….. ☐1☐2.......... ☐3...... ☐4...... ☐5........... ☐6...... ☐7...... ☐8...... ☐77 ☐88

[XECT]

	Didn't use	More than once a day	More than Once a day Ref	More than once a week Once week Don't	Less than Once a month week	Once a once a month month	Once a month

(once a Know)

j. Special K (ketamine)………...☐1☐2......... ☐3...... ☐4...... ☐5........... ☐6...... ☐7...... ☐8...... ☐77 ☐88

[SPECK]

k. GHB……………………… ☐1☐2.......... ☐3...... ☐4...... ☐5........... ☐6...... ☐7...... ☐8...... ☐77 ☐88

[GHB]

l. Heroin/opium that is
  smoked or snorted…….. .... …...☐1☐2...... ☐3...... ☐4...... ☐5........... ☐6...... ☐7...... ☐8...... ☐77 ☐88

[HEROINS]

m. Marijuana………………. ☐1☐2.......... ☐3...... ☐4...... ☐5........... ☐6...... ☐7...... ☐8...... ☐77 ☐88

[MARIJU]

n. Poppers (amyl nitrate)....... ☐1☐2.......... ☐3...... ☐4...... ☐5........... ☐6...... ☐7...... ☐8...... ☐77 ☐88

[POPPERS]

o. Steroids/Hormones............ ☐1☐2.......... ☐3...... ☐4...... ☐5........... ☐6...... ☐7...... ☐8...... ☐77 ☐88

[STRHORMS]

U9p. Did you use any other non-injection drugs that I haven't asked about? *[ONINJDY]*

No .... ☐ 0
Yes... ☐ 1
Refused to answer .... ☐ 7
Don't know.. ☐ 8

U9q. What other drug did you use? (*Specify:* _____) *[ONINJDR]*

U9r. How often did you use _____ *[RESPONSE TO U9q]*?

	once a **Know**	**Didn't** **use**	**More than once a day**	**More than Once a day**	**Once a week**	**once a week**	**More than Once a month**	**Once a month**	**Less than once a month**	**Once a month**	**Ref** **Don't**
Other drug…………….........	☐88	☐1	☐2	☐3	☐4	☐5	☐6	☐7	☐8	☐77	

[ONINJDRH]

106

DISCLOSURE

[*Interviewer read to participant:*] **We are trying to understand which people you are close to, and to figure out who does and does not know about your HIV infection. I am going to ask you about certain people in your life to whom you may have told about your HIV infection.**

DSC1.	Have you told your <u>spouse/significant other</u> that you have HIV? *[t#.dsc1]*	□0No	*	□1Yes	□9N/A
DSC2.	Have you told your <u>mother</u> that you have HIV? *[t#.dsc2]*	□0No	*	□1Yes	□9N/A
DSC3.	Have you told your <u>father</u> that you have HIV? *[t#.dsc3]*	□0No	*	□1Yes	□9N/A
DSC4.	Have you told any of your <u>other family members</u> that you have HIV? *[t#.dsc4]*	□0No	*	□1Yes	□9N/A

How many of … _____ … have you told that you have HIV?

		None	Some	All	N/A
DSC5.	…Your children…*[t#.dsc5]*	□0	□1	□2	□9
DSC6.	…Your brothers…*[t#.dsc6]*	□0	□1	□2	□9
DSC7.	…Your sisters…*[t#.dsc7]*	□0	□1	□2	□9
DSC8.	…Your other family members…*[t#.dsc8]*	□0	□1	□2	□9
DSC9.	…Your friends…*[t#.dsc9]*	□0	□1	□2	□9
DSC10.	…Your colleagues / the people you work with…*[t#.dsc10]*	□0	□1	□2	□9

Attitudes Toward Health Care Providers Scale

[*Interviewer: read aloud to participant*] **I am going to read some statements to you and then ask to tell me how strongly you agree (a score or 6) or disagree (a score of 1) that best describes how you feel about it.** *Medical team* **includes the doctor, nurses, dietician, social worker and any other medical staff member you interact with at the clinic.**

1. I believe that my medical team is knowledgeable about HIV/AIDS. *[t#.athcps_1]*

Strongly Disagree					Strongly Agree
1	2	3	4	5	6

2. My medical team puts an effort into my treatment. *[t#.athcps_2]*

Strongly Disagree					Strongly Agree
1	2	3	4	5	6

3. I believe my medical team is motivated to help me. *[t#.athcps_3]*

Strongly Disagree					Strongly Agree
1	2	3	4	5	6

4. My medical team cares about my health. *[t#.athcps_4]*

Strongly Disagree					Strongly Agree
1	2	3	4	5	6

5. I believe my medical team knows a lot about HIV drugs. *[t#.athcps_5]*

Strongly Disagree					Strongly Agree
1	2	3	4	5	6

6. I believe I receive the best available health care. *[t#.athcps_6]*

Strongly Disagree					Strongly Agree
1	2	3	4	5	6

7. My medical team is lazy. *[t#.athcps_7]*

Strongly Disagree					Strongly Agree
1	2	3	4	5	6

8. My medical team is knowledgeable about new HIV treatments. *[t#.athcps_8]*

Strongly Disagree					Strongly Agree
1	2	3	4	5	6

9.   I believe that my medical team cares about me. *[t#.athcps_9]*

Strongly   Strongly
Disagree   Agree
   1   2   3   4   5   6

10. My medical team supports me. *[t#.athcps_10]*

Strongly   Strongly
Disagree   Agree
   1   2   3   4   5   6

11. My medical team encourages me. *[t#.athcps_12]*

Strongly   Strongly
Disagree   Agree
   1   2   3   4   5   6

12. My medical team is helpful. *[t#.athcps_12]*

Strongly   Strongly
Disagree   Agree
   1   2   3   4   5   6

13. My medical team makes me feel comfortable. *[t#.athcps_13]*

Strongly   Strongly
Disagree   Agree
   1   2   3   4   5   6

14. The medical team spends enough time with me. *[t#.athcps_14]*

Strongly   Strongly
Disagree   Agree
   1   2   3   4   5   6

15. My medical team is sensitive to how I feel. *[t#.athcps_15]*

Strongly   Strongly
Disagree   Agree
   1   2   3   4   5   6

16. My medical team thinks I am a bad person because I have HIV. *[t#.athcps_16]*

Strongly   Strongly
Disagree   Agree
   1   2   3   4   5   6

17. My medical team cares about my opinion. *[t#.athcps_17]*

Strongly   Strongly
Disagree   Agree
   1   2   3   4   5   6

18. I believe that my medical team sees me as stupid. *[t#.athcps_18]*

Strongly   Strongly
Disagree   Agree
     1   2   3   4   5   6

19. My medical team judges me. *[t#.athcps_19]*
Strongly   Strongly
Disagree   Agree
     1   2   3   4   5   6

ENGAGEMENT WITH HEALTHCARE PROVIDER SCALE

[*Interviewer: Read aloud to participant*] **The next questions I will ask you are about your relationship with your HIV doctor. Please tell me on a scale from 1 to 4, with 1 = always, 2=usually, 3=sometimes, & 4=never, how well each of these statements fit how you feel about your relationship with your HIV doctor.**

My doctor…

	Always	**usually**	**sometimes**	**never**
a. Listens to me *[t#.ehps_a]*	1	2	3	4
b. Cares about me *[t#.ehps_b]*	1	2	3	4
c. Answers my questions *[t#.ehps_c*	1	2	3	4
d. Spends enough time with me *[t#.ehps_d]*	1	2	3	4
e. Involves me in decisions *[t#.ehps_e]*	1	2	3	4
f. Respects my choices *[t#.ehps_f]*	1	2	3	4
g. Deals with my problems *[t#.ehps_g]*	1	2	3	4
h. Engages me in my care *[t#.ehps_*	1	2	3	4
i. Is helpful to me *[t#.ehps_i]*	1	2	3	4
j. Respects me *[t#.ehps_j]*	1	2	3	4
k. Supports my decisions *[t#.ehps_*	1	2	3	4
l. Sees me when I ask *[t#.ehps_l]*	1	2	3	4
m. Provides me with information *[t#.ehps_m]*	1	2	3	4

HIV Stigma Scale

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement. Circle **one** number on each line.

		Not at All	Rarely	Sometimes	Often
1	I felt blamed by others for my illness.	1	2	3	4
2	I felt ashamed of my illness.	1	2	3	4
3	I thought my illness was a punishment for things I've don in the past.	1	2	3	4
4	I feared that I might lose my jo if someone found out about my illness.	1	2	3	4
5	I felt compelled to change my residence because of my illnes	1	2	3	4
6	I avoided getting treatment because someone might find ot about my illness.	1	2	3	4
7	I feared that people would hurt my family if they learned abou my illness.	1	2	3	4
8	I thought other people were uncomfortable being with me.	1	2	3	4
9	I felt people avoid me because my illness.	1	2	3	4
10	I feared I would lose my friend if they learned about my illnes	1	2	3	4
11	I feared my family would rejec me if they learned about my illness	1	2	3	4
12	I felt I wouldn't get as good health care if people knew abo my illness.	1	2	3	4
13	People who know I am HIV positive treat me with kid glov	1	2	3	4

APPENDIX 2: MEDICAL RECORD ABSTRACTION FORM

MEDICAL RECORDS DATA:

Date of baseline interview: _____

Date of T1 interview (7 months <u>after</u> baseline interview): _____

APPOINTMENTS

	Date of Appointment	Appointment Type	State of Appointment
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			
11			
12			
13			
14			
15			
16			
17			
18			
19			
20			
21			
22			
23			

24		
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31		
32		
33		
34		
35		
36		
37		
38		
39		
40		
41		
42		
43		

MR1. Number of appointments scheduled for medical doctor: _____

MR2. Number of "no-shows" to medical doctor appointments: _____

MR3. Number of appointments scheduled for lab tests: _____

MR4. Number of "no-shows" to medical lab test appointments: _____

MR5. Total number of scheduled appointments (MR1 + MR3): _____

MR6. Total number of "no-showed" appointments (MR2 + MR4): _____

LAB RESULTS

MR7. CD4 cell count baseline: _____

MR7a. Date of CD4 cell count at baseline: _____

MR8. CD4 cell count at T1: _____

MR8a. Date of CD4 cell count at T1: _____

MR9. Viral load baseline: _____

MR9a. Date of Viral load at baseline: _____

MR10. Viral load at T1: _____

MR10a. Date of Viral load at T1: _____

MR 11. Did CD4 count drop below 200 during 7 month follow-up?

    0   no
    1   yes

EMERGENCY ROOM SERVICES

	Date of ER Visit	Reason for ER Visit	State of ER Visit *Code 0 = Discharged from ER* *Code 1 = Admitted to Hospital*	HIV Related? *Code 0 = Not HIV Related* *Code 1 = HIV Relat*
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				
21				
22				
23				
24				
25				

MR12. Did participant use the ER during the 7 month follow-up period?

      0   no
      1   yes

MR12a. If yes, how many times were ER services used during the 7 month follow-up period? ___
_____

HOSPITALIZATION

	Date of Hospitalization	Reason for Hospitalizati	Medical Service	Number of Days Hospitalized
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				
21				
22				
23				
24				
25				

MR13. Was the participant hospitalized during the 7 month follow-up period?

    0   no

    1   yes

MR13a. If yes, How many days was the participant hospitalized during the 7 month follow-up period? _____

INSURANCE

MR14. Type of health insurance/how services are paid.

    A. Ryan White

    B. SFAN

    C. Private Insurance

    D. Medicaid

    E. Medicare

    F. No coverage

Mental Health Visits

	Date of Appointment	Appointment Type	State of Appointment
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			
11			
12			
13			
14			
15			
16			
17			
18			
19			
20			
21			
22			
23			
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27			

28			
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30			
31			
32			
33			
34			
35			
36			
37			
38			

MR15. Did the participant use mental health services during retrospective?

       2   no

       1   yes

MR15a. Number of appointments scheduled for mental health services: _____

MR16. Number of "no-shows" to mental health appointments: _____

REFERENCES

1.   Sayles JN, Ryan GW, Silver JS, Sarkisian CA, Cunningham WE. Experiences of social stigma and implications for healthcare among a diverse population of HIV positive adults. J Urban Health 2007; 84(6):814–28.

2.   Rintamaki LS, Davis TC, Skripkauskas S, et al. Social stigma concerns and HIV medication adherence. IDS Patient Care STDS 2006;20(5):359–68.

3.   Vanable PA, Carey MP, Blair DC, Littlewood RA. Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. AIDS Behav. 2006; 10(5):473–82.

4.   Prachakul W, Grant JS, Keltner NL. Relationships among functional social support, HIV-related stigma, social problem solving, and depressive symptoms in people living with HIV: a pilot study. J Assoc Nurses AIDS Care. 2007; 18(6):67–76.

5.   Link B; Struening E; Dohrenwend B; Cullen, F; Shrout P. Modified Labeling Theory Approach to Mental Disorders: An Empirical Assessment. American Sociological Review; Jun 1989; 54, 3

6.   White House Office of National AIDS Policy. National HIV/AIDS strategy for the United States. http://aids.gov/federal-resources/national-hiv-aids-strategy/nhas.pdf. Published July 2010. Accessed February 4, 2013.

7.   Health Resources and Services Administration. Outreach: engaging people in HIV care: summary of a HRSA/HAB 2005 consultation on linking PLWH into care. August 2006. Accessed February 4, 2013.

8.   Gardner E, McLees M, Steiner J, et al. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV Infection. Clin Infect Dis. 2011;52:793- 800.

9.   Marks G, Gardner LI, Craw J, Crepaz N. Entry and retention in medical care among HIV-diagnosed persons: a meta-analysis. AIDS. 2010 Nov 13;24(17):2665-78.

10.   Centers for Disease Control and Prevention. Vital Signs: HIV Prevention through Care and Treatment — United States. MMWR 2011;60:(1618-1623).

11.   Centers for Disease Control and Prevention. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas—2012. HIV Surveillance Supplemental Report 2014;19(No. 3).

12.   Paltiel AD, Walensky RP, Schackman BR, et al. Expanded HIV screening in the United States: Association on clinical outcomes, HIV transmission, and costs. Ann Intern Med 2006;145(11):797-806.

13.   Smit C, Hallett TB,Lange J, Garnett G, de WF. Late entry to HIV care limits the impact of anti-retroviral therapy in The Netherlands. PLoS One 2008;3(4):e1949.

14.   Parienti JJ, Massari V, Descamps D, et al. Predictors of virologic failure and resistance in HIV-infected patients treated with nevirapine- or efavirenz-based antiretroviral therapy. Clin Infect Dis 2004; 38:1311–6.

15.   Mugavero MJ, Lin HY, Willig JH, et al. Missed visits and mortality among patients establishing initial outpatient HIV treatment. Clin Infect Dis 2009; 48:248–56.

16.   Coleman S, Rajabiun S, Cabral H, Bradford J, and Tobias C. AIDS Patient Care and STDs. August 2009, 23(8): 639-645. doi:10.1089/apc.2008.0092.

17.   Metsch LR, Pereyra M, Messinger S, et al. HIV transmission risk behaviors among HIV-infected persons who are successfully linked to care. Clin Infect Dis. 2008;47(4):577–84.

18.   Skarbinski J, Rosenberg E, Paz-Bailey G, Hall I, Rose C, Viall A, Fagan J, Lansky A, Mermin J. Human Immunodeficiency Virus Transmission at Each Step of the Care Continuum in the United States. JAMA Internal Medicine, 2015; DOI: 10.1001/jamainternmed.2014.8180

19.   Montaner JS1, Lima VD, Barrios R, Yip B, Wood E, Kerr T, Shannon K, Harrigan PR, Hogg RS, Daly P, Kendall P. Association of highly active antiretroviral therapy coverage, population viral load, and yearly new HIV diagnoses in British Columbia, Canada: a population-based study. Lancet. 2010 Aug 14;376(9740):532-9.

20.   Institute of Medicine. Access to health care in America. Wash¬ington, DC: National Academies Press; 1993. Available from: www.nap.edu/catalog.php?record_id=2009. Accessed February 3, 2013.

21.   Goldstein RB, Rotheram-Borus MJ, Johnson MO, et al. Insurance coverage, usual source of care, and receipt of clinically indicated care for comorbid conditions among adults living with human immunodeficiency virus. Med Care. 2005;43(4):401–10.

22.   Williams B, Amico KR, Konkle-Parker D. Qualitative assessment of barriers and facilitators to HIV treatment. J Assoc Nurses AIDS Care. 2011;22(4):307–12.

23.   Andersen M, Hockman E, Smereck G, et al. Retaining women in HIV medical care. J Assoc Nurses AIDS Care. 2007;18(3):33–41.

24.   Giordano TP, Gifford AL, White AC Jr., et al. Retention in care: a challenge to survival with HIV infection. Clin Infect Dis 2007; 44:1493–9. 33.

25.   Mugavero MJ, Norton WE, Saag MS. Health care system and policy factors influencing engagement in HIV medical care: piecing together the fragments of a fractured health care Delivery System. Clin Infect Dis. 2011;52 Suppl 2:S238–46.

26.   Cabral HJ, Tobias C, Rajabiun S, et al. Outreach program contacts: do they increase the likelihood of engagement and retention in HIV primary care for hard-to-reach patients? AIDS Patient Care STDS. 2007;21 Suppl 1:S59–67.

27.   Ulett KB, Willig JH, Lin HY, et al. The therapeutic implications of timely linkage and early retention in HIV care. AIDS Patient Care STDS. 2009;23(1):41–9.

28.   Magnus M, Jones K, Phillips G, et al. Characteristics associated with retention among African American and Latino adolescent HIV-positive men: results from the outreach, care, and prevention to engage HIV-seropositive young MSM of color special project of national significance initiative. J Acquir Immune Defic Syndr.2010;53(4):529–36.

29.   Marx KA, Malka ES, Ravishankar J, Schwartz RM. Measurement of retention in care among adults infected with HIV in an urban clinic. AIDS Care. 2011;23(10):1298–304.

30.   Catz SL, McClure JB, Jones GN, Brantley PJ. Predictors of outpatient medical appointment attendance among persons with HIV.AIDS Care. 1999;11(3):361–73.

31.   Stein MD, Crystal S, Cunningham WE, et al. Delays in seeking HIV care due to competing caregiver responsibilities. Am J Public Health. 2000;90(7):1138–40.

32.   Tobias CR, Cunningham W, Cabral HD, et al. Living with HIV but without medical care: barriers to engagement. AIDS Patient Care STDS. 2007;21(6):426–34.

33.   Bakken T. Constitutional and social equality: legacies and limits of law, politics and culture. Indian J Gend Stud. 2000;7(1):71–82.

34.   Cunningham CO, Sohler NL, Korin L, Gao W, Anastos K. HIVstatus, trust in health care providers, and distrust in the health care system among Bronx women. AIDS Care. 2007;19(2):226–34.

35.   Kalichman SC, Graham J, LukeW. Perceptions of health care among persons living with HIV/AIDS who are not receiving antiretroviral medications. AIDS Patient Care STDS. 2002;16(5):233–40.

36.   Aidala AA, Lee G, Abramson DM, Messeri P, Siegler A. Housing need, housing assistance, and connection to HIV medical care. AIDS Behav. 2007;11 Suppl 6:101–15.

37.   Smith MY, Rapkin BD, Winkel G, Springer C, Chhabra R, Feldman IS. Housing status and health care service utilization among low-income persons with HIV/AIDS. J Gen Intern Med. 2000;15(10):731–8.

38.   Goffman E. Stigma: Notes on the Management of Spoiled Identity. Garden City, NY: Anchor Books; 1963.

39.   Link, B; Phelan, J. Conceptualizing Stigma. Annu. Rev. Sociol. 2001. 27:363–85

40.   Link B, Struening E, Dohrenwend B, Cullen P, Francis T, Shrout P. A Modified Labeling Theory Approach to Mental Disorders: An Empirical Assessment. American Sociological Review; Jun 1989; 54, 3; ProQuest, pg. 400-423.

41.   Scheff T. 1966. Beinf Mentally Ill: A Sociological Theory. 2nd Edition. Chicago: Aldine

42.   Eaton LA1, Driffin DD, Kegler C, Smith H, Conway-Washington C, White D, Cherry C. The role of stigma and medical mistrust in the routine health care engagement of black men who have sex with men. Am J Public Health. 2015 Feb;105(2):e75-82. doi: 10.2105/AJPH.2014.302322.

43.   Layer EH, Kennedy CE, Beckham SW, Mbwambo JK, Likindikoki S, Davis WW, Kerrigan DL, Brahmbhatt H; LTC Tanzania Collaborative Study Team. Multi-level factors affecting entry into and engagement in the HIV continuum of care in Iringa, Tanzania. PLoS One. 2014 Aug 13;9(8):e104961. doi: 10.1371/journal.pone.0104961. eCollection 2014.

44.   Magnus M, Herwehe J, Murtaza-Rossini M, Reine P, Cuffie D, Gruber D, Kaiser M. Linking and retaining HIV patients in care: the importance of provider attitudes and behaviors. AIDS Patient Care STDS. 2013 May;27(5):297-303.

45.   Mugavero MJ, Davila JA, Nevin CR, Giordano TP. From access to engagement: measuring retention in outpatient HIV clinical care. AIDS Patient Care STDS. 2010 Oct;24(10):607-13.

46.   Mugavero MJ, Westfall AO, Zinski A, Davila J, Drainoni ML, Gardner LI, Keruly JC, Malitz F, Marks G, Metsch L, Wilson TE, Giordano TP; Retention in Care (RIC) Study Group. Measuring retention in HIV care: the elusive gold standard. J Acquir Immune Defic Syndr. 2012 Dec 15;61(5):574-80.

47.   Horstmann E, Brown J, Islam F, Buck J, Agins BD. Retaining HIV-infected patients in care: Where are we? Where do we go from here? Clin Infect Dis. Mar 1; 2010 50(5):752–761.

48.   Mugavero MJ, Westfall AO, Cole SR, Geng EH, Crane HM, Kitahata MM, Mathews WC, Napravnik S, Eron JJ, Moore RD, Keruly JC, Mayer KH, Giordano TP, Raper JL; Centers for AIDS Research Network of Integrated Clinical Systems (CNICS). Beyond core indicators of retention in HIV care: missed clinic visits are independently associated with all-cause mortality. Clin Infect Dis. 2014 Nov 15;59(10):1471-9. doi: 10.1093/cid/ciu603.

49.   Park WB, Choe PG, Kim SH, et al. One-year adherence to clinic visits after highly active antiretroviral therapy: a predictor of clinical progress in HIV patients. J Intern Med. Mar; 2007. 261(3):268–275.

50.   Turner BJ, Cunningham WE, Duan N, et al. Delayed medical care after diagnosis in a US national probability sample of persons infected with human immunodeficiency virus. Arch Intern Med.2000;160(17):2614–22.

51.   Cree M, Bell NR, Johnson D, Carriere KC. Increased continuity of care associated with decreased hospital care and emergency department visits for patients with asthma. Dis Manag 2006;9(1):63-71.

52.   Gill JM, Mainous AG III, Nsereko M. The Association of continuity of care on emergency department use. Arch Fam Med 2000;9(4):333-338.

53.   Wolf HT, Halpern-Felsher BL, Bukusi EA, Agot KE, Cohen CR, Auerswald CL. "It is all about the fear of being discriminated [against]…the person suffering from HIV will not be accepted": a qualitative study exploring the reasons for loss to follow-up among HIV-positive youth in Kisumu, Kenya. BMC Public Health. 2014 Nov 6;14:1154. doi: 10.1186/1471-2458-14-1154.

54.   Valenzuela C, Ugarte-Gil C, Paz J, Echevarria J, Gotuzzo E, Vermund SH, Kipp AM. HIV Stigma as a Barrier to Retention in HIV Care at a General Hospital in Lima, Peru: A Case-Control Study. AIDS Behav. 2015 Feb;19(2):235-45. doi: 10.1007/s10461-014-0908-7.

55.   Dasgupta S, Sullivan PS, Dasgupta A, Saha B, Salazar LF. Stigma and Access to HIV Care among HIV-Infected Women in Kolkata, West Bengal. J Int Assoc Provid AIDS Care. 2013 Feb;12(1):44-9. doi: 10.1177/1545109711401410.

56.   Earnshaw VA, Smith LR, Chaudoir SR, Amico KR, Copenhaver MM. HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. AIDS Behav. 2013;17(5): 1785–95.

57.   Wohl AR, Galvan FH, Myers HF, Garland W, George S, Witt M, Cadden J, Operskalski E, Jordan W, Carpio F, Lee ML. Do social support, stress, disclosure and stigma influence retention in HIV care for Latino and African American men who have sex with men and women? AIDS Behav. 2011 Aug;15(6):1098-110.

58.   Dietz E, Clum GA, Chung S-E, et al. Adherence to scheduled appointments among HIV-infected female youth in five US cities. J Adolesc Health. 2010;46(3):278–83.

59.   Naar-King S1, Bradford J, Coleman S, Green-Jones M, Cabral H, Tobias C. Retention in care of persons newly diagnosed with HIV: outcomes of the Outreach Initiative. AIDS Patient Care STDS. 2007;21 Suppl 1:S40-8.

60.   Lifson AR, Demissie W, Tadesse A, Ketema K, May R, Yakob B, Metekia M, Slater L, Shenie T. Barriers to Retention in Care as Perceived by Persons Living with HIV in Rural Ethiopia: Focus Group Results and Recommended Strategies. J Int Assoc Provid AIDS Care. 2013 Feb;12(1):32-8.

61.   Smith LR, Fisher JD, Cunningham CO, Amico KR. Understanding the behavioral determinants of retention in HIV care: a qualitative evaluation of a situated information, motivation, behavioral skills model of care initiation and maintenance. AIDS Patient Care STDS. 2012 Jun;26(6):344-55.

62.   Kempf MC, McLeod J, Boehme AK, Walcott MW, Wright L, Seal P, Norton WE, Schumacher JE, Mugavero M, Moneyham L. 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. 2010 Aug;24(8):515-20.

63.   Rajabiun S, Mallinson RK, McCoy K, Coleman S, Drainoni ML, Rebholz C, Holbert T. "Getting me back on track": the role of outreach interventions in engaging and retaining people living with HIV/AIDS in medical care. AIDS Patient Care STDS. 2007;21 Suppl 1:S20-9. 14

64.   Tomori C1, Kennedy CE, Brahmbhatt H, Wagman JA, Mbwambo JK, Likindikoki S, Kerrigan DL. Barriers and facilitators of retention in HIV care and treatment services in Iringa, Tanzania: the importance of socioeconomic and sociocultural factors. AIDS Care. 2014;26(7):907-13. doi: 10.1080/09540121.2013.861574.

65.   Pecoraro A, Royer-Malvestuto C, Rosenwasser B, Moore K, Howell A, Ma M, Woody GE. Factors contributing to dropping out from and returning to HIV treatment in an inner city primary care HIV clinic in the United States. AIDS Care. 2013 Feb 21.

66.   Berger BE. Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. Res Nurs Health. 2001;24(6): 518-529

67.   Sayles JN, Wong MD, Kinsler JJ, Martins D, Cunningham WE. The association of stigma with self-reported access to medical care and antiretroviral therapy adherence in persons living with HIV/AIDS. J Gen Intern Med. 2009 Oct;24(10):1101-8.

68.   Emlet, C. (2005). Measuring stigma in older and younger adults with HIV/AIDS: An analysis of an HIV stigma scale and initial exploration of subscales. Research on Social Work Practice, 15, 291–300.

69.   Zimmerman M, Farber NJ, Hartung J, Lush DT, Kuzma MA. Screening for psychiatric disorders in medical patients: a feasibility and patient acceptance study. Med Care. 1994 Jun;32(6):603-8.

70.   Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents. Department of Health and Human Services. Available at http://aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf. [2013]

71.   Sowell, R. L., Lowenstein, A., Moneyham, L., Demi, A., Mizuno, Y., & Seals, B. F. (1997). Resources, stigma, and patterns of disclosure in rural women with HIV infection. Public Health Nursing, 14, 302–312.

72.   Zich J, Temoshok L. Perceptions of social support in men with AIDS and ARC: relationships with distress and hardiness. J Appl Soc Psych. 1987;17(3):193–215.

73.   Andersen EM, Malmgren JA, Carter WB, Patrick DL. Screening for depression in well older adults: evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). Am J Prev Med. 1994;10(2):77-84. Epub 1994/03/01

74.   Bakken, S., Holzemer, W.L., Brown, M., Powelll-Cope, G.M., Turner, J.G., Inouye, J., Nokes, K.M., & Corless, I.B. (2000). Relationships between perception of engagement with health care provider and demographic characteristics, health status and adherence to therapeutic regimen in persons with HIV/AIDS. AIDS Patient Care and STDs, 14, 189-197.

75.   Waldrop-Valverde D, Guo Y, Ownby RL, Rodriguez A, Jones DL. Risk and protective factors for retention in HIV care. AIDS Behav. 2014 Aug;18(8):1483-91.

76.   Cohen, J. (1988). Statistical power analysis for the behavioral sciences (2nd ed.). Hillsdale, NJ: Erlbaum

77.   Katz IT1, Ryu AE, Onuegbu AG, Psaros C, Weiser SD, Bangsberg DR, Tsai AC. Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. J Int AIDS Soc. 2013 Nov 13;16(3 Suppl 2):18640.

78.   Bradley H, Hall I, Wolitski R, Van Handel M, et al. Vital Signs: HIV Diagnosis, Care, and Treatment Among Persons Living with HIV — United States, 2011. Morbidity and Mortality Weekly Report. November 28, 2014 / 63(47);1113-1117

79.   Rolfe A1, Cash-Gibson L, Car J, Sheikh A, McKinstry B. Interventions for improving patients' trust in doctors and groups of doctors. Cochrane Database Syst Rev. 2014 Mar 4;3:CD004134. doi: 10.1002/14651858.CD004134.pub3.

80.   Tulsky JA, Arnold RM, Alexander SC, Olsen MK, Jeffreys AS, Rodriguez KL, et al. Enhancing communication between oncologists and patients with a computer-based training program. Annals of Internal Medicine 2011;155: 593–601.

81.   Clancy DE, Cope DW, Magruder KM, Huang P, Salter KH, Fields AW. Evaluating group visits in an uninsured or inadequately insured patient population with uncontrolled type 2 diabetes. The Diabetes Educator 2003;29:292–302.

82.   Hsu J, Schmittdiel, Krupat E, Stein T, Thom D, Fireman B, et al. Patient choice: a randomized controlled trial of provider selection. Journal of General Internal Medicine 2003;18: 319–25.

83.   Barroso J1, Relf MV, Williams MS, Arscott J, Moore ED, Caiola C, Silva SG. A randomized controlled trial of the efficacy of a stigma reduction intervention for HIV-infected women in the Deep South. AIDS Patient Care STDS. 2014 Sep;28(9):489-98. doi: 10.1089/apc.2014.0014. Epub 2014 Aug 1

84.   Rao D, Desmond M, Andrasik M, Rasberry T, Lambert N, Cohn SE, Simoni J. Feasibility, acceptability, and preliminary efficacy of the unity workshop: an internalized stigma reduction intervention for African American women living with HIV. AIDS Patient Care STDS. 2012 Oct;26(10):614-20. doi: 10.1089/apc.2012.0106. Epub 2012 Sep 17.

85.   Kidd R, Clay S, Chiiya C. Understanding and Challenging HIV/AIDS Stigma: A Toolkit for Action: International Center for Research on Women, Academy for Educational Development (AED), International AIDS Alliance, 2007.

86.   Harper GW1, Lemos D, Hosek SG. Stigma reduction in adolescents and young adults newly diagnosed with HIV: findings from the Project ACCEPT intervention. AIDS Patient Care STDS. 2014 Oct;28(10):543-54. doi: 10.1089/apc.2013.0331. Epub 2014 Sep 12.

87.   Wallander JL, Varni JW. Appraisal, coping, and adjustment in adolescents with a physical disability. In: J.L. Wallander and L.J. Siegel (Eds.), Adolescent Health Problems. Guilford Press: New York, 1995.

88.   Gardner LI, Giordano TP, Marks G, Wilson TE, Craw JA, Drainoni ML, Keruly JC, Rodriguez AE, Malitz F, Moore RD, Bradley-Springer LA, Holman S, Rose CE, Girde S, Sullivan M, Metsch LR, Saag M, Mugavero MJ; Retention in Care Study Group. Enhanced personal contact with HIV patients improves retention in primary care: a randomized trial in 6 US HIV clinics. Clin Infect Dis. 2014 Sep 1;59(5):725-34. doi: 10.1093/cid/ciu357. Epub 2014 May 15.

89.   Higa DH, Marks G, Crepaz N, Liau A, Lyles CM. Interventions to improve retention in HIV primary care: a systematic review of U.S. studies. Curr HIV/AIDS Rep. 2012 Dec;9(4):313-25. doi: 10.1007/s11904-012-0136-6.

90.   Gardner LI, Marks G, Craw JA, Wilson TE, Drainoni ML, Moore RD, Mugavero MJ, Rodriguez AE, Bradley-Springer LA, Holman S, Keruly JC, Sullivan M, Skolnik PR, Malitz F, Metsch LR, Raper JL, Giordano TP; Retention in Care Study Group. A low-effort, clinic-wide intervention improves attendance for HIV primary care. Clin Infect Dis. 2012 Oct;55(8):1124-34.

91.   Traeger L, O'Cleirigh C, Skeer M, Mayer K, Safren SA. Risk factors for missed HIV primary care visits among men who have sex with men. J Behav Med. 2011;35(5):548–56.

92.   Centers for Disease Control and Prevention. HIV Surveillance Report, 2013; vol. 25. http://www.cdc.gov/hiv/library/reports/surveillance/. Published February 2015.

93.   Gardner LI, Marks G, Wilson TE, Giordano TP, Sullivan M, Raper JL, Rodriguez AE, Keruly J, Malitz F. Clinic-wide intervention lowers financial risk and improves revenue to HIV clinics through fewer missed primary care visits. J Acquir Immune Defic Syndr. 2015 Apr 1;68(4):472-6. doi: 10.1097

94.   Kotter, J. P. Leading Change. Boston: Harvard Business School Press, 1996.