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## ABSTRACT

This study is about whether doctors have the potential to influence adherence by forming a solid patient-doctor relationship. This study is also about health disparities; specifically, if racialized life experiences have any association with either adherence or the formation of a solid patient-doctor relationship.

Self-reported racial discrimination was shown to be a risk factor for non-adherence (OR 4.725, *p-value* <0.05), while compassionate behavior on the part of the clinician predicted adherence (OR 0.062, *p-value* <0.1, trend).

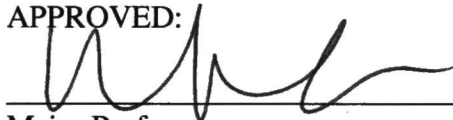
Future directions include applying for extramural funding to conduct a clinical trial emphasizing communication as a way to eliminate health disparities. In the long term, the goal of medical educators should be to recruit more non-white physicians in order to further eliminate health disparities.



DOCTORS, PATIENTS, AND ADHERENCE TO HIV MEDICATION: FINDINGS  
OF THE COMMUNICATION, COMMUNITIES, AND HEALTH STUDY

Margaret Seater, D.O.

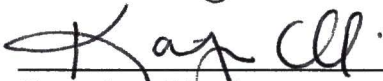
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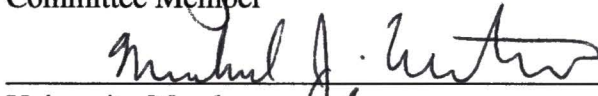
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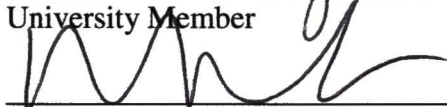
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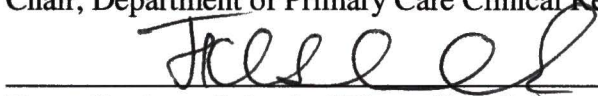
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**DOCTORS, PATIENTS, AND ADHERENCE TO HIV MEDICATION: FINDINGS OF  
THE COMMUNICATION, COMMUNITIES, AND HEALTH STUDY**

**THESIS**

**Presented to the Graduate Council of the Graduate School of Biomedical Sciences**

**University of North Texas Health Science Center at Fort Worth**

**In Partial Fulfillment of the Requirements**

**For the Degree of**

**MASTER OF SCIENCE**

**By**

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**Fort Worth, Texas**

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# CHAPTER I

## INTRODUCTION

### Specific Aims

With the advent of highly active antiretroviral therapy (HAART) in 1996, dramatic improvements have been achieved in reducing morbidity and mortality in patients infected with HIV <sup>1</sup>. While HAART is effective in achieving complete viral suppression, treatment regimens are complex and are associated with many side effects and complications including nausea, vomiting, dyslipidemia, hyperglycemia, insulin resistance, and liver failure <sup>1</sup>. Thus, encouraging patients to adhere to HAART consistently over months and years is a major treatment goal. In fact, 95% adherence is required to maintain undetectable viral loads in 80% of patients <sup>1-3</sup>. Unfortunately, this rate of adherence has only been cited in 40-50% of cases <sup>1,4,5</sup>. Strategies to optimize the efficacy of HAART have focused on screening for characteristics that may predict adherence. Thus, much research has focused on identifying reliable predictors of adherence including patient characteristics, treatment factors, and only recently, satisfaction with the patient-physician interaction <sup>3,6-8</sup>.

My *long range goal* is to identify methods to improve adherence behavior. As my *objective* in the pursuit of this goal, I investigated the psychosocial aspects of the patient-doctor relationship and its influence on adherence. The *central hypothesis* of the study is that HIV patients who enjoy a satisfactory patient-doctor relationship will also be more likely to adhere to HAART (see Figure 1). In particular, I theorize that psychosocial

factors such as open communication, shared decision making, friendly interpersonal style, sense of control, and social support, all encourage adherence. Furthermore, I contend that patient-physician interactions take place within a racialized social terrain. I wish to uncover if racialized life experiences have any bearing on either adherence or patients' interactions with their physicians. I hypothesize that perceived discrimination will be negatively associated with both adherence and the quality of one's patient doctor relationship. Perceived discrimination refers to having been prevented from doing something, having been hassled, or made to feel inferior because of race or color. The *rationale* behind this research centers on the fact that psychosocial factors drive patient behaviors such as paying attention to symptoms of illness and interpreting those symptoms, deciding to seek care, and deciding to follow recommended treatments <sup>9</sup>. Equally important, a doctor's comfort level or curiosity about people unlike himself may be an important element in establishing a trusting relationship with patients infected with HIV, a disease which disproportionately affects disadvantaged populations. Psychosocial aspects of the patient-physician relationship may be shaped by notions of race or ethnicity, as well as religious, educational, or professional orientation. Therefore, doctor and patient may find that they "interpret terms, idioms, and metaphors differently, and patients may omit information they think their doctors may find inappropriate" <sup>9</sup>. These behaviors ultimately influence health outcomes, as has been shown by evidence based studies of chronic disease management <sup>9</sup>.

To accomplish the objectives of this study, I pursued the following *specific aims*:

1. *Identify adherent and non-adherent patients using a validated survey.*
2. *Assess the quality of the participant's patient-doctor relationship using the Interpersonal Processes of Care (IPC) survey.*
3. *Describe the association between adherence behavior and having a satisfactory patient-doctor relationship.*
4. *Using the Experiences of Discrimination (EOD) survey, determine the prevalence of racialized life experiences among the patients in our sample.*
5. *Find out if any relationship exists between adherence and patterns of racialized life experience.*

My *expectations* were that, at the conclusion of the study, I would have determined the role of the patient-doctor relationship, specifically the influence of psychosocial factors and perceived discrimination, in predicting adherence behavior. The objective of the study was to obtain a more nuanced picture of the patient-physician relationship than can be obtained by asking patients simply to rate their relationship with their physician as either poor, good, or excellent. Finally, I expect that capturing these elements of the patient-physician interaction will be helpful in coaching patients and physicians about how to achieve better adherence. Ultimately, this data could possibly be used to apply for extramural funding in order to conduct a clinical trial of adherence interventions.



**Figure 1. Statement of Hypotheses**

**Hypothesis #1**

*Patients who experience poor or inadequate interpersonal processes of care are less likely to be adherent to their HAART regimen.*

**Hypothesis #2**

*Patients who experience perceived racial discrimination are less likely to be adherent to their HAART regimen.*

## CHAPTER II

### BACKGROUND

#### Highly active antiretroviral therapy (HAART)

It has been more than two decades since the first diagnoses of AIDS in the United States. Since the introduction of highly active antiretroviral therapy (HAART) in 1996, dramatic improvements have been achieved in reducing morbidity and mortality in patients infected with HIV allowing patients to live longer, healthier lives <sup>5</sup>. HAART consists of combinations of several classes of drugs designed to disrupt the life cycle of the virus. These include protease inhibitors (PI), nucleoside reverse transcriptase inhibitors (NRTI), and non-nucleoside reverse transcriptase inhibitors (NNRTI). While HAART is effective in achieving complete viral suppression, treatment regimens are complex and are associated with many side effects and complications including nausea, vomiting, depression, anemia, dyslipidemia, hyperglycemia, insulin resistance, and liver failure <sup>4, 5, 10-12</sup>. Thus, the patient's ability to adhere to HAART consistently over months and years is of major concern to health professionals involved in the care of HIV infected patients.

#### The importance of adherence

Adherence is a key issue in the management of HIV infection, as non-adherence is the most common cause of therapeutic failure <sup>1-5, 13, 14</sup>. One encouraging finding has been that adherence among HIV-infected patients is better than with patients suffering from other chronic illnesses such as hypertension. Hypertensive patients admit to taking

only 50% of dosages of medication as compared to HIV patients who report taking an average of 80-90% of dosages, suggesting that HIV patients are hearing the message of the importance of adherence <sup>1, 4, 5</sup>. However, it has been demonstrated that 95% adherence is required to maintain undetectable viral loads in 80% of patients <sup>1, 4, 5</sup>. Unfortunately, this rate of adherence has only been cited in 40-50% of cases <sup>1, 4, 5</sup>.

Non-adherence is not only problematic from the individual patient's perspective as skipping dosages shortens average life span, but also presents a public health challenge. Non-adherence can result in the evolution of drug resistant strains of virus, making persons newly infected with resistant virus harder to treat <sup>1-5, 13, 14</sup>.

#### What factors affect adherence?

Strategies to optimize the efficacy of HAART have focused on screening for characteristics that may predict adherence. Thus, much research has focused on identifying reliable predictors of adherence including patient characteristics, treatment factors, and to a lesser extent, satisfaction with the patient-physician interaction.

##### *Patient characteristics*

Patient characteristics refer to baseline factors unique to the patient that may influence adherence. These include sociodemographic information, personality traits, mental health, and other psychosocial factors.

Efforts to define patient characteristics that predict adherence have had mixed results. A 2002 prospective study conducted by Spire *et al*, a French research team, identified younger age, poor housing conditions, lack of social support, and a history of non-adherence to previous antiretroviral regimens as predictors of non-adherence <sup>2</sup>.



Conversely, a 2001 literature review by Valerie Stone pointed out that sociodemographic characteristics have not always been reliable indicators of adherence <sup>15</sup>. Stone writes that while a few studies have found adherence to be lower among blacks and women, no consistent correlation has been established between race/ethnicity, sex, or age with respect to adherence <sup>15</sup>. However, Stone points out that education and literacy have been shown to influence adherence <sup>15</sup>. Thus education and literacy seem to be more important to adherence than race, gender, or age.

A number of studies have shown that alcohol and substance abuse, depression, and social situation are among the consistent predictors of non-adherence. For example, adherence has been shown to be lower among IV drug users <sup>4, 16-19</sup>. A 2003 qualitative study, focusing on patients with excellent adherence, supported these findings and also shed light on the nature of this relationship <sup>14</sup>. While substance abusers tended to be suboptimal adherers, interestingly this study showed that former substance abusers were just as adherent as nonusers. The same study also showed that excellent adherers believed that it was important to take medications even when actively using substances of abuse. Patients in the study made the following statements <sup>14</sup>:

“I would wake up and take them [after cocaine use] ... I knew I had to.”

“[After drinking] I'd still take them [medications]...it's very important so whatever I'm doing I remember <sup>14</sup>.”

Furthermore, none of the excellent adherers in this study were depressed. All had normal CES-D scores (Center for Epidemiological Studies Depression scale), supporting the repeated finding in the literature that depression is highly associated with non-

adherence<sup>14</sup>. Current practice guidelines encourage physicians to evaluate mental health and treat depression before starting HAART<sup>5</sup>.

Other characteristics associated with excellent adherers included 1. the belief that adherence rates need to be 90-100% for medication efficacy, 2. great trust in primary care providers, 3. openness about HIV status, receiving substantial social support, and 4. being motivated by staying healthy<sup>5</sup>.

Housing issues were not addressed in this study; however, Stone writes in her literature review that chaotic and unstable living conditions can have a dramatic impact on a patient's ability to maintain access to health care and obtain medications on schedule<sup>4</sup>. However, Directly Observed Treatment programs (DOT) administered at half-way houses and homeless shelters have been shown to be effective<sup>4</sup>. Based on the finding that homeless patients in DOT programs achieved high levels of adherence, Stone warns doctors against viewing homelessness as a reason to withhold HAART<sup>4</sup>.

The disadvantage of using patient characteristics to screen for likely adherence behavior is that they are stereotypes. Although these predictors are evidence based, they do not hold true 100% of the time. Furthermore, physicians have little power to change factors like education level and housing conditions. Thus, an individualized, inventive approach must be used.

### *Treatment factors*

It has been suggested that the likelihood of short term adherence hinges on patient characteristics, while long term adherence is better predicted by treatment factors that capture the patient's subjective experience of taking HIV drugs<sup>2</sup>. These include

treatment side effects, becoming depressed during the course of treatment, perception of individual state of health, and beliefs toward the effectiveness and toxicity of HAART. These treatment factors were studied in the French prospective study by Spire *et al* who found that the most often cited reason for not taking medication was forgetfulness (36.1%), and the least often cited reason was the avoidance of an adverse event (13.4%)<sup>2</sup>. Spire *et al* concluded that in the short term or long term, adherence was more closely correlated with *a priori* patient characteristics<sup>2</sup>.

However, Spire *et al.* did not evaluate the complexity of treatment regimens in their study, a topic Stone addresses at length in her review. Treatment complexity refers to the number of pills in each dose, the number of doses given each day, and the number of meal/fluid restrictions required by the regimen<sup>4</sup>. A number of studies have linked simplified treatment plans with lower viral loads, fewer cases of treatment fatigue, and better adherence rates<sup>4</sup>. Current practice guidelines advise physicians to simplify regimens whenever possible and tailor treatment regimens to patients' lifestyles and schedules<sup>5</sup>.

In the years since these articles were published, numerous studies have attempted to settle the debate over which characteristics are the most important contributors to adherence. Social support, depression, health status, age, gender, race have all been found to be inconsistent predictors<sup>11, 12, 16, 18-29</sup>. Despite these efforts, the search for reliable predictors of adherence has been inconclusive.

### *The patient-physician relationship*

While most adherence research thus far has focused on patient and treatment characteristics, investigators interested in improving adherence to HAART have identified satisfaction with the patient-physician relationship as an important factor in adherence<sup>3, 6-8, 30</sup>. The French cohort study by Spire *et al* reported that patients who did not talk about their personal problems with their physicians were more likely to be non-adherent, as was the case for those who did not have complete trust in their relationship with their physician<sup>2</sup>. As mentioned before, the study of excellent adherers by Malcolm *et al* showed that trusting their physician was regarded as very important to their adherence behavior<sup>14</sup>. In interviews, one patient with excellent adherence stated: "Whatever the doctor say, that's what I go along with. Because I, you know Dr.'s...there to help me, not hurt me, so I put all my trust in Dr..."

Another excellent adherer stated:

"They talk to me, they tell me how I'm doing and whether everything looks good. I wouldn't hold nothing back from them."

While the excellent adherers in the study all had a great deal of trust in their physicians and respected their opinions and treatment decisions, most non-adherers were more suspicious of their physicians and had a less satisfactory relationship overall<sup>14</sup>. In the words of one non adherer in the study:

"These doctors they don't get involved with their patients. So their patients have no trust in them, you know what I'm saying."



Others said:

“All he's going by is what the drug company tells him.”

“My personal opinion is he's a practitioner, but this is my body...I have average faith in him...nobody knows my body like I do.”

Thus the findings of Malcolm *et al* -- that all excellent adherers in the study expressed trust in their physician while most non adherers expressed suspicion --provides evidence for the notion that a strong patient-physician relationship can play a pivotal role in adherence to HAART <sup>14</sup>.

The studies of Spire *et al* and Malcolm *et al* both addressed the patient -physician relationship in conjunction with a number of other factors believed to influence adherence. The first study devoted entirely to the role of the patient-provider relationship was published in 2004 by a group of nurse investigators, Russell *et al* <sup>3</sup>. By comparing patient satisfaction survey results between adherers and non adherers, Russell *et al* concluded that the nature of the patient provider relationship was important to adherence.

While the link between the patient-physician relationship has been established, it has been less well studied than the predictive value of patient and treatment characteristics. Furthermore, the studies of Spire, Malcolm, and Russell *et al* have been limited by sample size and geography and have focused on a few nebulous aspects of the patient-physician relationship, mainly support, trust and caring <sup>2, 3, 14, 30</sup>. Also, the study by Russell *et al* was written for a nursing readership and was designed to draw conclusions about the aspects of care which are the partial responsibility of the nurse, such as education and inquiring about problems associated with treatment. Thus, there

has never been a study designed to illuminate the specifics of the patient-physician relationship and its role in HAART adherence. I feel the role of the patient-physician relationship deserves further investigation because unlike patient and treatment characteristics, which the physician has little power to change, the physician has a realistic opportunity to improve his or her relationship with patients.

### *Studying the patient-physician interaction*

As mentioned, previous efforts to describe the nature of the patient-physician relationship have used only a few nebulous concepts such as support, caring and trust. These findings offer little in the way of corrective action other than to advise physicians to try to be more caring or trustworthy. It may be instructive to be more specific in the study of the patient-physician interaction and design an investigation that is capable of deconstructing communication patterns and relationship characteristics in order to illuminate the ways in which the patient-physician relationship can optimize adherence. I would like to expand the study of the patient-physician approach by using Klienman's explanatory model of sickness as my theoretical framework <sup>9</sup>. This model has been used extensively in the study of chronic disease management and more recently in health disparities research but does not appear to have made inroads in the study of HAART adherence <sup>9</sup>.

The explanatory model of sickness is a construct for thinking about patient-physician interactions. It posits that doctors and patients have a fundamental misunderstanding that undermines their shared goal of helping the patient stay healthy. This misunderstanding arises from different explanations of the health problem. Both

doctors and patients think of health problems in terms of cause, symptom onset, control and meaning, psychophysiology, prognosis and course, and treatment. However, as Klienman writes, “modern [Western] physicians diagnose and treat diseases (abnormalities in structure and function of bodily organs and systems), whereas patients suffer illnesses (experiences of disvalued changes in state of being and in social function)<sup>9</sup>. In other words, doctors tend to understand disease in others as a set of biomedical processes, whereas patients experience illness and understand it in the larger context of their personal life history. For both doctor and patient, explanatory models, or narratives, depend on one's collective identity. In other words, one's narrative is a product of national culture, religious culture, professional culture, gender culture, racial/ethnic culture, or generational culture.

Proponents of this framework argue that explanatory models are important because they determine behavior. The doctor's narrative dictates his differential diagnoses and treatment plan. The patient's narrative drives behaviors such as paying attention to symptoms of illness and the interpreting those symptoms, deciding to seek care, and deciding to follow recommended treatments. These behaviors ultimately influence health outcomes, as has been demonstrated in evidence based studies of chronic disease management<sup>9</sup>.

An illustration of this model includes the disparate meanings that the diagnosis of hypertension can have for doctor and patient. A patient who attributes her high blood pressure to stress and believes it will resolve with a sedative may not be keen to follow her physician's advice of restricting salt intake and buying costly blood pressure

medications<sup>9</sup>. Another familiar example of doctor's and patients conflicting explanations is when patients request antibiotics for viral upper respiratory infections<sup>9</sup>.

The explanatory model of sickness argues that the patient and physician should work together to achieve an understanding of one another's perspective and that the key goal of a clinical interaction should be to develop congruence between explanatory models. According to this model, developing congruence is a prerequisite for establishing trust, satisfaction, and respect between doctor and patient. It follows that effective communication is crucial to developing trusting, satisfactory clinical relationships. This model advises patients and doctors to elicit information from each other, ask questions, and negotiate and reconcile differences in their sickness narratives. By providing openings and prompts to help the patient share his or her narrative, ask questions, express concerns, and be assertive, doctors improve communication and ultimately improve health outcomes<sup>9</sup>. Doctors who approach patient care in this way are more likely to have satisfactory relationships with patients, and their patients will likely be healthier.

The explanatory model of sickness may provide insight into the elements of the patient-physician relationship that result in better adherence behavior in the HIV patient population. Rather than measuring abstract notions such as trust and empathy, the explanatory model allows us to describe the anatomy and physiology, so to speak, of what constitutes a satisfactory relationship and establish its relationship to HAART adherence. Additionally, for the same reason that health disparities researchers are interested in the explanatory model, this style of patient care may help to explain patient



characteristics sometimes associated with HAART compliance such as race/ethnicity and educational level. Because sickness narratives depend on racial, ethnic, religious, educational, or professional orientation, doctor and patient may find that they “interpret terms, idioms, and metaphors differently, and patients may omit information they think their doctors may find inappropriate”<sup>9</sup>. Thus, cultural competence, or a doctor's comfort level or curiosity about people unlike himself, may be an important element in establishing a trusting relationship with patients infected with HIV, a disease which disproportionately affects disadvantaged populations. Thus a study designed to capture these elements of the patient-physician interaction and their correlation with adherence may be helpful in coaching physicians about how better to influence patient behavior.

#### *Measuring Psychosocial Factors, Perceived Discrimination, and Adherence*

#### *Operationalizing the Patient-Doctor Relationship: Interpersonal Processes of Care*

The lessons and methodology of health disparities research may be particularly valuable to our study in unraveling the psychosocial factors of care that drive health behaviors such as HAART adherence. Health disparities research aims to explain why persons of lower economic status or from racial and ethnic minority groups have substantially poorer health and more health risk factors than their counterparts<sup>31</sup>. Several mechanisms have been proposed to explain this phenomenon including differences in social, environmental, economic, and lifestyle factors, and restricted access to care<sup>31</sup>.

Other researchers hypothesize that health disparities can be accounted for on the basis of differences in quality of care owing to the specific interpersonal processes that occur between doctor and patient<sup>31</sup>. Interpersonal processes refer to the social-



psychological aspects of the patient-physician relationship, such as communication, friendliness, explanations, caring, and sensitivity to patients' needs. Similar to Kleinman's arguments, proponents of this hypothesis suggest that if physicians make unilateral decisions, or if they are unaware of patient's cultural beliefs and preferences, then patient adherence to instructions about self-care and drug dose might be poor, leading to worse outcomes<sup>31</sup>. Conversely, when doctor and patient share information, patients gain knowledge, become more empowered, motivated, and capable of managing their own health and outcomes may improve<sup>31</sup>.

The Interpersonal Processes of Care (IPC) survey, developed by Stewart et al, has been validated in order to measure these aspects of the patient-physician relationship<sup>31</sup>. For Stewart et al, the IPC survey was intended to overcome some of the limitations of other quality of care surveys which inquired about satisfaction rather than what actually happened during the doctor's appointment<sup>31</sup>. For example, rather than asking for a qualitative statement about satisfaction, the IPC asks, "How often did your doctor listen carefully to what you had to say?" Furthermore, in contrast to previous patient care quality surveys, the IPC was developed with special attention to the perspective of persons of lower socioeconomic status as well as racial and ethnic minorities. For example, the IPC asks, "How often did your doctor talk in front of you as though you weren't there?" The IPC, in the view of Stewart et al, is more reflective of the experiences of people of disadvantaged populations.

The IPC survey breaks down the patient-physician relationship into the following categories: communication, decision making, interpersonal style. Communication is

especially important to our study of adherence given the finding that in a study of indigent and minority patients, 35% of English speakers and 62% of Spanish speakers had trouble reading and understanding medical instructions<sup>31</sup>. Another study of older minority women found that adherence was related to the clarity and explicitness of the physician's instructions<sup>31</sup>. Communication is addressed in the IPC in terms of general clarity, elicitation and responsiveness to patient's problems, concerns, and expectations, explanations, and empowerment. The IPC covers decision making and interpersonal style in great depth as well, with 4 or 5 items in each category addressing various issues such as discrimination, respectfulness, and considering a patient's desire and ability to comply with recommendations. Administering this survey to the participants in this study may contribute meaningfully to our understanding of both the problems of health disparities as well as HAART adherence.

### *Studying Racism: Perceived Discrimination*

It has long been believed that racial injustice *directly* harms health as this idea was written about as long ago as the 18<sup>th</sup> century<sup>32, 33</sup>. Studies have been conducted showing the impact of racism on mental health, smoking, and other illnesses, and of particular interest to our study, research focused on racial discrimination in the provision of health care<sup>34, 35</sup>.

While the link between discrimination and health has been repeatedly established, the development of valid and reliable measures of discrimination has been more recent. In 2005 publication, Krieger et al describe the validation of an instrument to measure

exposure to discrimination, which they refer to as the Experiences of Discrimination measure (EOD) <sup>34</sup>.

The EOD asks respondents about experiences of discrimination, (being prevented from doing something, being hassled or made to feel inferior, etc.) in a number of situations (at home, at work, in public, etc) for a number of different reasons (gender, race, age, religion, etc).

The EOD has been shown to be valid and reliable as confirmatory factor analysis demonstrated high scale reliability, with a Cronbach's alpha of higher than 0.74 (#). The test to retest co-efficient was 0.70, The EOD was validated in both Spanish and English <sup>34</sup>.

The EOD has never been administered to HIV patients. We used the EOD in our study to discover if non-adherent HIV patients report discrimination more frequently than do adherent HIV patients. As suggested by Klineman's model of health behavior as well as the findings of previous work on race and health, experiences of discrimination may play a role in a patient's decision to follow recommended therapy. I expected that this also applied in the context of HAART adherence.

### Measuring Adherence

There is no gold standard for measuring adherence, and there is an ongoing debate in HAART adherence research about which is the most reliable method. Clinical trials investigators often use electric monitoring devices that indicate when a pill bottle has been opened; however, this is costly and imperfect <sup>4,5</sup>. Another method is patient self-report, although patients tend to overestimate adherence <sup>4,5</sup>. Knobel et al have developed

and validated a Simplified Medication Adherence Questionnaire (SMAQ) in a large cohort of HIV-infected patients, using electric monitoring devices for comparison<sup>36</sup>. Sensitivity was reported to be 72% (95% CI: 58-86), specificity was 91% (82-100), positive predictive value was 87% (76-97), and negative predictive value was 80% (68-92)<sup>36</sup>. The SMAQ appears suitable to use in our study as an instrument for assessing adherence in HIV patients.

## CHAPTER III

### METHODS

This chapter will describe how the study was conducted. Outlined here are the study design, recruitment procedures, information about the surveys used, and a description of data analysis techniques.

#### Study Design

This study used a cross-sectional survey design to assess the relationship between racial discrimination, the patient-doctor relationship, and a patient's decision to take medicines in a sample of patients at an HIV clinic in Fort Worth, TX.

#### Participants

The survey was administered to a convenient sample of patients who came to their HIV clinic visits. The sample was divided into subsets of whites (N=30), African Americans (N=37), and Hispanics (N=30). A subset of African participants was also recruited for a future analysis.

The study site was a grant-funded "clinic of last resort" which accepts only patients with Medicaid or Medicare and who earn below 200% of the Federal Poverty Level. While some of the office staff was non-white, all four clinicians employed at the clinic were white.



### Locating Participants

A total of 101 patients attending a county HIV clinic during a 6 month period participated in the study. Research staff approached the participants during their clinic appointment. Data was not collected regarding how many participants were invited to join the study and how many declined. Therefore, participations rates are not available.

### Power Analysis

The study has an 80% power to detect an effect size of 0.2 at a 5% significance level, based on an *a priori* assumption. This study is powered to detect a 20% difference in non-adherents who have a “good” patient-doctor relationship and those who report a “bad” patient-doctor relationship. No data exist on the prevalence of “good” versus “bad” patient-doctor relationships in the HIV patient population at large. Therefore, the prevalence was estimated in order to determine the sample size needed for a study with 80% power. The goal was to recruit 30 whites, 35 Hispanics, and 35 blacks.

### Inclusion/Exclusion Criteria

Criteria for inclusion in the study were: a) being HIV positive, b) being age over the age of 18, c) having no previous diagnosis of dementia, and d) having taken HAART for at least 3 months (see Figure 2).

### Procedures

Once eligibility had been determined using a screening form, participants completed the survey in a private office. Participants were given a retail gift card worth \$15 for completing the survey which took about an hour. One or more interview staff was bilingual in English and Spanish and was available to answer participants' questions.

All participants provided written informed consent, and conduct of the study was approved by the Institutional Review Board of the University of North Texas Health Science Center.

Clinical data were obtained from participants' medical records. Participants' viral load, CD4 cell count, number of medications, and number of AIDS associated illnesses were transcribed using a data collection protocol.

#### *Protection of Participants' Confidentiality*

In order to minimize the risk of a breach of confidentiality, each participant was randomly assigned a unique identifying number. This unique identifying number was the sole link between the participant and his or her survey responses. The participant's consent form also a potential tie to the survey responses; however, these forms were stored separately under lock and key.

Surveys were anonymous and participants were informed that their responses would never be shared with their physician. Once data were collected, protected health information was destroyed, and surveys were stored in locked files. This study received a Certificate of Confidentiality from the National Institutes of Health. This certificate protects participants' privacy in the event of legal investigations. For instance, if a participant later committed a drug-related crime, their survey responses admitting current or previous drug abuse would be shielded from being used as evidence in the investigation.

## Instrumentation

### *Adherence*

Adherence status was determined using a validated instrument. The Simplified Medication Questionnaire (SMAQ) is a 6 item measure asking patients about their short term and long term medicine taking habits. A sample item is, “Do you ever forget to take your medicine?” Other items ask about missing doses over the past week and the last three months. A participant was considered non-adherent if they admitted missing any doses. The SMAQ was validated in a large cohort of HIV-infected patients using electronic monitoring devices for comparison <sup>36</sup>. Sensitivity for this scale was 72%, specificity was 91%, positive predictive value was 87% and negative predictive value was 80% <sup>36</sup>.

### *The Patient-Doctor Relationship*

A 29 item scale was used to assess patient’s perceptions of interactions with their doctors. Interpersonal Processes of Care (IPC) is a Likert-type tool that quantifies 7 aspects of the patient-doctor relationship. Respondents are asked if physicians have done certain things during recent clinic visits such as using words that were hard to understand, finding out what the patient’s concerns were, and giving support and encouragement. A sample item is, “How often did the doctor ask if you would have any problems following what they recommended? Items on the scale are grouped into 7 major areas: “Hurried Communication,” “Elicited Concerns and Responded Appropriately,” “Explained Results and Medications,” “Patient-Centered Decision Making,” “Compassionate and Respectful,” “Discrimination, and Disrespectful.” For the domains, “Hurried

Communication,” “Discrimination,” and “Disrespectful,” a high score is correlated with a worse outcome. A high score is correlated to a better outcome for the other domains (“Elicited Concerns,” “Explained Results,” “Patient-Centered Decision Making,” and “Compassionate/Respectful”). The IPC was validated in a sample of ethnically diverse patients of low socioeconomic status. Reliability coefficients for all domains were  $> 0.70$

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### *Perceived Discrimination*

Exposure to racial discrimination was measured using a 9 item self-report instrument called Experiences of Discrimination (EOD). Respondents were asked about discrimination in each of 7 situations. A sample item is, “Have you ever experienced discrimination, been prevented from doing something, been hassled or made to feel inferior because of your race, ethnicity, or color while getting hired for a job?” Other situations included being discriminated against at school, work, getting housing, getting medical care, getting service in a store or restaurant, getting credit, bank loans, or a mortgage, on the street or in a public setting, and from the police or in the courts. The EOD was scored by counting the number of situations in which a participant reported experiencing racial discrimination. This measure was validated in a sample of working adults in Boston, MA using Audio-Computer Assisted Self-Interviewing <sup>34</sup>. In this study, the EOD was administered verbally. Cronbach’s alpha was 0.74 <sup>34</sup>.

### *Demographics and Psychosocial Variables*

All demographic data on race/ethnicity, gender, sexual orientation, age, and socioeconomic position were based on self-report. Extensive data were obtained on



psychosocial variables such as social support, stress, depression, substance abuse, reaction to unfair treatment, HIV symptoms, and HIV stigma. Survey instruments used are listed below. Interpretation is described as well.

#### Validated Scales

- Social Support <sup>37</sup>
- CES-D depression screen <sup>38</sup>
- HIV Stigma <sup>39</sup>
- Perceived Stress Scale <sup>40</sup>
- Mental Health and Substance Abuse Screener <sup>41</sup>

#### Interpretation

- Lower score ~ higher social support
- Score above 16 ~ depression; dichotomized into depressed and not depressed
- Higher score ~ greater perception of stigma
- Higher score ~ greater perception of stress
- Dichotomized into positive and negative substance abuse

All measures used were validated. Scales were translated into Spanish by a certified translator. The Interpersonal Processes of Care, Experiences of Discrimination, and Simplified Medication Adherence Questionnaires were validated in Spanish; these versions were used for Spanish-speaking participants. Table 1 is a comprehensive interpretation guide for all variables.

#### Data Entry and Quality Control

Data were entered in SPSS Version 14. Coding rules for data entry are listed in Table 2. After initial data entry was complete, data were re-entered to verify accuracy.

#### Missing Data

Missing data presented a challenge for this study, as is the case for studies with small sample sizes. Based on a worst-case estimate, approximately 16% of respondents



had missing data, leaving only 86 respondents with data available for analysis (see Figure 3). To salvage as much data as possible, data were imputed using the individual mean imputation method. This method has been shown to be accurate when compared to other methods <sup>42</sup>.

### Data Analysis

To test the proposition that adherers and non-adherers differ with respect to the quality of the patient-doctor relationship and/or exposure to racial discrimination, comparisons were made using the studentized independent t test for continuous variables and chi squared analysis for categorical variables. For descriptive analyses, data were stratified by race to identify possible white/non-white differences. Analysis of variance was used when comparing continuous characteristics among Hispanics, blacks, and whites. Chi-squared was used for categorical data.  $R^2$  was used for sensitivity analysis to find the best explanatory models.

The strength of the association between explanatory variables in relation to HAART adherence was determined through odds ratios (OR) and their 95% confidence intervals (CI). Comparisons were considered significant if their corresponding *p-values* were below 0.05. For comparisons with *p-values* between 0.05 and 0.1, the term “trend” was used to signify that perhaps with a larger sample size, these associations may have been significant.

Interaction terms were tested for each of the three predictive models. There was no significant interaction between race and any other variable; however, several other

significant interactions were discovered (see Appendix F). No stratified analyses were undertaken due to the limitation of a small sample size.

Multiple logistic regression analyses were performed to find the best predictive models and to eliminate the influence of known confounding variables. The best predictive models were built through sensitivity analyses. The criterion for choosing the best predictive models was that these models should maximize the  $R^2$  value and also result in narrower confidence intervals. Separate regression analyses were carried out for both explanatory variables under question, Interpersonal Processes of Care and Experiences of Discrimination. In order to describe the joint influence of Interpersonal Processes of Care and Experiences of Discrimination on HAART adherence, a predictive model was also built assessing these two variables simultaneously. Multicollinearity diagnostics were computed, revealing weak collinearity ( $VIF < 2.8$ ). For this reason also, separate regressions were performed for IPC and EOD as predictors of medication adherence in case both instruments were actually measuring similar constructs. Both scales aimed to measure discrimination; therefore, separate regressions were conducted to minimize the chance that the discrimination component would be double counted.

#### *Final Model Justification*

In the multivariate analysis examining the unique influence of Interpersonal Processes of Care, the best predictive model for adherence included age, race, gender, and social support, and all 7 IPC domains. Two interaction terms were found to be significant: 1) hurried communication and number of medications, and 2) patient-

centered decision making and number of medications. Neither interaction term was used in the final analysis due to the instability of the confidence intervals.

In the multivariate analysis measuring Experiences of Discrimination as a stand-alone predictor, the best regression model for adherence included age, race, gender, stress, reaction to unfair treatment, yearly income, social support, and the interaction between the last two variables. The interaction term for social support and yearly income was removed from the final analysis because the confidence intervals were unreliable.

In the multivariate analysis simultaneously assessing Interpersonal Processes of Care and Experiences of Discrimination, the best predictive model for adherence included age, race, gender, home ownership, social support, stress, reaction to unfair treatment, viral load, number of medications, all 7 IPC domains, and experiences of discrimination. Flow charts for each model are illustrated in Figures 4-6.

#### Demographics and psychosocial variables

Age, race, and gender were retained in all final models since these variables have been associated with adherence in previous studies<sup>18, 24</sup>. Social support, stress, and treatment complexity are known confounders of HAART adherence<sup>18</sup>. These variables were retained in the final model whenever their inclusion resulted in more precise confidence intervals and explained a greater proportion of the difference between adherers and non-adherers. Reaction to unfair treatment was included as a covariate in models containing “Experiences of Discrimination” because it serves as a measure of internal validity for that scale. If someone tends to keep things to himself, that person may also be less likely to report discrimination. In this way, reaction to unfair treatment

may help to identify underreporting of racial discrimination. Substance abuse was not included in any of the three final models due to the low prevalence of this characteristic in the sample. Only 7 of 101 participants reported positive substance abuse. Other psychosocial variables such as depression and HIV stigma were excluded from the final analysis due to the limitations of small sample size.

### Socioeconomic variables

Socioeconomic variables such as home ownership, income, employment, and education have been shown to predict adherence in some situations<sup>18</sup>. However, there is often collinearity between these four variables. Home ownership and income were retained as covariates in 2 of 3 final models, but never in the same model together. Home ownership is an indicator of wealth and also stability of lifestyle, and therefore, may also be related to interpersonal processes of care, discrimination, and ultimately adherence. Income is an indicator of cash flow rather than overall wealth and also reflects employment status. This may also be an important factor shaping the patient-doctor interaction, experiences of discrimination, and a patient's decision to adhere to HAART. These variables may be related in several ways. Expendable income and housing may be a topic of discussion between patient and doctor; this may influence participant's responses to items on the Interpersonal Processes of Care scale. Income may shape exposures to discrimination in the following fashion. Participants with low incomes may fall behind on bills, have unpaid traffic fines, write hot checks and so on and may have more reasons to interact with police officers or the courts. Conversely, participants with higher incomes may be employed or looking to own a home and may have more reasons



to interact with employers or bank loan officers. Finally, variables such as low income and unstable housing may pose barriers to keeping appointments and obtaining medications, even if medications are paid for by various social programs as they are for this study population. Thus, home ownership, income, interpersonal processes of care, and discrimination may all help to explain the total picture of what predicts HAART adherence.

### *Clinical Data*

Clinical variables such as viral load, CD4 cell count, disease stage, and health-related quality of life have sometimes been shown to impact adherence<sup>18</sup>. Viral load was included in the model which examined both interpersonal processes of care and experiences of discrimination on adherence. Viral load is most likely the result of medication adherence rather than its cause; however it is possible that viral load is also related to interpersonal processes of care as well as experiences of discrimination. For established patients, monitoring viral load is one of the main objectives of the clinic visit, especially from the physician's standpoint. For a hypothetical patient, say the doctor focused on lab values during the clinic visit while the patient desired a listening ear for his or her experience of coping with a major illness, this disconnect may be reflected in the Interpersonal Processes of Care scale as a high score for "Explained results," but a low score for "Elicited Concerns" or "Compassionate/Respectful." Similarly, viral load may expose patients to discrimination in the following way. Consider another hypothetical patient, say a young, black female. The patient presents to the ER with diarrhea and a remote history of IV drug abuse whose viral load is >5,000. The nurse



struggles to start the IV. The nurse becomes frustrated and blames the difficulty of the stick on the patient's continued drug abuse. The nurse's mercy is tested all the more when she learns of the patient's viral load and apparent non-compliance. Both nurse and patient recognize the tension between them. The patient may or may not perceive this as racial discrimination and may or may not report it as being discriminated against while getting health care. In any case, viral load may be an important factor in explaining how interpersonal processes of care and experiences of discrimination predict adherence.

## CHAPTER IV

### RESULTS

#### Population Characteristics

Table 3 presents data on socioeconomic, psychological, and clinical variables for the study population (n=101). When stratified by race, the 36 Hispanic, 37 black, and 30 white participants were mostly in their early to mid-forties (mean age=43.42 years, SD=9.125) and described their sexual orientation as straight/heterosexual (n=54, 52.4%) (Table 4). While most participants in the study were male, the largest percentages of female participants were also black (37.8%, p-value 0.033). All 3 groups were overwhelmingly non-adherent. Only 9 Hispanics, 8 blacks, and 11 whites were identified as having adequate adherence, and there was no significant association between race and adherence.

With one exception, there were no significant differences between groups for psychological variables at the time of the interview. Again, few respondents admitted current substance abuse and no significant difference was found with respect to race (6.8% overall, p-value 0.471). There was a high prevalence of depression among participants in the study, but again, no white/non-white disparity (47.2% overall, p-value 0.942).

Hispanics, blacks, and whites reported similar levels of social support and stigma related to HIV status. Regardless of race, most respondents reported inadequate social support. For the entire population, mean score for social support was 3.07 which

reflected disagreement with statements about having someone they could turn to for emotional and material support. Similarly, for Hispanics, blacks, and whites alike, the majority of participants reported feeling stigmatized by having HIV. The best score possible on the HIV Stigma scale was a 40, representing an ideal scenario where the notion of stigma was a non-issue for the patient. For the population as a whole, the mean HIV Stigma score was 92.65 with no group reporting more stigma than any other (p-value 0.985). Mean scores for stress were equivalent for Hispanics, blacks, and whites. The one psychological variable which differed significantly by race was “Doing something about unfair treatment.” Compared to Hispanics, blacks and whites were more likely to accept unfair treatment as a fact of life whereas Hispanics were more likely to do something about it (p-value 0.046). Other than for reactions to unfair treatment, Hispanic, black, and white respondents were found to have similar psychosocial characteristics overall.

All three groups were alike with respect to disease progression. The bulk of participants had CD4 cell counts below 200 at their earliest clinic visit and counts between 200 and 499 at their most recent clinic visit. Likewise, most individuals had viral loads of 5,000 at their earliest clinic visit and viral loads below 5,000 at their most recent clinic visit. Most participants reported having one or fewer AIDS associated illnesses (n=64, 62.1%), and most considered themselves to be in good health (n=74, 71.8%). Whites were prescribed more medications than Hispanic or black participants even though clinical data was not statistically different between the three groups (mean number of medications 6.33, 6.0, and 4.64 respectively, p-value 0.039).

A significant gap in wealth existed between whites and non-whites in the study population. Without considering race, most participants in the study were working, had a high school education or less, and made less than \$20,000 per year. Nearly a third did not own a vehicle. Only a minority of respondents were home owners. However, social inequality was more likely to affect non-whites than whites. White participants were twice as likely as Hispanics and 1.5 times as likely as blacks to have education beyond high school (*p-value* 0.005); whites were 3 times as likely as blacks to own homes (*p-value* 0.023). Thus, while the entire study population was economically disadvantaged, indicators of social capital were distributed unevenly between Hispanics, blacks, and whites.

Table 5 shows population characteristics stratified by adherence.

### *Descriptive Analyses*

The original hypothesis was that there would be significant differences between adherents and non-adherents with respect to the nature of the patient-doctor relationship as well as lifetime experience with racial discrimination and that these differences could possibly explain white/non-white gaps in outcomes for patients with HIV. Specifically, it was predicted that non-whites would rate their doctors worse and also report higher levels of racial discrimination. As a preliminary test of this hypothesis, descriptive analyses were carried out for the two predictors under question: Interpersonal Processes of Care and Experiences of Discrimination. Responses to these two scales were first compared between Hispanic, black, and white participants in order to identify disparate answers corresponding to race (Table 6).

Whites reported significantly more dissatisfaction with their physicians than Hispanics or blacks. More than any other group, Whites complained that their doctors were in a hurry, explained results insufficiently, made unilateral decisions without their input, and were disrespectful on occasion. These findings trended toward significance, except for “Explained Results,” which reached the level of statistical significance ( $p$ -value 0.035). Again, the term “trend” is taken to mean having a  $p$ -value between 0.05 and 0.1. No statistically significant differences were found for Experiences of Racial Discrimination. Paradoxically, whites complained of racial discrimination equally as often as Hispanic or black respondents; 53% of whites reported racial discrimination in 1 or more situations versus 61.1% for Hispanic respondents and 62.2% for respondents describing their race as black ( $p$ -value 0.735). For both predictive variables of interest, interpersonal processes of care and experiences of discrimination, blacks and Hispanics gave more favorable ratings to their physicians while reporting experiences of discrimination at rates similar to whites.

Table 7 presents descriptive analyses for primary study variables stratified by adherence

#### *Variables Associated with Adherence: Univariate Analyses*

Out of a total of 103 participants, two were excluded because they did not provide adherence information on the questionnaire, leaving a sample of 101 participants. Adherence was considered adequate in 28 (27.2%) patients. Table 8 shows the unadjusted OR for variables thought to influence HAART adherence. Neither Interpersonal Processes of Care nor Experiences of Discrimination reached significance



in the univariate analyses. Adherence was more common among home-owners and those who earned more than \$20,000 (OR 2.670, 2.526; *p-values* 0.059 and 0.088 for non-homeowners and those earning less than \$20,000 respectively, trend). Poor adherence was seen among those who reported more stress and the tendency to do something about unfair treatment. Adherents reported better social support than non-adherents. As expected, viral loads above 5,000 copies/ml were also correlated with poor adherence. These findings all reached statistical significance.

#### *Variables Associated with Adherence: Multivariate Analysis*

In the multivariate analysis, the best predictive models for adherence included Interpersonal Processes of Care, Experiences of Discrimination, or both. Covariates included age, race, and gender in all three models. For the model examining the patient-doctor relationship as a stand-alone predictor, social support was the only other variable included. For the model looking specifically at racial discrimination, in addition to demographic information, yearly income, social support, stress, and reaction to unfair treatment were retained as covariates. Finally, for the model regressing both Interpersonal Processes of Care and Experiences of Discrimination, covariates included home ownership, social support, stress, reaction to unfair treatment, viral load, and number of medications.

As can be seen in Table 9, certain domains of the Interpersonal Processes of Care scale predicted adherence (Model 1). Patients who responded that their doctors were compassionate were more likely to be adherent (trend, OR 0.084, *p-value* 0.063). Paradoxically, patients who responded that their doctors elicited concerns and responded

appropriately were 6 times more likely to be non-adherent (OR, 6.222, 95% CI 1.267-30.562, *p-value* 0.024). Social support was also associated with adherence in this model. Racial discrimination as a stand-alone predictor was not found to explain adherence (Model 2). However, when Interpersonal Processes of Care was added back into the model, racial discrimination was significantly associated with non-adherence (Model 3). In the full model, patients reporting racial discrimination in 1 or more situations were 4 times as likely to be non-adherent (*p-value* 0.041). Assessing the patient-doctor relationship and discrimination at the same time also weakened the association between Interpersonal Processes of Care and adherence. In the full model, Elicited Concerns/Responded was no longer significant and Compassionate/Respectful became a weaker trend. Also, social support was no longer significant in the full model. Rather, age became significant while stress and number of medications showed a trend towards significance. Reaction to Unfair treatment was included in models containing Experiences of Discrimination in order to detect potential underreporting of racial discrimination. Since the reaction to unfair treatment variable was not hypothesized to directly influence adherence, interpreting its adjusted odds ratio for non-adherence is inappropriate.

## CHAPTER V

### DISCUSSION

Research on adherence to antiretrovirals has usually focused on a priori patient characteristics in order to identify individuals “at risk” for non-adherence<sup>16-22, 25, 28, 43-47</sup>. This study attempted to study the interaction between doctor and patient as a realistic area for improvement. Furthermore, this study acknowledges that health care interactions take place in a social landscape in which the color of one’s skin is a non-random determinant of the distribution of wealth, opportunities for upward mobility, and health<sup>32-34, 48-51</sup>. Given that race has been shown to have nothing to do whatsoever with inherent biology but is nonetheless experienced as social fact, for non-white patients with HIV, interacting with white physicians, interactions may be racialized<sup>48, 49, 52-59</sup>. In other words, the way in which patients and doctors view each other may be conditioned by one’s past experience with “others like them.” This study posits that the act of “racing” each other, applying “stick on labels” to each other, is a fundamental barrier to the establishment of trust between patient and doctor<sup>60-62</sup>. Lack of trust, I hypothesize, may result in non-adherence. To test this hypothesis, I examined the association between Interpersonal Processes of Care, Experiences of Discrimination, and adherence to antiretrovirals among patients with HIV, predicting that those who rated their physicians worse would be less likely to adhere to their HAART regimen and secondly that non-adherents would also report greater levels of racial discrimination. In short, the findings of this study did not

match the hypothesis as expected but revealed some valuable information about doctors, patients, and adherence to HIV medications.

The study found an overall prevalence of HAART adherence of 27.2%. This figure is lower than other published reports on adherence that have reported adherence rates as high as 83%<sup>3</sup>. However, this study is among the first to use a validated adherence measure<sup>18</sup>. Even so, the adherence questionnaire used in this study was validated in Spain and was developed first in Spanish<sup>36</sup>. Therefore, as a check of internal validity for the population in this study, viral loads were dichotomized as detectable and undetectable and were then regressed on adherence. This univariate analysis showed strong association between viral load and adherence, suggesting that the Simplified Medication Questionnaire was appropriate to use in the present study (*p-value* <0.001)<sup>63</sup>.

This study identified a number of variables which were associated with adherence in univariate analysis such as home ownership, income, stress, social support, and reaction to unfair treatment. Social support was found to be highly associated with adherence as has been found repeatedly in the literature, lending credence to the associations discovered in this study<sup>2, 14, 17, 18, 20, 23, 26, 28, 29, 45, 47</sup>.

Without removing the influence of known confounders, neither interpersonal processes of care nor racial discrimination were linked to adherence. In light of the finding in this study that black respondents were more likely to accept unfair treatment as a fact of life rather than talk to others about it, racial discrimination may have been underreported among blacks in this study. There are at least two possible explanations for this finding. The first is that whites may have over-reported racial discrimination as a



matter of conservative ideology or so-called “reverse discrimination” in a state which tends to elect conservative political leaders. The Experiences of Discrimination survey was validated in Boston, Massachusetts which is thought of as a liberal city in the popular imagination. In other studies where this survey has been used, whites have reported significantly less discrimination than blacks<sup>35</sup>. In a study of preterm birth and racial discrimination, 50% of blacks reported discrimination while only 5% of whites did so. In this study, the proportions were 62.2% of blacks and 53.3% of whites reporting racial discrimination. In addition to possible geographic variation, underreporting of racial discrimination by blacks may also have been due to the fact that this survey is typically administered anonymously through mailed surveys or interactive media<sup>34</sup>. In this study, underreporting of discrimination may be attributable to the face-to-face interview protocol as well as differences between the population in this study and the population in which the measure was validated.

In multiple logistic regression analysis, interpersonal processes of care and experiences of racial discrimination were associated with adherence even after removing the effect of known confounders such as social support and treatment complexity. Compassion was found to be a protective factor against non-adherence while racial discrimination was found to be a significant risk factor. However, one unexpected finding was that the Eliciting Concerns domain, which is intended to measure a positive behavior on the part of physicians, actually had a strong association with non-adherence. One possible explanation is that for this cross-sectional study, this association may be effect-cause rather than cause-and-effect. For patients who they perceive as non-



adherent, physicians may question patients more closely about problems encountered in taking medicines. Alternatively, the finding that Eliciting Concerns predicted non-adherence may be due to social desirability bias. Non-adherent patients may want to avoid being viewed as blaming others for their problems or failings. Unfortunately, there are few comparisons available in the literature to make sense of this finding<sup>3, 6, 7, 30, 43, 64</sup>.

One of the objectives of this study was to contribute to the current understanding of what predicts HAART adherence and also what physicians can do about it. The most robust predictive model identified in this study was Model 3, looking at the joint influence of the Patient-Doctor Relationship and Racial Discrimination ( $R^2$  0.247, 0.192, and 0.362 for Models 1, 2, and 3 respectively). This model explained a greater portion of the difference between adherents and non-adherents than taking either predictor in isolation. Model 1 which examined IPC as a stand-alone predictor showed several trends and significant associations with adherence and suggests that the use of this measure could be extended to other chronic diseases for which white/non-white disparities play a smaller role. Model 2 which examined Racial Discrimination as a stand-alone predictor showed no trends or significant associations. However, Model 3 which added the IPC domains back in, uncovered a significant association between discrimination and adherence. This suggests that it was overly simplistic to assume that non-adherence necessarily follows exposure to racial discrimination. Furthermore, the association between disrespectful score and non-adherence was strengthened between the partial model and the full model. This finding suggests that patients who have been discriminated against in the past may also be less likely to adhere to HAART if they are

treated disrespectfully in the doctor's office. The full model indicates that past experiences with racial discrimination and how a patient views experiences with doctors are related in some way and not truly independent variables.

Although racial discrimination was found to be significant in model 3, the discrimination component may have been exaggerated as this construct was measured in both surveys albeit in different formulations. Again, multicollinearity tests showed weak collinearity, but values which were still within acceptable limits. Cross-sectional studies elucidate associations rather than cause-and-effect mechanisms. However, it is possible that for patients who have been hassled or made to feel inferior at school, work, in restaurants, in banks, in public settings, or by the police, this may result in generalized distrust of white people in positions of authority. However, if a physician demonstrates genuine compassion and respect, this may help to overcome barriers of trust between doctor and patient, which is probably the case for most human beings regardless of "race." That being said, this study demonstrates the proof of concept that both interpersonal processes of care and self-reported racial discrimination are probably related and both can be used to explain patient-centered outcomes such as adherence to medications for HIV, a disease which increasingly affects marginalized populations.

### Limitations

This study found that in addition to traditional risk factors, adherence to HAART can be explained in part by the nature of the patient-doctor relationship in light of past experiences with racial discrimination. This is a promising finding for two reasons. First, it provides an area of focus for future interventional research. Second, it provides

an avenue to study the extent to which health disparities are attributable to health care system factors. However, the generalizability of our findings are limited in several important ways in addition to the inherent constraints of small sample size and cross-sectional study design which are unable to establish causality. First, small sample size precluded any stratified analyses which would have revealed more about interactions between variables. Also, since only 27% of participants were adherent, a larger sample size may or may not have revealed a greater number of significant associations. Second, this study was intended to contribute to health disparities research. The problem was that there were no disparities discovered in this population which is good news for the individual participants. However, health disparities in HIV are well documented<sup>15, 23, 31-35, 48, 49, 51, 55, 59, 65, 66</sup>. Our failure to identify health disparities in this study may have been due to a design flaw which can be addressed in future studies. Since we recruited participants at an outpatient clinic, we were only finding participants who were healthy enough to be managed as outpatients. It may be worthwhile to interview patients at later clinical stages, perhaps in hospitals.

Finally, the results of this study should not be extrapolated beyond the study population because the participants were among the poorest members of an urban Texas community.

## CHAPTER VI

### CONCLUSION

#### *Future Directions*

As mentioned, short term goals for working to close health gaps should focus on designing interventions which make physicians aware of how they can help patients gain the most benefit from existing HIV treatments. This study hopefully provides pilot data which can be used to apply for extramural funding for such a project. Longer term goals could include designing medical school curricula to teach future physicians to be more critical of how social constructs such as race influence the practice of medicine<sup>50, 53, 53, 56-58, 60-62</sup>. Lastly, another important goal for medical education should be to train more non-white doctors as this solves three problems simultaneously. Increased diversity within the medical profession would potentially lessen health disparities and social inequalities and would also provide future physicians a richer educational experience.

**Table 1. Coding rules used for SPSS Data Entry**

<b>Variable</b>	<b>Rule</b>
<b>Interpersonal Processes of Care</b>	
Hurried Communication Score	Mean (SD)
Elicited Concerns/Responded Score	Mean (SD)
Explained Results Score	Mean (SD)
Patient Centered Decision Making Score	Mean (SD)
Compassionate/Respectful Score	Mean (SD)
Discrimination Score	Mean (SD)
Disrespectful Score	Mean (SD)
<b>Self-Reported Discrimination</b>	
Experiences of Discrimination: Number of situations mentioned	0 = 0 situations 1 = 1 or more situations
<b>Covariates</b>	
Age	Actual value entered (in years)
Race	1 = Hispanic 2 = Black 3 = White
Sexual Orientation	0 = Gay/Homosexual 1 = Bisexual 2 = Straight/Heterosexual
Gender	0 = Women 1 = Men
Employment Status	0 = Employed 1 = Unemployed



**Table 1. Coding rules used for SPSS Data Entry (continued)**

<b>Variable</b>	<b>Rule</b>
Yearly income	0 = $\geq$ \$20,000 1 = $<$ \$20,000
Home ownership	0 = Home owner 1 = Non home owner
Number of vehicles owned	0 = Zero 1 = One 2 = Two or more
Substance Abuse	0 = Negative 1 = Positive
Social Support Score	Mean (SD)
CES Depression	0 = Not depressed ( $<16$ ) 1 = Depressed ( $\geq 16$ )
Stress Score	Mean (SD)
HIV Stigma Score	Mean (SD)
Reaction to unfair treatment	0 = Passive 1 = Active
General Health	0 = Good/very good/excellent 1 = Fair/poor
Viral load at most recent clinic visit (no. copies/ml)	0 = $<5000$ 1 = $\geq 5000$
Number of medications	Actual value entered
Number HIV Associated Illnesses	0 = One or fewer 1 = Two or more

**Table 2. Interpretation of Survey Scores**

<b>Variable</b>	<b>Interpretation</b>
<b>Interpersonal Processes of Care</b>	
Hurried Communication Score	Higher score ~ worse outcome
Elicited Concerns/Responded Score	Higher score ~ better outcome
Explained Results Score	Higher score ~ better outcome
Patient Centered Decision Making Score	Higher score ~ better outcome
Compassionate/Respectful Score	Higher score ~ better outcome
Discrimination Score	Higher score ~ worse outcome
Disrespectful Score	Higher score ~ worse outcome
<b>Covariates</b>	
Social Support Score	Lower score ~ higher social support
CES Depression Score	Score above 16 ~ depression
HIV Stigma Score	Higher score ~ greater perception of stigma
Stress Score	Higher score ~ greater perception of stress

**Table 3. Population characteristics: Communication, Communities, and Health Study, Tarrant County, TX, 2006 (N=103)\***

<b>Variables</b>	<i>n (%)</i>
<b>Demographics</b>	
Age : mean (SD)	43.52 (9.125)
Race	
Hispanic	36 (35.0)
Black	37 (35.9)
White	30 (29.1)
Gender	
Women	26 (25.2)
Men	77 (74.8)
Sexual Orientation**	
Gay/Homosexual	41 (39.8)
Bisexual	8 (7.8)
Straight/Heterosexual	54 (52.4)
Employment Status	
Employed	60 (58.3)
Unemployed	43 (41.7)
Education level	
Greater than high school	37 (35.9)
High school graduate	28 (27.2)
Some high school or less	38 (36.9)
Yearly Income	
≥ \$20,000	18 (17.5)
< \$20,000	81 (78.6)
Home ownership	
Home owner	21 (20.4)
Non home owner	82 (79.6)

**Table 3. Population characteristics (continued)**

	<i>n (%)</i>
Number of vehicles owned	
Zero	29 (28.2)
One	52 (50.5)
Two or more	22 (21.4)
<b>Psychosocial Data</b>	
Substance Abuse**	
Negative	96 (93.2)
Positive	7 (6.8)
Social Support: mean (SD)	3.07 (0.68)
Depression	
Not depressed	59 (57.3)
Depressed	44 (47.2)
Stress Score: mean (SD)	16.02 (7.93)
HIV Stigma Score: mean (SD)	92.65 (22.77)
Reaction to Unfair Treatment	
Passive	80 (77.7)
Active	23 (22.3)
General Health	
Good/very good/excellent	74 (71.8)
Fair/Poor	29 (28.2)
<b>Clinical Data</b>	
Viral load at most recent clinic visit (no. copies/ml)	
<5000	84 (81.6)
≥5000	19 (18.4)
Number of medications: mean (SD)	5.62 (5.0)
Number HIV Associated Illnesses	
One or fewer	64 (62.1)
Two or more	38 (36.9)



**Table 3. Population characteristics (continued)**

	<i>n (%)</i>
<b>Adherence</b>	
Adherence	
Adherent	28 (27.2)
Non-adherent	73 (70.9)
<b>Interpersonal Processes of Care</b>	
Hurried Communication Score: mean (SD)	1.30 (0.40)
Elicited Concerns/Responded Score: mean (SD)	4.71 (0.53)
Explained Results Score: mean (SD)	4.69 (0.55)
Patient Centered Decision Making Score: mean (SD)	4.21 (0.99)
Compassionate/Respectful Score: mean (SD)	4.82 (0.40)
Discrimination Score: mean (SD)	1.25 (0.46)
Disrespectful Score: mean (SD)	1.28 (0.54)
<b>Self-Reported Discrimination</b>	
Experiences of Discrimination: Number of situations mentioned	
0 situations	42 (40.8)
1 or more situations	61 (59.2)

\* may not add up to 103 due to missing data; \*\*One or more cells had expected count less than 5

**Table 4. Population characteristics stratified by race: Communication, Communities, and Health Study, Tarrant County, TX, 2006 (N=103)\***

	Hispanic (n=36) <i>n (%)</i>	Black (n=37) <i>n (%)</i>	White (n=30) <i>n (%)</i>	<i>p-value</i>
<b>Demographics</b>				
Age : mean (SD)	41.06 (9.15)	44.76 (8.66)	44.97 (9.33)	0.131
Gender				0.033
Women	9 (25.0)	14 (37.8)	3 (10.0)	
Men	27 (75.0)	23 (62.2)	27 (90.0)	
Sexual Orientation**				0.053
Gay/ Homosexual	13 (36.1)	10 (27.0)	18 (60.0)	
Bisexual	2 (5.6)	3 (8.1)	3 (10.0)	
Straight/ Heterosexual	21 (58.3)	24 (64.9)	9 (30.0)	
Employment Status				<0.001
Employed	36 (100.0)	12 (32.4)	12 (40.0)	
Unemployed	0 (0.0)	25 (67.6)	18 (60.0)	
Education level				0.005
Greater than high school	9 (25.0)	12 (32.4)	16 (53.3)	
High school graduate	6 (16.7)	15 (40.5)	7 (23.3)	
Some high school or less	21 (58.3)	10 (27.0)	7 (23.3)	
Yearly Income				0.658
≥ \$20,000	5 (14.7)	6 (17.1)	7 (23.3)	
< \$20,000	29 (85.3)	29 (82.9)	23 (76.7)	
Home ownership				0.026
Home owner	6 (16.7)	4 (10.8)	11 (36.7)	
Non home owner	30 (83.3)	33 (89.2)	19 (63.3)	

**Table 4. Population characteristics stratified by race (continued)**

	<b>Hispanic (n=36)</b>	<b>Black (n=37)</b>	<b>White (n=30)</b>	
<b>Variables</b>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>p-value</i>
Number of vehicles owned				0.023
Zero	10 (27.8)	14 (37.8)	5 (16.7)	
One	14 (38.9)	21 (56.8)	17 (56.7)	
Two or more	12 (33.3)	2 (5.4)	8 (26.7)	
<b>Psychosocial Data</b>				
Substance Abuse**				0.471
Negative	35 (97.2)	34 (91.9)	27 (90.0)	
Positive	1 (2.8)	3 (8.1)	3 (10.0)	
Social Support: mean (SD)	3.03 (0.58)	3.15 (0.59)	3.02 (0.87)	0.684
Depression				0.942
Not depressed	20 (55.6)	22 (59.5)	17 (56.7)	
Depressed	16 (44.4)	15 (40.5)	13 (43.3)	
Stress Score: mean (SD)	13.91 (8.10)	17.05 (7.08)	17.13 (8.49)	0.164
HIV Stigma Score: mean (SD)	92.19 (25.14)	93.14 (22.38)	92.60 (20.92)	0.985
Reaction to Unfair Treatment				0.046
Passive	23 (63.9)	32 (86.5)	25 (83.3)	
Active	13 (36.1)	5 (13.5)	5 (16.7)	
General Health				0.468
Good/very good/excellent	27 (75.0)	28 (75.7)	19 (63.3)	
Fair/Poor	9 (25.0)	9 (24.3)	11 (36.7)	

**Table 4. Population characteristics stratified by race (continued)**

	<b>Hispanic (n=36)</b>	<b>Black (n=37)</b>	<b>White (n=30)</b>	
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>p-value</i>
<b>Clinical Variables</b>				
Viral load at most recent clinic visit (no. copies/ml)				0.494
<5000	31 (86.1)	28 (75.7)	25 (83.3)	
≥5000	5 (13.9)	9 (24.3)	5 (16.7)	
Number of medications: mean (SD)	4.64 (2.51)	6.0 (3.25)	6.33 (2.80)	0.039
Number HIV Associated Illnesses				0.733
One or fewer	22 (61.1)	25 (67.6)	17 (58.6)	
Two or more	14 (38.9)	12 (32.4)	12 (41.4)	
Adherence				0.404
Adherent	9 (25.7)	8 (22.2)	11 (36.7)	
Non-adherent	26 (74.3)	28 (77.8)	19 (63.3)	

\* may not add up to 103 due to missing data; \*\*One or more cells had expected count less than 5



**Table 5. Population characteristics stratified by adherence:  
Communication, Communities, and Health Study, Tarrant County,  
TX, 2006 (N=101)\***

	<b>Adherent</b> <b>(n=28)</b>	<b>Non-adherent</b> <b>(n=73)</b>	
	<i>n (%)</i>	<i>n (%)</i>	<i>p-value</i>
<b>Demographics</b>			
Age : mean (SD)	45.32 (8.55)	42.49 (9.11)	0.159
Race			0.404
Hispanic	9 (32.1)	26 (35.6)	
Black	8 (28.6)	28 (38.4)	
White	11 (39.3)	19 (26.0)	
Gender			0.262
Women	5 (17.9)	21 (28.8)	
Men	23 (82.1)	52 (71.2)	
Sexual Orientation**			0.147
Gay/ Homosexual	14 (50.0)	26 (35.6)	
Bisexual	0 (0.0)	7 (9.6)	
Straight/ Heterosexual	14 (50.0)	40 (54.8)	
Employment Status			0.233
Employed	19 (67.9)	40 (54.8)	
Unemployed	9 (32.1)	33 (45.2)	
Education level			0.299
Greater than high school	13 (46.4)	22 (30.1)	
High school graduate	6 (21.4)	22 (30.1)	
Some high school or less	9 (32.1)	29 (39.7)	
Yearly Income			0.081
≥ \$20,000	8 (29.6)	10 (14.3)	
< \$20,000	19 (70.4)	60 (85.7)	

**Table 5. Population characteristics stratified by adherence (continued)**

	<b>Adherent (n=28) n (%)</b>	<b>Non-adherent (n=73) n (%)</b>	<b>p-value</b>
Home ownership			0.054
Home owner	9 (32.1)	11 (15.1)	
Non home owner	19 (67.9)	62 (84.9)	
Number of vehicles owned			0.667
Zero	6 (21.4)	22 (30.1)	
One	15 (53.6)	36 (49.3)	
Two or more	7 (25.0)	15 (20.5)	
<b>Psychosocial Data</b>			
Substance Abuse**			0.410
Negative	27 (96.4)	67 (91.8)	
Positive	1 (3.6)	6 (8.2)	
Social Support: mean (SD)	3.38 (0.68)	2.97 (0.65)	0.006
Depression			0.189
Not depressed	19 (67.9)	39 (53.4)	
Depressed	9 (32.1)	34 (46.6)	
Stress Score: mean (SD)	13.33 (7.88)	17.19 (7.78)	0.031
HIV Stigma Score: mean (SD)	86.07 (21.11)	94.73 (22.99)	0.087
Reaction to Unfair Treatment			0.027
Passive	26 (92.9)	53 (72.6)	
Active	2 (7.1)	20 (27.4)	
General Health			0.018
Good/very good/excellent	25 (89.3)	48 (65.8)	
Fair/Poor	3 (10.7)	25 (34.2)	

**Table 5. Population characteristics stratified by adherence (continued)**

	<b>Adherent (n=28)</b>	<b>Non-adherent (n=73)</b>	
	<i>n (%)</i>	<i>n (%)</i>	<i>p-value</i>
<b>Clinical Data</b>			
Viral load at most recent clinic visit (no. copies/ml)			0.015
<5000	27 (96.4)	55 (75.3)	
≥5000	1 (3.6)	18 (24.7)	
Number of medications: mean (SD)	5.43 (2.426)	5.64 (3.151)	0.745
Number HIV Associated Illnesses			0.768
One or fewer	17 (60.7)	46 (63.9)	
Two or more	11 (39.3)	26 (36.1)	

\*may not add up to 101 due to missing data; \*\*One or more cells had expected count less than 5

**Table 6. Descriptive analysis of primary study variables stratified by race: Communication, Communities, and Health Study, Tarrant County, TX, 2006 (N=103)\***

	Hispanic (n= 36)	Black (n= 37)	White (n=30 )	
Variables	mean (SD)	mean (SD)	mean (SD)	<i>p-value</i>
<b>Interpersonal Processes of Care</b>				
Hurried Communication Score	1.21 (0.288)	1.31 (0.385)	1.42 (0.507)	0.096
Elicited Concerns/Responded Score	4.81 (0.440)	4.68 (0.616)	4.63 (0.501)	0.303
Explained Results Score	4.76 (0.427)	4.80 (0.413)	4.48 (0.750)	0.035
Patient Centered Decision Making Score	4.30 (0.872)	4.41 (0.692)	3.86 (1.322)	0.062
Compassionate/Respectful Score	4.87 (0.397)	4.88 (0.268)	4.69 (0.498)	0.107
Discrimination Score	1.22 (0.474)	1.30 (0.513)	1.21 (0.360)	0.681
Disrespectful Score	1.26 (0.536)	1.17 (0.405)	1.46 (0.660)	0.088
<b>Self-Reported Discrimination</b>				
	n (%)	n (%)	n (%)	<i>p-value</i>
Experiences of Discrimination: Number of situations mentioned				0.735
0 situations	14 (38.9)	14 (37.8)	14 (46.7)	
1 or more situations	22 (61.1)	23 (62.2)	16 (53.3)	

\*May not add up to 103 due to missing data



**Table 7. Descriptive analysis of primary study variables stratified by adherence: Communication, Communities, and Health Study, Tarrant County, TX, 2006 (N=101)\***

	<b>Adherent (n=28)</b>	<b>Non-Adherent (n=73)</b>	
<b>Variables</b>	mean (SD)	mean (SD)	<i>p-value</i>
<b>Interpersonal Processes of Care</b>			
Hurried Communication Score	1.31 (0.485)	1.30 (0.371)	0.886
Elicited Concerns/Responded Score	4.61 (0.697)	4.76 (0.421)	0.277
Explained Results Score	4.69 (0.622)	4.69 (0.528)	0.994
Patient Centered Decision Making Score	4.32 (0.969)	4.16 (1.011)	0.472
Compassionate/Respectful Score	4.90 (0.264)	4.79 (0.437)	0.124
Discrimination Score	1.17 (0.360)	1.25 (0.476)	0.392
Disrespectful Score	1.38 (0.698)	1.26 (0.482)	0.405
<b>Self-Reported Discrimination</b>			
	n (%)	n (%)	<i>p-value</i>
Experiences of Discrimination: Number of situations mentioned			0.460
0 situations	13 (46.4)	28 (38.4)	
1 or more situations	15 (53.6)	45 (61.6)	

\*May not add up to 101 due to missing data

**Table 8. Unadjusted models for factors associated with HAART non-adherence: Communication, Communities, and Health Study, Tarrant County, TX, 2006 (N=101)**

Variables	Non-Adherent to HAART Regimen		
	OR*	95% CI*	<i>p</i> -value
<b>Interpersonal Processes of Care</b>			
Hurried Communication	0.924	0.315-2.706	0.885
Elicited Concerns/Responded	1.720	0.774-3.821	0.183
Explained Results	1.003	0.454-2.213	0.994
Patient Centered Decision Making	0.841	0.525-1.345	0.469
Compassionate/Respectful	0.405	0.094-1.743	0.225
Discrimination	1.637	0.529-5.069	0.393
Disrespectful	0.681	0.319-1.456	0.322
<b>Self-Reported Racial Discrimination</b>			
Experiences of Discrimination: Number of situations mentioned			
0 situations	...	...	...
1 or more situations	1.393	0.578-3.358	0.460
<b>Covariates</b>			
Age	0.965	0.918-1.014	0.160
Race			
Hispanic	1.673	0.579-4.833	0.342
Black	2.026	0.687-5.973	0.200
White	...	...	...
Gender			
Women	...	...	...
Men	0.538	0.181-1.604	0.266

**Table 8. Unadjusted models for factors associated with HAART non-adherence (continued)**

	<b>Non-Adherent to HAART Regimen</b>		
	<b>OR*</b>	<b>95% CI*</b>	<b>p- value</b>
<b>Sexual Orientation**</b>			
Gay/	...	...	...
Homosexual			
Bisexual	0.650	0.267-1.583	0.343
Straight/	6E + 008	NA	0.999
Heterosexual			
<b>Employment Status</b>			
Employed	...	...	...
Unemployed	1.742	0.696-4.359	0.236
<b>Home ownership</b>			
Home owner	...	...	...
Non home owner	2.670	0.963-7.403	0.059
<b>Number of vehicles owned</b>			
Zero	...	...	...
One	1.711	0.479-6.109	0.408
Two or more	1.120	0.380-3.300	0.837
<b>Education level</b>			
Greater than high school	...	...	...
High school graduate	0.525	0.190-1.449	0.213
Some high school or less	1.138	0.352-3.675	0.829
<b>Yearly income</b>			
≥\$20,000	...	...	...
<\$20,000	2.526	0.872-7.316	0.088
<b>Substance Abuse**</b>			
Negative	...	...	...
	2.418	0.278-21.042	0.424
Positive			
<b>Social Support</b>	0.324	0.140-0.748	0.008
<b>Depression</b>			
Not depressed	...	...	...
Depressed	1.840	0.736-4.603	0.192

**Table 8. Unadjusted models for factors associated with HAART non-adherence (continued)**

	Non-Adherent to HAART Regimen		
	OR*	95% CI*	<i>p</i> - value
Stress	1.066	1.005-1.131	0.034
HIV Stigma Score: mean (SD)	1.018	0.997-1.040	0.089
General Health			
Good/very good/excellent	...	...	...
Fair/Poor	4.340	1.193-15.790	0.026
Reaction to unfair treatment			
Passive	...	...	...
Active	4.906	1.065-22.597	0.041
Viral load at most recent clinic visit (no. copies/ml)			
<5000	...	...	...
≥5000	8.836	1.120-69.724	0.039
Number of medications	1.026	0.883-1.129	0.742
Number HIV Associated Illnesses			
One or fewer	...	...	...
Two or more	0.874	0.356-2.144	0.768

OR- Odds Ratio from univariate analysis, \*\*One or more cells had expected count less than 5, CI- Confidence Interval, ...-reference group

**Table 9. Adjusted predictive models for non-adherence to HAART: The Communication, Communities, and Health Study, Tarrant County, TX, 2006 (N=101)**

	Non-Adherent to HAART Regimen						Model 3: Joint Influence of Pt-Doctor Relationship and Racial Discrimination		
	Model 1: Pt-Doctor Relationship as Stand-Alone Predictor			Model 2: Racial Discrimination as Stand-Alone Predictor					
	AOR*	95% CI	p-value*	AOR	95% CI	p-value	AOR	95% CI	p-value
<b>Interpersonal Processes of Care</b>									
Hurried Communication	0.567	0.095-3.391	0.534	_____	_____	_____	0.243	0.029-2.071	0.196
Elicited Concerns/ Responded	6.222	1.267-30.562	0.024	_____	_____	_____	7.967	0.893-71.100	0.063
Explained Results	2.242	0.477-10.547	0.307	_____	_____	_____	1.429	0.191-10.702	0.728
Patient Centered Decision Making	0.609	0.219-1.695	0.343	_____	_____	_____	0.481	0.134-1.729	0.262
Compassionate/ Respectful	0.084	0.006-1.141	0.063	_____	_____	_____	0.062	0.003-1.519	0.088
Discrimination	3.150	0.529-18.766	0.208	_____	_____	_____	4.331	0.416-45.055	0.220
Disrespectful	0.649	0.232-1.817	0.410	_____	_____	_____	0.270	0.066-1.095	0.067



**Table 9. Adjusted predictive models for non-adherence to HAART: The Communication, Communities, and Health Study, Tarrant County, TX, 2006 (N=101) (continued)**

Non-Adherent to HAART Regimen									
	Model 1: Pt-Doctor Relationship as Stand-Alone Predictor			Model 2: Racial Discrimination as Stand-Alone Predictor			Model 3: Joint Influence of Pt-Doctor Relationship and Racial Discrimination		
	AOR*	95% CI	p-value*	AOR	95% CI	p-value	AOR	95% CI	p-value
<b>Self-Reported Discrimination</b>									
Experiences of Discrimination:									
Number of situations mentioned									
0 situations				...	...	...	...	...	...
1 or more situations				1.834	0.598-5.622	0.289	4.725	1.066-20.941	0.041
<b>Covariates</b>									
Age	0.952	0.890-1.018	0.150	0.955	0.895-1.019	0.167	0.888	0.808-0.976	0.014
Race									
Hispanic	1.170	0.306-4.476	0.819	1.143	0.301-4.350	0.844	0.947	0.153-5.849	0.953
Black	2.306	0.581-9.147	0.235	2.096	0.569-7.713	0.266	1.915	0.331-11.086	0.468
White	...	...	...	...	...	...	...	...	...
Gender									
Women	...	...	...	...	...	...	...	...	...
Men	0.456	0.110-1.882	0.277	0.677	0.177-2.588	0.569	0.190	0.030-1.190	0.076

**Table 9. Adjusted predictive models for non-adherence to HAART: The Communication, Communities, and Health Study, Tarrant County, TX, 2006 (N=101) (continued)**

	Non-Adherent to HAART Regimen						Model 3: Joint Influence of Pt-Doctor Relationship and Racial Discrimination		
	Model 1: Pt-Doctor Relationship as Stand-Alone Predictor			Model 2: Racial Discrimination as Stand-Alone Predictor					
	AOR*	95% CI	p-value*	AOR	95% CI	p-value	AOR	95% CI	p-value
Social Support	0.311	0.128-0.755	0.010	0.488	0.186-1.283	0.146	0.734	0.239-2.257	0.589
Stress	_____	_____	_____	1.054	0.984-1.130	0.133	1.090	0.996-1.192	0.061
Reaction to unfair treatment									
Passive	_____	_____	_____	...	...	...	...	...	...
Active	_____	_____	_____	4.626	0.791-27.054	0.089	11.571	1.222-109.556	0.033
Viral load at most recent clinic visit (no. copies/ml)									
<5000	_____	_____	_____	_____	_____	_____	...	...	...
≥5000	_____	_____	_____	_____	_____	_____	7.772	0.571-105.854	0.124
Number of medications	_____	_____	_____	_____	_____	_____	1.265	0.971-1.648	0.082

\* AOR- Adjusted Odds Ratio from multivariate analysis, CI- Confidence Interval, ...-reference group

Participants	Recruitment and Survey Protocol
<b>Initial Sample</b>	<p><b>Recruitment Pool:</b> Patients having clinic visits at the Tarrant County Preventive Medicine Clinic</p> <p><b>Eligible:</b> HIV positive, over the age of 18, no previous diagnosis of dementia, on HAART for at least 3 months, English or Spanish</p>
<b>Study</b>	<p><b>Interview Mode:</b> The following measures were read by the interviewer: Interpersonal Processes Of Care, Experiences Of Discrimination, and the Medication Adherence Questionnaire. For the remainder of the survey, some portions were read by the interviewer and other portions were participant self-administered.</p> <p><b>Compensation:</b> At completion, \$15 retail gift card.</p>

Figure 2. Recruitment and survey protocol for the Communication, Communities, and Health Study, Tarrant County, Texas, 2006.

## PARTICIPATION

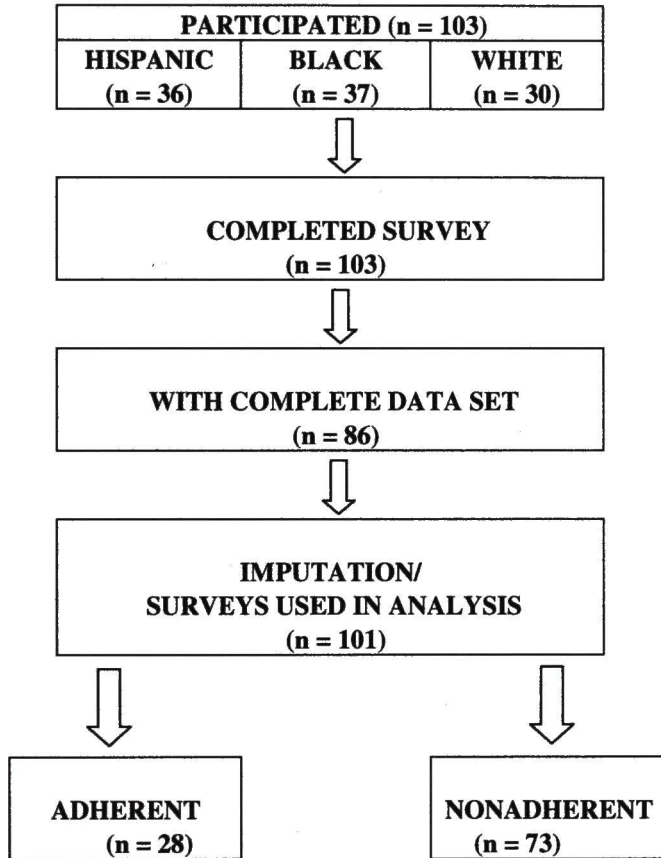


Figure 3. Participation for the Communication, Communication, and Health Study, Tarrant County, Texas, 2006.

## What Predicts Adherence?

Quality Of The  
Patient - Doctor Relationship  
("Interpersonal Process of Care")



### Predictors Under Question

1. Hurried Communication
2. Elicited Concerns/Responded
3. Explained Results
4. Patient Centered Decision Making
5. Compassionate/Respectful
6. Discrimination
7. Disrespectful



### Known Confounders

Stress  
Social Support  
Treatment Complexity  
Reaction to Unfair Treatment



### Other Potential Confounders

Demographics: Age, Race, Gender

Psychological Variables: Depression, Substance Abuse

Clinical Variables: Viral Load, CD4 cell count, # of AIDS Defining Illnesses, General Health

Socioeconomic Variables: Home ownership, Income, Education



### Final Model ( $R^2$ 0.247)

Age  
Race  
Gender  
Social Support  
Interpersonal Processes of Care

**Figure 4. Building a predictive model for adherence**



## What Predicts Adherence?

Experiences of Discrimination



### Predictors Under Question

Discrimination in the following situations:

1. At School?
2. Getting hired for a job?
3. At work?
4. Getting housing?
5. Getting medical care?
6. Getting service in a store or restaurant?
7. Getting credit, bank loans, or a mortgage
8. On the street or in a public setting?
9. From the police or in the courts?



### Known Confounders

Stress  
Social Support  
Treatment Complexity  
Reaction to Unfair Treatment



### Other Potential Confounders

Demographics: Age, Race, Gender  
Psychological Variables: Depression, Substance Abuse  
Clinical Variables: Viral Load, CD4 cell count, # of AIDS Defining Illnesses, General Health  
Socioeconomic Variables: Home ownership, Income, Education



### Final Model ( $R^2$ 0.192)

Age  
Race  
Gender  
Social Support  
Stress  
Unfair Treatment  
Income  
Experiences Of Discrimination

**Figure 5. Building a predictive model for adherence with Experiences of Discrimination as an independent variable**

### What Predicts Adherence?

The joint influence of exposure to racism and the nature of the patient-doctor relationship.



**Predictors Under Question**  
Experiences of Discrimination  
Interpersonal Processes of Care



**Known Confounders**  
Stress  
Social Support  
Treatment Complexity  
Reaction to Unfair Treatment



**Other Potential Confounders**  
Demographics: Age, Race, Gender  
  
Psychological Variables: Depression, Substance Abuse  
  
Clinical Variables: Viral Load, CD4 cell count, # of AIDS Defining Illnesses, General Health  
  
Socioeconomic Variables: Home ownership, Income, Education



**Final Model ( $R^2$  0.362)**  
Age  
Race  
Gender  
  
Social Support  
Stress  
Unfair Treatment  
Home Ownership  
Viral Load  
Number of Medications  
  
Experiences of Discrimination  
Interpersonal Processes of Care

**Figure 6. Building a predictive model for adherence examining discrimination and the patient-doctor relationship simultaneously**

**APPENDIX A**

**INFORMED CONSENT**

## **INFORMED CONSENT AUTHORIZATION TO PARTICIPATE IN A RESEARCH PROJECT**

**TITLE:** The Communication, Communities, and Health study

**PRINCIPAL INVESTIGATOR:** Roberto Cardarelli, D.O., M.P.H

**SPONSOR:** None

**SUBJECT NAME (Please print):** \_\_\_\_\_

**This is an invitation to participate in research. This form explains your rights as a research participant. Please take your time to make your decision. Feel free to discuss it with your doctors, family, or anyone you wish. The 'research team' may include physicians and/or other licensed practitioners.**

**The researchers must give you a copy of this form to keep.**

### **I. STUDY PURPOSE**

The purpose of this research study is to find out if how people's communication with their doctor and different life stresses affect how people take their medicines.

### **II. STUDY PROCEDURES**

You will be asked to take part in an interview. The interview is about your experiences in various life situations, such as at work and at home. In addition, we are going to ask about some personal information about yourself, your lifestyle, how you feel you are treated by your doctor and other people, your support from family and friends, as well as questions about symptoms of depression. This interview will take about one and a half hours. We are also asking for your permission to review your medical chart only to obtain laboratory results, current and past medical problems, and your list of medicines.

The following is a list of things that will take place:

#### **The Interview**

- You will answer a survey that will take about one and a half hours to complete. The Research Assistant (RA) will read the first part,

and you will read and answer the 2<sup>nd</sup> part of the survey. If you prefer, the RA can read all of the questions to you.

### **Medical chart review**

- After the interview, the RA will review your medical chart for information about your medical history, how long you have been going to the clinic, and medicines you are taking.

## **III. RISKS AND DISCOMFORTS OF THE STUDY**

The risks associated with this study are minimal.

### **Questionnaire –**

- a. You may experience some discomfort when answering some of the questions in the survey. If this happens, you may refuse to answer any questions that you find uncomfortable. You will be referred to your physician if you experience high levels of distress brought on by any questions in the survey.
- b. There is the possibility that the results of your interview and tests may accidentally be revealed to someone other than the study investigators. If your clinician is either Dr. Weis or Dr. Adams, they will not know how you answered. Your name will not appear in the computer where we enter your responses. We will only enter a number in the computer and only Dr. Cardarelli and Ana Chiapa, the research coordinator, will know whose name goes with what number. The study investigators will take all precautions necessary to protect your confidentiality as a research study participant. None of your personal identifying information, such as name or address, will be recorded in the study data.

## **IV. CONTACTS**

If a study-related problem should occur, or if you have any questions at any time about the study, you may contact Dr. Roberto Cardarelli's office at (817) 735-2228. If you have any questions about your rights as a participant in this study, you may contact Dr. Jerry McGill, Chairman of the Institutional Review Board, University of North Texas Health Science Center at Fort Worth at (817) 735-5457.

## **V. BENEFITS**



You may receive no direct benefit from participating in this study. The information gained from this research may lead to the development of better ways to help HIV/AIDS patients take their medicines regularly.

## **VI. ALTERNATIVES**

This study involves one interview. There are no additional treatments or interventions involved in our study, other than what has been explained. Therefore, the only alternative to our study is to not participate in the study.

## **VII. CONFIDENTIALITY**

Your interview responses will be kept as confidential as possible under current local, state, and federal laws. However, the Office for Human Research Protections, possibly other federal regulatory agencies, and the Institutional Review Board may examine your interview responses and the study data. In the case the final results of this study should be published, no individual results will be reported, and your name will not appear in any published material.

## **VIII. COMPENSATION FOR INJURY**

The investigators conducting this study, nor the University of North Texas Health Sciences Center at Fort Worth are able to offer financial compensation nor absorb the costs of medical treatment should you be injured as a result of your participation in this research.

You should know that by signing this form you are neither waiving any of your legal rights against nor releasing the investigators conducting this study, nor the University of North Texas Health Sciences Center at Fort Worth or any of their respective agents from liability for negligence with respect to the conduct of this study. If you are harmed and you feel that this harm justifies pursuing a legal remedy, you have the right to do so.

## **IX. COSTS AND PAYMENTS OF THE STUDY**

You will receive a \$15 gift card/certificate as a reimbursement for your time and effort for participating in the study. You will receive this at the end of the interview.

## **X. LEAVING THE STUDY**

You can choose not to be in the study or leave it (discontinue the interviews) at any time without penalty or loss of benefits that you are otherwise entitled. Your participation (or non-participation), or any response that you give, will in no way affect the care that you receive at your clinic.

If you are a student or employee of the University of North Texas Health Science Center at Fort Worth, your participation (or non-participation) will in no way affect your academic standing or employment status.

## **XI. CONSENT**

I voluntarily agree to participate in this study. I have had the chance to ask the study investigators any questions I have regarding this study.

**YOU WILL RECEIVE A COPY OF THIS SIGNED INFORMED CONSENT AGREEMENT.**

---

Signature of Study Participant

Date

---

Signature of Person Obtaining Informed Consent

Date

**Protocol Title:** The Communication, Communities, and Health study

**Principal Investigator:** Roberto Cardarelli, D.O., M.P.H

**ADDENDUM TO INFORM CONSENT FORM FOR PARTICIPATING IN A  
HUMAN RESEARCH STUDY  
(HIPAA AUTHORIZATION FOR USE OF PROTECTED HEALTH  
INFORMATION IN RESEARCH)**

The word “you” means both the person who takes part in the research, and the person who gives permission to be in the research. This form and the attached research consent form need to be kept together.

**Purpose of this form:**

You have been asked to take part in a research study. The consent form for this study describes your participation, and that information still applies. This addendum is required by the federal “Health Insurance Portability and Accountability Act” (HIPAA). The purpose is to get your permission (authorization) to use health information about you that is created by or used in connection with the research. If you are signing on behalf of someone other than yourself, this permission applies to that person’s health records.

**Authorization to Use Health Information:**

The investigators named above and their assistants will be allowed to see and to use your health information for this research study. We may share your health information with people at the hospital or Health Science Center who help with the research. We may share your information with other researchers outside of the Health Science Center or with labs running additional tests. We may also share your information with people outside of the Health Science Center who are in charge of the research, pay for or work with us on the research, or by the U.S. Food and Drug Administration (FDA), in order to check for quality, safety or effectiveness. Some of these people make sure we do the research properly. The “confidentiality” section of the consent form says who these people are. Some of these people may share your health information with someone else. If they do, the same laws that the Health Science Center must obey may not protect your health information.

We are asking you to take part in the research described in the attached consent form. To do this research, we need to collect health information that identifies you. The information we might use or disclose includes:



- Supporting information from your medical record, including laboratory test results, dates of your visits, medical conditions, and medication list.
- Your responses to the study interview questions.

In order for you to participate in this study, we need your permission to collect and share this information.

#### Term of Authorization:

If you sign this form, we will collect your health information until the end of the research. We may collect some information from your medical records even after your direct participation in the research project ends. We will keep all the information as long as necessary, in case we need to look at it again. We will protect the information and keep it confidential.

#### Refusal to sign/Right to Revoke:

If you sign this form, you are giving us permission to collect, use and share your health information. You do not need to sign this form. If you decide not to sign this form, you cannot be in the research study. You need to sign this form and the attached consent form if you want to be in the research study. We cannot do the research if we cannot collect, use and share your health information.

If you change your mind later and do not want us to collect or share your health information, you need to send a letter to the researcher listed on the attached consent form. The letter needs to say that you have changed your mind and do not want the researcher to collect and share your health information. You may also need to leave the research study if we cannot collect any more health information. However, we may still use the information we have already collected, since we need to know what happens to everyone who starts a research study, not just those people who stay in it.

#### Questions regarding your privacy rights:

Any questions? Please ask the researcher. You can also call 817-735-2496 with questions about the research use of your health information. The researcher will give you a signed copy of this form.

#### SIGNATURE, DATE, AND IDENTITY OF PERSON SIGNING

By signing this form, I am giving permission for the personal health information about \_\_\_\_\_ to be collected and used as described above by the researchers and staff for the research study described in this form

and the attached consent form. I will be given a copy of this authorization form after I have signed it.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_  
Print  
name: \_\_\_\_\_ Relation: \_\_\_\_\_



**APPENDIX B**

**PARTICIPATION SCREENING FORM**

## **"Communication, Communities, and Health" Study**

### **Screening Form**

**Date:** \_\_\_\_\_ **Investigator:** \_\_\_\_\_

**"Hi, my name is \_\_\_\_\_ and I work at the University of North Texas Health Science Center. I am here because we are recruiting participants for a study that wants to find out if people who experience different stresses in their life are less likely to take their medicines. The study only involves answering a survey and you will be compensated for your time. Would you be interested in participating?"**

**NO (STOP) - "Thank you for your time"**

**YES – "Great, I will first ask you some questions to see if you qualify":**

1. What is your date of birth? \_\_\_\_\_
2. What is your age? \_\_\_\_\_
3. What is your race/ethnicity? \_\_\_\_\_
4. Do you test positive for HIV/AIDS? \_\_\_\_\_
5. Have you ever been diagnosed with problems with your memory? \_\_\_\_\_
6. Are you currently taking medications for HIV/AIDS? \_\_\_\_\_
  - a. For how long? (needs to be at least 3 months) \_\_\_\_\_
7. Was there anything in the past month that may have affected the way you take your medicines? (ex. Went out of town and forgot medication)  
Yes                      No

**IF THEY QUALIFY:** "You do qualify for our study, would you have some time right now to answer the survey? The survey takes about 1 hour to 1 ½ hours to complete".

**YES** (Bring participant to private room)

**NO:** If they answer they don't have time right now, tell them we will be in the clinic every week, and they can come at any time and request to participate in the study.

**IF THEY DO NOT QUALIFY:** "Thank you for your interest in our study. At this time you don't qualify, but we may have future projects that you may be able to participate later on. Thank you for your time".

**APPENDIX C**

**SURVEY INSTRUMENT**

**University of North Texas Health Science Center  
Texas College of Osteopathic Medicine  
Department of Family Medicine  
The North Texas Primary Care Practice-Based Research Network**

**Psychosocial factors and Highly Active Anti-Retroviral Therapy adherence among HIV/AIDS treated individuals  
"Communication, Communities, and Health Study"**

**Primary Investigator: Dr. Roberto Cardarelli (817) 735-0282**

**Survey Date** (*sdate*): \_\_\_\_\_ **Site** (*site*): \_\_\_\_\_ **Data Entry** (*dateent*): \_\_\_\_\_

**Interviewer** (*intervwr*): \_\_\_\_\_

**TO BE READ BY INTERVIEWER**

**All answers are CONFIDENTIAL. Your doctor or nurse will not know how you answered and your answers will not affect the medical care you receive.**

**UIN** (*uin*): \_\_\_\_\_

**Also includes:**

- ☐ **Hispanic/Latino Accult scale**

☐ AfAm Belief/Attitudes scale

☐ Neither

## ADMINISTERED BY INTERVIEWER

### TO BE READ BY INTERVIEWER

The next questions are about your experiences talking with your doctors at the Preventive Medicine clinic in the past 12 months. If you see more than one doctor at the Preventive Medicine clinic, please tell us, on average, how often they did the following:

	Never	Rarely	Sometimes	Usually	Always
Q1. How often did doctors speak too fast?	1	2	3	4	5 (spkfast)
Q2. How often did doctors use words that were hard to understand?	1	2	3	4	5 (wrdunder)
Q3. How often did doctors ignore what you told them?	1	2	3	4	5 (ignore)
Q4. How often did doctors appear to be distracted when they were with you?	1	2	3	4	5 (distracted)



Q5. How often did doctors seem bothered if you asked several questions?

1

2

3

4

5

(bothered)

Q6. How often did doctors really find out what your concerns were?

1

2

3

4

5

(findout)

Q7. How often did doctors let you say what you thought was important?

1

2

3

4

5

(important)

**Never**

**Rarely**

**Sometimes**

**Usually**

**Always**

Q8. How often did doctors take your health concerns very seriously?

(serious)

Q9. How often did doctors explain your test results such as blood tests, x-rays, or cancer screening tests?

1

2

3

4

5

(explain tests)

Q10. How often did doctors clearly explain the results of your physical exam?

1

2

3

4

5

(response)

Q11. How often did doctors tell you what could happen if you didn't take a medicine that they prescribed for you?

(tellrx)

1	2	3	4	5
Q12. How often did doctors tell you about side effects you might get from a medicine?				
1	2	3	4	5
				(tells)

**TO BE READ BY INTERVIEWER**  
**Now I have some questions about how you and your medical doctors decide about your health care.**

	Never	Rarely	Sometimes	Usually	Always
Q13. How often did doctors ask if you would have any problems following what they recommended?	1	2	3	4	5 (probrec)
Q14. How often did doctors ask if you felt you could do the recommended treatment?	1	2	3	4	5 (felttx)
	Never	Rarely	Sometimes	Usually	Always
Q15. How often did you and your doctors work out a treatment plan together?	1	2	3	4	5 (plantog eth)
Q16. If there were treatment choices, how often did doctors ask if you would like to help decide your treatment?	1	2	3	4	5 (decidetx )

**TO BE READ BY INTERVIEWER**

**These questions are about the personal interactions between you and your doctor(s).  
Please continue to think about your experiences over the past 12 months.**

	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Usually</b>	<b>Always</b>
Q17. How often were doctors compassionate?	1	2	3	4	5 (compass)
Q18. How often did doctors give you support and encouragement?	1	2	3	4	5 (encoura)
Q19. How often were doctors concerned about your feelings?	1	2	3	4	5 (yrfeeling)
Q20. How often did doctors really respect you as a person?	1	2	3	4	5 (respecty)
Q21. How often did doctors treat you as an equal?	1	2	3	4	5 (trtequal)
Q22. How often did doctors make assumptions about your level of education?	1	2	3	4	5 (assume)
	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Usually</b>	<b>Always</b>
Q23. How often did doctors make assumptions about your income?	1	2	3	4	5 (assumei)
Q24. How often did doctors pay less attention to you because of your race or ethnicity?	1	2	3	4	5 (lessatte)

	1	2	3	4	5	
Q25. How often did you feel discriminated against by doctors because of your race or ethnicity?						(docdiscr)
	1	2	3	4	5	

<p><b><u>TO BE READ BY INTERVIEWER</u></b></p> <p><b>The next four questions ask about the doctor's front office staff, meaning the receptionist or the person you talk to on the phone to make an appointment.</b></p>
---

	Never	Rarely	Sometimes	Usually	Always	
Q26. How often were office staff rude to you?						(staffrud)
	1	2	3	4	5	
Q27. How often did office staff talk down to you?						(talkdwn)
	1	2	3	4	5	
Q28. How often did office staff give you a hard time?						(hrdtime)
	1	2	3	4	5	
Q29. How often did office staff have a negative attitude toward you?						(negatt)
	1	2	3	4	5	

<p><b><u>TO BE READ BY INTERVIEWER</u></b></p> <p><b>"This section is going to ask about how you and others like you are treated, and how you typically respond."</b></p>
---

1. If you feel you have been treated unfairly, do you usually: (select the **best** response). (dcunfair 1)

☐ Accept it as a fact of life <sub>1</sub>

- ☐ Try to do something about it<sub>0</sub>

2. And if you have been treated unfairly, do you usually: (select the **best** response)

(dcunfair  
2)

- ☐ Talk to other people about it<sub>0</sub>
- ☐ Keep it to yourself<sub>1</sub>

3. Have you ever experienced discrimination, been prevented from doing something, or been hassled or made to feel inferior in any of the following seven situations because of your race, ethnicity, or color...

**If response is "YES"**

How many times did this happen?

						Once <sub>1</sub>	2-3 times <sub>2</sub>	4 or more times <sub>3</sub>	
3a.	<input type="checkbox"/> No <sub>0</sub>	<input type="checkbox"/> Yes <sub>1</sub>	<b>At school?</b>	(dcschool)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(schooly)	
3b.	<input type="checkbox"/> No <sub>0</sub>	<input type="checkbox"/> Yes <sub>1</sub>	<b>Getting hired for a job?</b>	(dcjob)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(joby)	
3c.	<input type="checkbox"/> No <sub>0</sub>	<input type="checkbox"/> Yes <sub>1</sub>	<b>At work?</b>	(dcwork)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(worky)	
3d.	<input type="checkbox"/> No <sub>0</sub>	<input type="checkbox"/> Yes <sub>1</sub>	<b>Getting housing?</b>	(dchouse)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(housey)	
3e.	<input type="checkbox"/> No <sub>0</sub>	<input type="checkbox"/> Yes <sub>1</sub>	<b>Getting medical care?</b>	(cdmedca)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(medcay )	
3f.	<input type="checkbox"/> No <sub>0</sub>	<input type="checkbox"/> Yes <sub>1</sub>	<b>Getting service in a store or restaurant?</b>	(dcservice)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(servicey )	
3g.	<input type="checkbox"/> No <sub>0</sub>	<input type="checkbox"/> Yes <sub>1</sub>	<b>Getting credit, bank loans, or mortgage?</b>	(dcbank)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(banky)	
3h.	<input type="checkbox"/> No <sub>0</sub>	<input type="checkbox"/> Yes <sub>1</sub>	<b>On the street or in a public setting?</b>	(dcstreet)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(streety)	
3i.	<input type="checkbox"/> No <sub>0</sub>	<input type="checkbox"/> Yes <sub>1</sub>	<b>From the police</b>	(dcpolice)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(policey)	



or in the courts?

**TO BE READ BY INTERVIEWER**

"The next questions are about how you feel."

"These are some statements people have made. For each of the following please tell me if you strongly agree, agree, disagree, or strongly disagree"

**SENSE OF CONTROL**

	Strongly Agree-2	Agree-1	Neutral0	Disagree-1	Strongly Disagree2	Unknown7	
<i>Control over good</i>							
1. I am responsible for my own successes.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(scresp)
2. I can do just about anything I really set my mind to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(scmind)
<i>Control over bad</i>							
3. My misfortunes are the result of mistakes I have made.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(scmisf)
4. I am responsible for my failures.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(scfail)
<i>Powerlessness over good</i>							
5. The really good things that happen to me are mostly luck.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(scluck)
6. There's no sense in planning a lot—if something good is going to happen, it will.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(scnopai n)
<i>Powerlessness over bad</i>							
7. Most of my problems are due to bad breaks.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(scbadbk s)

8. I have little control over the bad things that happen to me.

(snocont)

☐ ☐ ☐ ☐ ☐ ☐

## SOCIAL SUPPORT

**Strongly**

**Agree<sub>1</sub>**

**Agree<sub>2</sub>**

**Disagree<sub>3</sub>**

**Strongly**

**Disagree<sub>4</sub>**

**DON'T**

**KNOW<sub>7</sub>**

**REFUSED<sub>9</sub>**

### *Emotional support*

1. I have someone I can turn to for support and understanding when things get rough.

(sssupp)

☐ ☐ ☐ ☐ ☐ ☐

2. I have someone I can really talk to.

(sstalk)

☐ ☐ ☐ ☐ ☐ ☐

### *Instrumental support*

3. I have someone who would help me out with things, like give me a ride, watch the kids or house, or fix something.

(sshelp)

☐ ☐ ☐ ☐ ☐ ☐

4. I have someone who would take care of me if I were sick.

(sssick)

☐ ☐ ☐ ☐ ☐ ☐

## **TO BE READ BY INTERVIEWER**

**"The next questions are about ways you might have felt or behaved. Please tell me how often you have felt this way during the PAST WEEK."**

## **DEPRESSION**

**Rarely or**

**none of the**  
**time (less**

**than 1 day)<sub>0</sub>**

**Some or a**  
**little of the**

**time(1-2 days)<sub>1</sub>**

**Occasionally**  
**or a moderate**  
**amount of the**

**time(3-4 days)<sub>2</sub>**

**Most or**  
**all of the**  
**time(5-7 days)<sub>3</sub>**

1. I was bothered by things that usually don't bother me.

(dbother)

☐ ☐ ☐ ☐ ☐ ☐

2. I did not feel like eating; my appetite was poor.

(dnoeat)

- |  |                          |                          |                          |            |
|--|--------------------------|--------------------------|--------------------------|------------|
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |            |
| 3. I felt that I could not shake off the blues even with help from my family or friends. |                          |                          |                          | (dshake)   |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |            |
| 4. I felt I was just as good as other people.  |                          |                          |                          | (dgood)    |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |            |
| 5. I had trouble keeping my mind on what I was doing.                                    |                          |                          |                          | (dmindon)  |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |            |
| 6. I felt depressed.   |                          |                          |                          | (ddepress) |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |            |
| 7. I felt that everything I did was an effort.   |                          |                          |                          | (deffort)  |

**DEPRESSION (continued)**

- | <b>Rarely or<br/>none of the<br/>time (less<br/>than 1 day)<sub>0</sub></b> | <b>Some or a<br/>little of the<br/>time(1-2 days)<sub>1</sub></b> | <b>Occasionally<br/>or a moderate<br/>amount of the<br/>time(3-4 days)<sub>2</sub></b> | <b>Most or<br/>all of the<br/>time(5-7 days)<sub>3</sub></b> |             |
|---|---|--|--|-------------|
| 8. I felt hopeful about the future.   | <input type="checkbox"/>  | <input type="checkbox"/>   | <input type="checkbox"/>                                     | (dhope)     |
| 9. I thought my life had been a failure.                                    | <input type="checkbox"/>  | <input type="checkbox"/>   | <input type="checkbox"/>                                     | (dfailure)  |
| 10. I felt fearful.   | <input type="checkbox"/>  | <input type="checkbox"/>   | <input type="checkbox"/>                                     | (dfear)     |
| 11. My sleep was restless.  | <input type="checkbox"/>  | <input type="checkbox"/>   | <input type="checkbox"/>                                     | (drestless) |
| 12. I was happy.  | <input type="checkbox"/>  | <input type="checkbox"/>   | <input type="checkbox"/>                                     | (dhappy)    |
| 13. I talked less than usual.   | <input type="checkbox"/>  | <input type="checkbox"/>   | <input type="checkbox"/>                                     | (dtalkless) |

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
14. I felt lonely.				(dlonely)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
15. People were unfriendly.				(dunfriend)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
16. I enjoyed life.				(denjoy)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
17. I had crying spells.				(dcry)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
18. I felt sad.				(dsad)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
19. I felt that people dislike me.				(ddislike)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
20. I could not get "going."				(dgoing)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

### Medication Adherence

1. Do you ever forget to take your medicine?  
☐ Yes<sub>1</sub>  
☐ No<sub>0</sub>
(adhforg)
2. Are you careless at times about taking your medicine?  
☐ Yes<sub>1</sub>  
☐ No<sub>0</sub>
(adhcarls)
3. Sometimes if you feel worse, do you stop taking your medicines?  
☐ Yes<sub>1</sub>  
☐ No<sub>0</sub>
(adhworse)
4. Thinking about the last week, how often have you not taken your medicine?  
(adhlstwk)

- ☐ Never<sub>0</sub>
- ☐ 1-2 times<sub>1</sub>
- ☐ 3-5 times<sub>2</sub>
- ☐ 6-10 times<sub>3</sub>
- ☐ > 10 times<sub>4</sub>

5. Did you not take any of your medicine over the past weekend?

(adhwk  
nd)

- ☐ Yes<sub>1</sub>
- ☐ No<sub>0</sub>

6. Over the past 3 months, how many days have you not taken any medicine at all?

(adh3mn  
t)

- ☐ ≤ 2 days<sub>1</sub>
- ☐ > 2 days<sub>0</sub>

**TO BE READ BY INTERVIEWER**

**"Now some information about yourself"**

1. Have you smoked at least 100 cigarettes in your entire life?

(100smo  
k)

- |   |   |
|---|---|
| <input type="checkbox"/> Yes <sub>1</sub> | <input type="checkbox"/> Don't know/Not sure <sub>7</sub> |
| <input type="checkbox"/> No <sub>0</sub>  | <input type="checkbox"/> Refused <sub>9</sub>             |

2. Do you now smoke cigarettes every day, some days, or not at all?

(smokefr  
q)

- ☐ Every day<sub>1</sub>
- ☐ Some days<sub>2</sub>
- ☐ Not at all<sub>0</sub>
- ☐ Don't know/Not sure<sub>7</sub>
- ☐ Refused<sub>9</sub>

3. During the past 12 months, have you stopped smoking for one day or longer because you were trying to quit smoking?

(smokest  
p)

- ☐ Yes<sub>1</sub>



- ☐ No<sub>0</sub>
- ☐ Don't know/Not Sure<sub>7</sub>
- ☐ Refused<sub>9</sub>

4. How would you rate your diet?

(diet)

- ☐ Healthy (High amount of fiber, fruits, vegetable, poultry, fish)<sub>0</sub>
- ☐ Unhealthy (Majority of red meats, fried foods, fast-foods)<sub>1</sub>

5. Do you take any type of vitamins on a daily basis?

(vitamins  
)

- ☐ Yes<sub>1</sub>
- ☐ No<sub>0</sub>

6. How often do you have a drink containing alcohol? (Alcoholic drinks include one beer, one glass of wine, a mixed drink of hard liquor, or one wine cooler.

(EtOH2f)

Each of these counts as one drink, unless they have double shots, which would equal two drinks.)

- ☐ Never<sub>0</sub>
- ☐ Monthly or less<sub>1</sub>
- ☐ 2-4 times a month<sub>2</sub>
- ☐ 2-3 times a week<sub>3</sub>
- ☐ 4 or more times a week<sub>4</sub>

7. How many drinks do you have on a typical day when you are drinking?

(EtOH2#  
)

- ☐ 1 or 2<sub>0</sub>
- ☐ 3 or 4<sub>1</sub>
- ☐ 5 or 6<sub>2</sub>
- ☐ 7 to 9<sub>3</sub>
- ☐ 10 or more<sub>4</sub>

8. How often do you have four or more drinks on one occasion?

(EtOH4  
mr)

- ☐ Never<sub>0</sub>
- ☐ Monthly or less<sub>1</sub>

- ☐ 2-4 times a month<sub>2</sub>
- ☐ 2-3 times a week<sub>3</sub>
- ☐ 4 or more times a week<sub>4</sub>

9. In the past year, how often did you use nonprescription drugs to get high or change the way you feel?

(nonrx)

- ☐ Never<sub>0</sub>
- ☐ Monthly or less<sub>1</sub>
- ☐ 2-4 times a month<sub>2</sub>
- ☐ 2-3 times a week<sub>3</sub>
- ☐ 4 or more times a week<sub>4</sub>

10. In the past year, how often did you use drugs prescribed to you or to someone else to get high or change the way you feel?

(rx)

- ☐ Never<sub>0</sub>
- ☐ Monthly or less<sub>1</sub>
- ☐ 2-4 times a month<sub>2</sub>
- ☐ 2-3 times a week<sub>3</sub>
- ☐ 4 or more times a week<sub>4</sub>

11. In the last year, how often did you drink or use drugs more than you meant to?

(fdrinks)

- ☐ Never<sub>0</sub>
- ☐ Monthly or less<sub>1</sub>
- ☐ 2-4 times a month<sub>2</sub>
- ☐ 2-3 times a week<sub>3</sub>
- ☐ 4 or more times a week<sub>4</sub>

12. How often did you feel you wanted or needed to cut down on your drinking or drug use in the last year and not been able to?

(cutdown  
)

- ☐ Never<sub>0</sub>
- ☐ Monthly or less<sub>1</sub>
- ☐ 2-4 times a month<sub>2</sub>
- ☐ 2-3 times a week<sub>3</sub>
- ☐ 4 or more times a week<sub>4</sub>

13. In general, would you say your health is:

(gnhealth)

h)

- ☐ Excellent<sub>0</sub>
- ☐ Very Good<sub>1</sub>
- ☐ Good<sub>2</sub>
- ☐ Fair<sub>3</sub>
- ☐ Poor<sub>4</sub>
- ☐ Don't Know<sub>7</sub>
- ☐ Refused<sub>9</sub>

14. During the past month, other than your regular job, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, or walking for exercise?

(exercise  
)

- ☐ Yes<sub>1</sub>
- ☐ No<sub>0</sub>
- ☐ Don't know/Not sure<sub>7</sub>
- ☐ Refused<sub>9</sub>

15. Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs or government plans such as Medicare or Medicaid?

(hlthcov)

- ☐ Yes<sub>1</sub>
- ☐ No<sub>0</sub>
- ☐ Don't know/Not sure<sub>3</sub>
- ☐ Refused<sub>4</sub>

16. If so, what kind of coverage do you have?

(typecov)

- ☐ Private health insurance<sub>0</sub>
- ☐ HMO<sub>1</sub>
- ☐ Medicare<sub>2</sub>
- ☐ Medicaid<sub>3</sub>
- ☐ Other \_\_\_\_\_

(covothe)

17. If you don't have any kind of coverage, what are some reasons why?

- ☐ Can't afford to have it
- ☐ I don't qualify for government programs
- ☐ I don't know if I qualify for government programs
- ☐ My employer doesn't provide health benefits
- ☐ Other \_\_\_\_\_

18. Do you have one person you think of as your personal doctor or healthcare provider?

(provider  
)

**If NO, ask: Is there more than one, or is there no person who you think of as your personal doctor or health care provider?**

- ☐ Yes, only one<sub>0</sub>
- ☐ More than one<sub>1</sub>
- ☐ No<sub>2</sub>
- ☐ Don't Know/Not sure<sub>7</sub>
- ☐ Refused<sub>9</sub>

19. Was there a time in the past 12 months when you needed to see a doctor but could not because of cost?

(drcost)

- ☐ Yes<sub>1</sub>
- ☐ No<sub>0</sub>
- ☐ Don't know/Not sure<sub>7</sub>
- ☐ Refused<sub>9</sub>

20. About how long has it been since you last visited a doctor for a routine checkup?

(rtcheck)

A routine checkup is a general physical exam, not an exam for a specific injury, illness, or condition.

- ☐ Within past year (1-12 months ago)<sub>0</sub>
- ☐ Within past 2 years (1-2 years ago)<sub>1</sub>
- ☐ Within past 5 years (2-5 years ago)<sub>2</sub>
- ☐ 5 or more years ago<sub>3</sub>





- ☐ Other \_\_\_\_\_ (raceoth)  
 26. Are you...? (marstat)
- |   |   |
|---|---|
| <input type="checkbox"/> Married <sub>0</sub>   | <input type="checkbox"/> Never married <sub>4</sub>     |
| <input type="checkbox"/> Divorced <sub>1</sub>  | <input type="checkbox"/> In a relationship <sub>5</sub> |
| <input type="checkbox"/> Widowed <sub>2</sub>   | <input type="checkbox"/> Refused <sub>9</sub>           |
| <input type="checkbox"/> Separated <sub>3</sub> |   |
27. How many children less than 18 years of age live in your household? (children)  
 Number of children \_\_\_\_\_ )
- ☐ None<sub>0</sub>  
☐ Refused<sub>9</sub>
28. How many years of education have you completed? (yrsed)  
 Note: Give example: elementary school- 5 yrs, high school- 12yrs
29. What is the highest grade or year of school that you completed? (school)
- ☐ Never attended school or only attended kindergarten<sub>7</sub>
  - ☐ Grades 1 through 8 (Elementary)<sub>6</sub>
  - ☐ Grades 9 through 11 (Some high school)<sub>5</sub>
  - ☐ Grade 12 or GED (High school graduate)<sub>4</sub>
  - ☐ College 1 year to 3 years (Some college or technical school)<sub>3</sub>
  - ☐ Bachelor's degree (4 years of college)<sub>2</sub>
  - ☐ Master's degree<sub>1</sub>
  - ☐ Doctorate degree<sub>0</sub>
30. Are you currently...? (work)

- ☐ Employed for wages<sub>0</sub>
- ☐ Self-employed<sub>1</sub>
- ☐ Out of work for more than 1 year<sub>2</sub>
- ☐ Out of work for less than 1 year<sub>3</sub>
- ☐ A Homemaker<sub>4</sub>

31. What is your occupation?

- ☐ Labor<sub>4</sub>
- ☐ Technical<sub>3</sub>
- ☐ Clerical<sub>2</sub>
- ☐ Managerial<sub>1</sub>
- ☐ Professional<sub>0</sub>
- ☐ Trade<sub>6</sub>
- ☐ Service<sub>7</sub>
- ☐ Student<sub>5</sub>
- ☐ Other(specify)<sub>9</sub>\_\_\_\_\_
- ☐ None<sub>10</sub>

- ☐ A Student<sub>5</sub>
- ☐ Retired<sub>6</sub>
- ☐ Unable to work due to disability<sub>7</sub>
- ☐ Refused<sub>8</sub>

(occup)

(otheroc  
c)

32. Last year, what was your total family income from all sources, before taxes?

(income)

- ☐ Below \$10,000<sub>7</sub>
- ☐ More than \$10,000 but less than \$20,000<sub>6</sub>
- ☐ More than \$20,000 but less than \$30,000<sub>5</sub>
- ☐ More than \$30,000 but less than \$40,000<sub>4</sub>
- ☐ More than \$40,000 but less than \$50,000<sub>3</sub>

- ☐ More than \$50,000 but less than \$75,000<sub>2</sub>
- ☐ More than \$75,000 but less than \$100,000<sub>1</sub>
- ☐ Above \$100,000<sub>0</sub>

33. Is the house, apartment, or mobile home where you live:

(ownhouse)

- ☐ Owned by you or someone in your household with a mortgage or loan<sub>0</sub>
- ☐ Owned by you or someone in your household free and clear (without a mortgage or loan)<sub>1</sub>
- ☐ Rented for cash rent<sub>2</sub>
- ☐ Occupied without payment of cash rent<sub>3</sub>

34. How many automobiles, vans, and trucks of one-ton capacity or less are kept at home for use by members of your household? \_\_\_\_\_

(vehicle)

### **Medical Information**

#### **TO BE READ BY INTERVIEWER**

**The following questions are related to your HIV status. They will allow us to see what your condition has been during the last three months.**

1. When were you diagnosed to be infected with HIV? (month/year) \_\_\_\_\_

(dxHIV)

2. Have you been diagnosed with AIDS?

(dxAIDS)

☐ Yes<sub>1</sub>

☐ No<sub>0</sub>

3. If yes, when? (month/year) \_\_\_\_\_

(dxAIDS  
dt)

4. Do you know your CD4 T-cell count?

(cd4t)

☐ Yes<sub>1</sub>

☐ No<sub>0</sub>

5. If so, what was your most recent CD4 T-cell count: \_\_\_\_\_

(cd4count)

Date: (month/year) \_\_\_\_\_

6. What was your CD4 T-cell count before the most recent one? \_\_\_\_\_

(cd4date)  
)  
(cd4befo  
r)  
(cd4bfda  
t))

Date: (month/year) \_\_\_\_\_

☐ Don't know<sub>9</sub>

7. Do you know your viral load?

(viralld)

☐ Yes<sub>1</sub>

☐ No<sub>0</sub>

8. If so, what was your most recent Viral Load: \_\_\_\_\_

(viralldct)

Date: (month/year) \_\_\_\_\_

(virallddt)

9. What was your viral load before the most recent one? \_\_\_\_\_

(viralldb)

Date: (month/year) \_\_\_\_\_

☐ Don't know<sub>9</sub>

(vraldbd  
)

### HIV Symptom Checklist

#### TO BE READ BY INTERVIEWER

Please indicate which of these symptoms have been present during the past 3 months and how severe the symptom was.

Not Present <sub>0</sub>	Mild <sub>1</sub>	Moderate <sub>2</sub>	Severe <sub>3</sub>	Very Severe <sub>4</sub>	
1. Persistent or recurring fever of more than 100 degrees					(sympt1)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Sweating at night for at least 2 weeks					(sympt2)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. Unintentional weight loss of at least 10 pounds (not dieting)					(sympt3)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4. Fatigue lasting for at least 2 weeks					(sympt4)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5. Frequent headaches					(sympt5)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	6. An unusual bump, bruise or skin discoloration	(sympt6)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	7. Shingles or herpes zoster	(sympt7)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8. Skin rash (other than the discoloration or shingles above)	(sympt8)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9. Thrush, Candida, hairy leukoplakia or other white patches in the mouth or throat	(sympt9)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10. Persistent sores in mouth or throat (other than the above)	(sympt10)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	11. Tender or enlarged glands or lymph nodes lasting for at least 2 weeks	(sympt11)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	12. Pain, tightness or heaviness in the chest	(sympt12)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	13. Shortness of breath or dry cough persisting at least 2 weeks	(sympt13)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	14. Frequent chest colds (other than dry cough above)	(sympt14)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	15. Repeated stomach pains	(sympt15)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	16. Diarrhea	(sympt16)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	17. Pains in back or spine	(sympt17)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		



18. Swollen ankles

☐ ☐ ☐ ☐ ☐

(sympt18  
)

19. Neuropathy or numbness, tingling or burning in hands or feet

☐ ☐ ☐ ☐ ☐

(sympt19  
)

20. Chronic stiffness, swelling or aching in any joint or muscle that is not due to swollen ankles or neuropathy listed above

☐ ☐ ☐ ☐ ☐

(sympt20  
)

### PARTICIPANT SELF-ADMINISTERED SECTION

Note to Interviewer: Allow the participant to read the following questions and answer them.

#### Stress

#### **PLEASE READ**

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you are asked to indicate by checking the appropriate box about *how often* you felt or thought a certain way.

Almost

Never<sub>0</sub>

Never<sub>1</sub>

Sometimes<sub>2</sub>

Fairly Often<sub>3</sub>

Very Often<sub>4</sub>

1. In the last month, how often have you been upset because of something that happened unexpectedly?

(supset)

☐ ☐ ☐ ☐ ☐

2. In the last month, how often have you felt that you were unable to control the important things in your life?

(scontrol  
)

☐ ☐ ☐ ☐ ☐

3. In the last month, how often have you felt nervous and "stressed"?

(sstress)

☐ ☐ ☐ ☐ ☐

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

(sconf)

- |  |                          |                          |                          |                          |              |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------|
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |              |
| 5. In the last month, how often have you felt that things were going your way?                                       |                          |                          |                          |                          | (sthings)    |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |              |
| 6. In the last month, how often have you found that you could not cope with all the things that you had to do?       |                          |                          |                          |                          | (snocope)    |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |              |
| 7. In the last month, how often have you been able to control irritations in your life?                              |                          |                          |                          |                          | (sableco nt) |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |              |
| 8. In the last month, how often have you felt that you were on top of things?  |                          |                          |                          |                          | (stopthgs)   |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |              |
| 9. In the last month, how often have you been angered because of things that were outside of your control?           |                          |                          |                          |                          | (sanger)     |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |              |
| 10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them? |                          |                          |                          |                          | (sdiffic)    |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |              |

### Ironson-Woods Spirituality/Religiousness Index

#### **PLEASE READ:**

The following statements refer to your spiritual or religious beliefs. Please indicate how strongly you agree with each statement. For example, if you *strongly disagree* with the statement, check the first box. Likewise, if you *strongly agree* with the statement, please check the last box. If your feelings lie somewhere in the middle, please indicate by checking the boxes in between, depending on whether you somewhat agree or disagree.

**Strongly Disagree**

**Strongly Agree**

1. My beliefs give me a sense of peace.

(iwpeace)

☐1

☐2

☐3

☐4

☐5

2. My beliefs help me to know everything will be fine.

(iwfine)

☐1

☐2

☐3

☐4

☐5

3. My beliefs give meaning to my life.

(iwmeaning)

☐1

☐2

☐3

☐4

☐5

4. My beliefs help me to be relaxed.

(iwrelaxd)

☐1

☐2

☐3

☐4

☐5

5. My beliefs help me to feel protected.

(iwprotcd)

☐1

☐2

☐3

☐4

☐5

6. My beliefs help me feel I am not alone.

(iwflalon)

☐1

☐2

☐3

☐4

☐5

7. My beliefs help me feel I have a relationship or a connection with a higher form or being.

(iwconntd)

☐1

☐2

☐3

☐4

☐5

8. My beliefs help me be less afraid of death.

(iwdeath)

☐1

☐2

☐3

☐4

☐5

9. I believe my soul will live on in some form after my body dies.

(iwliveon)

☐1

☐2

☐3

☐4

☐5

10. I believe God created all things in the universe.

(iwunivrs)

☐1

☐2

☐3

☐4

☐5

11. God will not turn his back on me no matter what I do.

(iwturnbk)

☐1

☐2

☐3

☐4

☐5

12. When I am ill, God gives me courage to cope with my illness.

(iwcourage)

☐1

☐2

☐3

☐4

☐5

13. When I am ill, God will answer my prayers for a recovery.

(iwprayer  
)

☐1

☐2

☐3

☐4

☐5

14. My beliefs are very influential in my recovery when I am ill.

(iwrecvill  
)

☐1

☐2

☐3

☐4

☐5

15. When I am ill, my faith gives me optimism that I will recover.

(iwoptim)

☐1

☐2

☐3

☐4

☐5

16. I attend religious services.

(iwreligs  
v)

☐1

☐2

☐3

☐4

☐5

17. I participate in religious rituals (ex. Communion, confession, seder, etc.)

(iwritual)

☐1

☐2

☐3

☐4

☐5

18. I pray or meditate to get in touch with God.

(iwmedit  
a)

☐1

☐2

☐3

☐4

☐5

19. I discuss my beliefs with others who share my beliefs.

(iwbelief)

☐1

☐2

☐3

☐4

☐5

20. My beliefs give me a set of rules I must obey.

(iwrules)

☐1

☐2

☐3

☐4

☐5

21. My beliefs teach me to help other people who are in need.

(iwhelp)

☐1

☐2

☐3

☐4

☐5

22. My beliefs help me feel compassion, love, and respect for others.

(iwcomp  
ss)

☐1

☐2

☐3

☐4

☐5

23. I have a responsibility to help others.

(iwhlpoth  
)

☐1

☐2

☐3

☐4

☐5

24. My beliefs increase my acceptance and tolerance of others.

(iwaccto  
)

☐1

☐2

☐3

☐4

☐5

25. I feel I am connected to all humanity.

(iwhuma  
n)

☐1

☐2

☐3

☐4

☐5

### The Multi-group Ethnic Identity Measure

#### **PLEASE READ**

**In this country, people come from many different countries and cultures, and there are many different words to describe the different backgrounds or ethnic groups that people come from. Some examples of the names of ethnic groups are:**

**Hispanic or Latino, Black or African American, Asian American, Chinese, Filipino, American Indian, Mexican American, Caucasian or White, Italian American, and many others.**

**These questions are about your ethnicity or your ethnic group and how you feel about it or react to it.**

**Strongly Disagree<sub>1</sub>**

**Disagree<sub>2</sub>**

**Agree<sub>3</sub>**

**Strongly Agree<sub>4</sub>**

1. I have spent time trying to find out more about my ethnic group, such as its history, traditions, and customs.

(eihist)

☐

☐

☐

☐

2. I am active in organizations or social groups that include mostly members of my own ethnic group.

(eiactive)

☐

☐

☐

☐

3. I have a clear sense of my ethnic background and what it means for me.

(eisense)

☐

☐

☐

☐

4. I think a lot about how my life will be affected by my ethnic group membership.

(eiaffect)

☐

☐

☐

☐

5. I am happy that I am a member of the group I belong to.

(eihappy  
)



- |  |                          |                          |                          |                 |
|--|--------------------------|--------------------------|--------------------------|-----------------|
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | (eibelong<br>)  |
| 6. I have a strong sense of belonging to my own ethnic group.  |                          |                          |                          |                 |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | (eiunder<br>s)  |
| 7. I understand pretty well what my ethnic group membership means to me.   |                          |                          |                          |                 |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | (eiethnbk<br>)  |
| 8. In order to learn more about my ethnic background, I have often talked to other people about my ethnic group. |                          |                          |                          |                 |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | (eipride)       |
| 9. I have a lot of pride in my ethnic group.   |                          |                          |                          |                 |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | (eicultpr)      |
| 10. I participate in cultural practices of my own group, such as special food, music, or customs.                |                          |                          |                          |                 |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | (eiattach<br>)  |
| 11. I feel a strong attachment towards my own ethnic group.  |                          |                          |                          |                 |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | (eicultbk)      |
| 12. I feel good about my cultural or ethnic background.  |                          |                          |                          |                 |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | (eimtpepl<br>)  |
| 13. I like meeting and getting to know people from ethnic groups other than my own.                              |                          |                          |                          |                 |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | (eidiffeth<br>) |
| 14. I sometimes feel it would be better if different ethnic groups didn't try to mix together.                   |                          |                          |                          |                 |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | (eiethnot<br>)  |
| 15. I often spend time with people from ethnic groups other than my own.   |                          |                          |                          |                 |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | (einotfrm)      |
| 16. I don't try to become friends with people from other ethnic groups.  |                          |                          |                          |                 |
| <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | (eiactoth)      |
| 17. I am involved in activities with people from other ethnic groups.  |                          |                          |                          |                 |

18. I enjoy being around people from ethnic groups other than my own. (eiardoth)

19. My ethnicity is: (eiethnic)

- ☐ Asian or Asian American, including Chinese, Japanese, and others<sub>1</sub>
- ☐ Black or African American<sub>2</sub>
- ☐ Hispanic or Latino, including Mexican American, Central American, and others<sub>3</sub>
- ☐ White, Caucasian, Anglo, European American; not Hispanic<sub>4</sub>
- ☐ American Indian/Native American<sub>5</sub>
- ☐ Mixed; Parents are from two different ethnic groups<sub>6</sub>
- ☐ Other \_\_\_\_\_<sub>7</sub> (eiethoth)

20. My father's ethnicity is: (eifateth)

- ☐ Asian or Asian American, including Chinese, Japanese, and others<sub>1</sub>
- ☐ Black or African American<sub>2</sub>
- ☐ Hispanic or Latino, including Mexican American, Central American, and others<sub>3</sub>
- ☐ White, Caucasian, Anglo, European American; not Hispanic<sub>4</sub>
- ☐ American Indian/Native American<sub>5</sub>
- ☐ Mixed; Parents are from two different ethnic groups<sub>6</sub>
- ☐ Other \_\_\_\_\_ (eifatoth)

21. My mother's ethnicity is: (eimome th)

- ☐ Asian or Asian American, including Chinese, Japanese, and others<sub>1</sub>
- ☐ Black or African American<sub>2</sub>
- ☐ Hispanic or Latino, including Mexican American, Central American, and others<sub>3</sub>

- ☐ White, Caucasian, Anglo, European American; not Hispanic<sub>4</sub>
- ☐ American Indian/Native American<sub>5</sub>
- ☐ Mixed; Parents are from two different ethnic groups<sub>6</sub>
- ☐ Other \_\_\_\_\_

(eimomo  
th)

### HIV Stigma Scale

The next set of questions asks about some of your experiences, feelings, and opinions as to how people with HIV feel and how they are treated. Please do your best to answer each question. For each item, check the box that best applies.

<i><b>Strongly Disagree<sub>1</sub></b></i>	<i><b>Disagree<sub>2</sub></b></i>	<i><b>Agree<sub>3</sub></b></i>	<i><b>Strongly Agree<sub>4</sub></b></i>	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stknows )
1. In many areas of my life, no one knows that I have HIV				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stguilty)
2. I feel guilty because I have HIV				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stattitu)
3. People's attitudes about HIV make me feel worse about myself				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stell)
4. Telling someone I have HIV is risky				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stjobs)
5. People with HIV lose their jobs when their employers find out				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stsecret )
6. I work hard to keep my HIV a secret.				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stgdper s)
7. I feel I am not as good a person as others because I have HIV				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stasham d)
8. I never feel ashamed of having HIV				

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stoucast )
9. People with HIV are treated like outcasts				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stdirty)
10. Most people believe that a person who has HIV is dirty				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stavfrind )
11. It is easier to avoid new friendships than worry about telling someone that I have HIV				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stunclea n)
12. Having HIV makes me feel unclean				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stapart)
13. Since learning that I have HIV, I feel set apart and isolated from the rest of the world				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stdisgus )
14. Most people think that a person with HIV is disgusting				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stbadpe r)
15. Having HIV makes me feel that I'm a bad person				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(streject)
16. Most people with HIV are rejected when others find out				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stcarefl)
17. I am very careful who I tell that I have HIV				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stdistan)
18. Some people who know I have HIV have grown more distant				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stdiscri)
19. Since learning I have HIV, I worry about people discriminating against me.				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(stuncom f)
20. Most people are uncomfortable around someone with HIV				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(sthide)
21. I never feel the need to hide the fact that I have HIV				

- |   |                          |                          |                          |           |
|---|--------------------------|--------------------------|--------------------------|-----------|
| <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |           |
| 22. I worry that people may judge me when they learn I have HIV |                          |                          |                          | (stjudge) |
| <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |           |
| 23. Having HIV in my body is disgusting to me                   |                          |                          |                          | (stbody)  |
| <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |           |

**Many of the items in this next section assume that you have told other people that you have HIV, or that others know. This may or may not be true for you. If the item refers to something that has not actually happened to you, please imagine yourself in that situation. Then give your answer (strongly disagree, disagree, agree, strongly agree) based on how you think you would feel or how you think others would react to you.**

- | <b><i>Strongly<br/>Disagree<sub>1</sub></i></b>                                    | <b><i>Disagree<sub>2</sub></i></b> | <b><i>Agree<sub>3</sub></i></b> | <b><i>Strongly Agree<sub>4</sub></i></b> |             |
|--|------------------------------------|---------------------------------|--|-------------|
| <input type="checkbox"/>   | <input type="checkbox"/>           | <input type="checkbox"/>        | <input type="checkbox"/>                 |             |
| 24. I have been hurt by how people reacted to learning I have HIV                  |                                    |                                 |  | (sthurt)    |
| <input type="checkbox"/>   | <input type="checkbox"/>           | <input type="checkbox"/>        | <input type="checkbox"/>                 |             |
| 25. I worry that people who know I have HIV will tell others                       |                                    |                                 |  | (stworry)   |
| <input type="checkbox"/>   | <input type="checkbox"/>           | <input type="checkbox"/>        | <input type="checkbox"/>                 |             |
| 26. I regret having told some people that I have HIV                               |                                    |                                 |  | (stregret)  |
| <input type="checkbox"/>   | <input type="checkbox"/>           | <input type="checkbox"/>        | <input type="checkbox"/>                 |             |
| 27. As a rule, telling others that I have HIV has been a mistake                   |                                    |                                 |  | (sttellt)   |
| <input type="checkbox"/>   | <input type="checkbox"/>           | <input type="checkbox"/>        | <input type="checkbox"/>                 |             |
| 28. Some people avoid touching me once they know I have HIV                        |                                    |                                 |  | (sttouch)   |
| <input type="checkbox"/>   | <input type="checkbox"/>           | <input type="checkbox"/>        | <input type="checkbox"/>                 |             |
| 29. People I care about stopped calling after learning I have HIV                  |                                    |                                 |  | (ststpcall) |
| <input type="checkbox"/>   | <input type="checkbox"/>           | <input type="checkbox"/>        | <input type="checkbox"/>                 |             |
| 30. People have told me that getting HIV is what I deserve for how I lived my life |                                    |                                 |  | (stdesev)   |
| <input type="checkbox"/>   | <input type="checkbox"/>           | <input type="checkbox"/>        | <input type="checkbox"/>                 |             |
| 31. Some people close to me are afraid others will reject them if it becomes known |                                    |                                 |  | (streject)  |



that I have HIV

- |   |                          |                          |                          |             |
|---|--------------------------|--------------------------|--------------------------|-------------|
| <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |             |
| 32. People don't want me around their children once they know I have HIV                    |                          |                          |                          | (stchild)   |
| <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |             |
| 33. People have physically backed away from me when they learn I have HIV                   |                          |                          |                          | (stbkaway)  |
| <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |             |
| 34. Some people act as though it's my fault I have HIV                                      |                          |                          |                          | (stfault)   |
| <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |             |
| 35. I have stopped socializing with some people because of their reactions to my having HIV |                          |                          |                          | (stsocial)  |
| <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |             |
| 36. I have lost friends by telling them I have HIV  |                          |                          |                          | (stlostfrd) |
| <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |             |
| 37. I have told people close to me to keep the fact that I have HIV a secret                |                          |                          |                          | (stsecret)  |
| <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |             |
| 38. People who know I have HIV tend to ignore my good points.                               |                          |                          |                          | (stignore)  |
| <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |             |
| 39. People seem afraid of me once they learn I have HIV                                     |                          |                          |                          | (stafraid)  |
| <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |             |
| 40. When people learn you have HIV, they look for flaws in your character                   |                          |                          |                          | (stflaws)   |
| <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |             |

### Aggression

#### **PLEASE READ**

**Please indicate how characteristic each statement is of you. For example, if the statement is extremely uncharacteristic of you, check the first box. Likewise, if the statement is extremely characteristic of you, please check the last box. If your feelings lie somewhere**

**in the middle, please indicate by checking the boxes in between, depending on whether you somewhat agree or disagree.**

<b>Extremely uncharacteristic of me</b>		<b>Extremely characteristic of me</b>	
	1. Once in a while I can't control the urge to strike another person.		(aggstk)
<input type="checkbox"/> 1		<input type="checkbox"/> 4	
	2. I tell my friends openly when I disagree with them.	<input type="checkbox"/> 5	(aggdisg)
<input type="checkbox"/> 1		<input type="checkbox"/> 4	
	3. I flare up quickly but get over it quickly.	<input type="checkbox"/> 5	(aggflare)
<input type="checkbox"/> 1		<input type="checkbox"/> 4	
	4. I am sometimes eaten up with jealousy.	<input type="checkbox"/> 5	(aggjeal)
<input type="checkbox"/> 1		<input type="checkbox"/> 4	
	5. Given enough provocation, I may hit another person.	<input type="checkbox"/> 5	(agghits)
<input type="checkbox"/> 1		<input type="checkbox"/> 4	
	6. I often find myself disagreeing with people.	<input type="checkbox"/> 5	(aggdisag)
<input type="checkbox"/> 1		<input type="checkbox"/> 4	
	7. When frustrated, I let my irritation show.	<input type="checkbox"/> 5	(aggfrust)
<input type="checkbox"/> 1		<input type="checkbox"/> 4	
	8. At times I feel I have gotten a raw deal out of life.	<input type="checkbox"/> 5	(aggdeal)
<input type="checkbox"/> 1		<input type="checkbox"/> 4	
	9. If somebody hits me, I hit back.	<input type="checkbox"/> 5	(agghitbk)
<input type="checkbox"/> 1		<input type="checkbox"/> 4	
	10. When people annoy me, I may tell them what I think of them.	<input type="checkbox"/> 5	(aggannoy )
<input type="checkbox"/> 1		<input type="checkbox"/> 4	

11. I sometimes feel like a powder keg ready to explode.

(aggexpld)

☐1

☐2

☐3

☐4

☐5

**Extremely  
uncharacteristic of  
me**

**Extremely  
characteristic  
of me**

12. Other people always seem to get the breaks.

(aggbreak  
)

☐1

☐2

☐3

☐4

☐5

13. I get into fights a little more than the average person.

(aggfights)

☐1

☐2

☐3

☐4

☐5

14. I can't help getting into arguments when people disagree with me.

(aggargu  
m)

☐1

☐2

☐3

☐4

☐5

15. I am an even-tempered person.

(aggevtm  
)

☐1

☐2

☐3

☐4

☐5

16. I wonder why sometimes I feel so bitter about things.

(aggbittr)

☐1

☐2

☐3

☐4

☐5

17. If I have to resort to violence to protect my rights, I will.

(aggviol)

☐1

☐2

☐3

☐4

☐5

18. My friends say that I'm somewhat argumentative.

(aggargu)

☐1

☐2

☐3

☐4

☐5

19. Some of my friends think I'm a hothead.

(aggthd  
)

☐1

☐2

☐3

☐4

☐5

20. I know that "friends" talk about me behind my back.

(aggfrnds)

☐1

☐2

☐3

☐4

☐5

21. There are people who pushed me so far that we came to blows.

(aggblows)

<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
22. Sometimes I fly off the handle for no good reason.					(aggflyof)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
23. I am suspicious of overly friendly strangers.					(aggstran)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
24. I can think of no good reason for ever hitting a person.					(agghittig)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
<b>Extremely uncharacteristic of me</b>			<b>Extremely characteristic of me</b>		
25. I have trouble controlling my temper.					(aggtemp)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
26. I sometimes feel that people are laughing at me behind my back.					(agglaugh)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
27. I have threatened people I know.					(aggthret)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
28. When people are especially nice, I wonder what they want.					(aggnice)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
29. I have become so mad that I have broken things.					(aggmad)
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	

**APPENDIX D**

**MEDICAL CHART REVIEW PROTOCOL**



### Medical Chart Review Form

UIN	
Date of HIV infection dx: (mm/dd/yy)	
Date of first clinic visit: Date of most recent clinic visit:	
Baseline/Pre-treatment CD4 count:  Most recent CD4 count:	Date: Date:
Baseline/Pre-treatment CBC:  Most recent CBC:	Date: Date:
Baseline/Pre-treatment viral sensitivity testing:  Most recent viral sensitivity testing:	Date:  Date:
Baseline/Pre-treatment viral load: Most recent viral load:	Date: Date:
Medication list 1. 2. 3. 4. 5. 6. 7. 8. 9. 10.	
HIV/AIDS dx associated medical conditions 1. 2. 3. 4. 5.	

## **APPENDIX E**

### **CLASSIFICATION OF AIDS ASSOCIATED ILLNESSES**

### **Classification of AIDS associated illnesses**

Acute retroviral syndrome  
Candidal vaginitis  
Persistent generalized lymphadenopathy  
Guillain-Barré syndrome  
Myopathy  
Aseptic meningitis  
Pneumococcal and other bacterial pneumonia  
Pulmonary tuberculosis  
Herpes Zoster  
Oropharyngeal candidiasis (thrush)  
Cryptosporidiosis, self-limited  
Kaposi's sarcoma  
Oral hairy leukoplakia  
Cervical intraepithelial neoplasia  
Cervical cancer  
B-cell lymphoma  
Anemia  
Mononeuronal multiplex  
Idiopathic thrombocytopenic purpura  
Hodgkin's lymphoma  
Lymphocytic interstitial pneumonia  
Pneumocystis carinii pneumonia  
Disseminated histoplasmosis and coccidiomycosis  
Miliary/extrapulmonary TB  
Progressive multifocal leukoencephalopathy (PML)  
Wasting Peripheral neuropathy  
HIV-associated dementia  
Cardiomyopathy  
Vacuolar myelopathy  
Progressive polyradiculopathy  
Non-Hodgkin's lymphoma  
Disseminated herpes simplex  
Toxoplasmosis  
Cryptococcosis  
Cryptosporidiosis, chronic  
Microsporidiosis  
Candidal esophagitis  
Disseminated cytomegalovirus (CMV)  
Disseminated Mycobacterium avium complex  
Central nervous system lymphoma (CNS)  
Salmonella septicemia  
Adapted from *Arch Intern Med* 1995; 155: 1573

## APPEDIX F

### INTERACTION ANALYSES

Interaction terms tested for Model 1						
	age	race	gender	social support	number of medications	IPC* (all 7 domains)
age						
race	not significant		not significant	not significant	not significant	not significant
gender						
social support	not significant	not significant	not significant		not significant	not significant
number of medications	not significant	not significant	not significant	not significant		Hurried communication ( <i>p-value</i> 0.005) Pt-centered decisions ( <i>p-value</i> 0.048)
IPC* (all 7 domains)						
*Interpersonal Processes of Care						



Interaction terms tested for Model 2								
	age	race	gender	social support	stress	unfair treatment	income	EOD*
age								
race	not significant		not significant	not significant	not significant	not significant	not significant	not significant
gender								
social support			not significant		not significant	not significant	<i>p-value</i> 0.016	
stress								
unfair treatment	not significant		not significant		not significant			not significant
income	not significant		not significant		not significant	not significant		not significant
EOD*	not significant		not significant	not significant	not significant			
* Experiences of Discrimination								

Interaction terms tested for Model 3		
	IPC* (all 7 domains)	EOD**
IPC* (all 7 domains)		not significant
EOD**	not significant	
*Interpersonal Processes of Care ** Experiences of Discrimination		

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