DISCRIMINATION, DISTRUST, AND RACIAL/ETHNIC DISPARITIES IN ANTIRETROVIRAL THERAPY ADHERENCE BY HIV+ PATIENTS

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ABSTRACT

ANGELA D. THRASHER: Discrimination, Distrust, and Racial/Ethnic Disparities in Antiretroviral Therapy Adherence by HIV+ Patients (Under the direction of Jo Anne L. Earp, ScD)

Little is known about the contribution of discriminatory healthcare experiences and healthcare provider distrust to racial/ethnic disparities in antiretroviral adherence among HIV+ patients. Among participants of the national HIV Cost and Services Utilization Study who completed three surveys over 12 months (n = 2267), I examined potential factors associated with discriminatory healthcare experiences and healthcare provider distrust. Among participants who reported antiretroviral therapy use at the last survey (n = 1911), I used structural equation modeling to test direct and indirect relationships among racial/ethnic minority status, discriminatory healthcare experiences, healthcare provider distrust, and medication adherence. I conceptualized minority status as a proxy for experiences with, and expectations about, racism in medicine. Attribution theory and models of antiretroviral therapy adherence informed the hypothesized relationships.

Almost half (41%) the participants reported experiencing discrimination in healthcare settings, while few participants reported distrust of their healthcare providers. Factors associated with discrimination were being white (an unexpected finding), younger age, some college education, earlier HIV diagnosis, poorer self-reported physical health, AIDS diagnosis, ever having a CD4 count < 200, any illicit drug use in the past year except heroin or cocaine, and less social support. Factors associated with distrust were younger age, some college education,

poorer self-reported physical and mental health, higher viral load, drug use in the past year, less social support, and more discrimination.

In the full structural equation model, the direct effect of minority status on adherence remained despite the presence of hypothesized mediators. The magnitude of indirect effects via discrimination, distrust, and medication efficacy beliefs was negligible, and their sum was not statistically significant. The effect of discrimination on adherence was entirely indirect via greater distrust and weaker medication efficacy beliefs. Greater distrust was unexpectedly associated with better adherence. Distrust indirectly affected adherence via participants' psychological distress about taking antiretroviral therapy and weaker medication efficacy beliefs. These findings offer partial support for the relationships posited among experiences and expectations of racism (as racial/ethnic minority status), discriminatory healthcare experiences, healthcare provider distrust, and antiretroviral therapy adherence. Future researchers should consider models with minority status as a contextual influence upon the hypothesized relationships.

To my parents

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CHAPTER ONE: INTRODUCTION

As research on racial/ethnic disparities in healthcare moves from description to explanation (Lurie, 2002), the relationship between healthcare providers and patients has come under greater scrutiny. Two landmark reports on the state of the American healthcare system by the Institute of Medicine, Crossing the Quality Chasm (Committee on Quality of Health Care in America, 2001) and Unequal Treatment (Smedley, Stith, & Nelson, 2003), as well as the Congressionally-mandated National Healthcare Disparities Report (Moy, Dayton, & Clancy, 2005), have conclusively documented the extent to which members of racial/ethnic minority groups experience poorer quality of care compared to whites. On the basis of the now-voluminous evidence, scholars have proposed explanations for these disparities that incorporate multiple factors such as racism (Gamble, 1997; Jones, 2000; Krieger, 2003; Williams, 1997), stereotyping and bias by physicians (Burgess, Fu, & van Ryn, 2004; van Ryn, 2002), miscommunication (Ashton et al., 2003; Cooper, Hill, & Powe, 2002; Kagawa-Singer & Kassim-Lakha, 2003), and patient preferences (Katz, 2001; Rathore & Krumholz, 2004). One pathway recently receiving much attention are the attitudes, beliefs, and biases that healthcare providers and racial/ethnic minority patients each bring to the clinical encounter. These emotions and opinions likely affect patients' care-seeking behavior, treatment preferences, and compliance with medical recommendations (Balsa & McGuire, 2003; Bogart, Bird, Walt, Delahanty, & Figler, 2004; Cooper, 2004; Johnson, Saha, Arbelaez, Beach, & Cooper, 2004; Smedley et al., 2003; van Ryn, 2002).

Patient perceptions of the way that healthcare providers deliver their services, also known as interpersonal care, are among the most proximate factors in the causal chain that explains poorer quality care experienced by many racial/ethnic minority groups (Smedley et al., 2003; van Ryn, 2002). Interpersonal care quality is the extent to which the patient-provider interaction meets or exceeds socially defined norms and values, reinforces professional ethics, and matches patients' expectations (Berwick, 2002; Cleary & McNeil, 1988; Donabedian, 1980). In turn, the quality of interpersonal care has been shown to influence patients' healthcare access, patterns of use, and outcomes (Berwick, 2002; Brook, McGlynn, & Cleary, 1996; Cleary & McNeil, 1988; Donabedian, 1980; Feinstein, 2002). Healthcare providers who are caring and sensitive to patient needs, communicate accurately and completely with patients, and consider patient preferences when making medical decisions are described as demonstrating high quality interpersonal care, also known as greater patient-centeredness (Bethell, 2000; Cleary & McNeil, 1988; Hurtado, Swift, & Corrigan, 2001). Healthcare institutions, accreditation boards, and national payers routinely use patients' assessments of interpersonal care in their quality improvement efforts (Cleary, 1999; Hurtado et al., 2001; Press, 2002) because "the manner in which care is delivered defines, for the patient, the nature and effectiveness of that care" (Press, 2002).

Racial/ethnic minority patients often report more difficult interactions with their healthcare providers than do white patients (Barr, 2004; Collins et al., 2002; Cooper-Patrick et al., 1999; Delia, Hall, Prinz, & Billings, 2004; Doescher, Saver, Franks, & Fiscella, 2000; Keating et al., 2002; LaVeist, Nickerson, & Bowie, 2000; Malat, 2001; Taira et al., 2001). However, few studies have explicitly considered poor interpersonal care quality as a predictor of racial/ethnic healthcare disparities. In particular, discriminatory healthcare experiences and healthcare provider distrust

are two patient-level¹ indicators of interpersonal care quality hypothesized as contributing to disparate outcomes by racial/ethnic minority status (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Gamble, 1997; Klassen, Hall, Saksvig, Curbow, & Klassen, 2002; Smedley et al., 2003). The present study explored discriminatory healthcare experiences and healthcare provider distrust in the context of human immunodeficiency virus (HIV) infection, a stigmatizing disease that disproportionately affects racial/ethnic minority populations (Centers for Disease Control and Prevention, 2006).

1.1. PROBLEM STATEMENT

The widespread use of antiretroviral therapy in the United States has dramatically reduced the morbidity and mortality associated with HIV infection (Centers for Disease Control and Prevention, 2002). Attaining the optimal health benefits of this regimen requires near-perfect adherence; patients with suboptimal adherence have greater morbidity, are more likely to experience treatment failure, and are at higher risk of developing drug resistance (Centers for Disease Control and Prevention, 2002). A recent review reported that about half of antiretroviral therapy adherence studies that included information about the racial/ethnic makeup of the sample found that racial/ethnic minority HIV+ patients had poorer adherence than white patients (Fogarty et al., 2002). One potential explanation may be unmeasured racial/ethnic disparities in interpersonal care quality experienced by HIV+ patients.

Recent studies suggest that interpersonal care quality is one of many determinants of antiretroviral therapy adherence (Bakken et al., 2000; Demmer, 2003; Ingersoll & Heckman, 2005; Russell, Krantz, & Neville, 2004; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004; van

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¹ The present study does not directly examine healthcare providers' actions or intentions (e.g., labeling, stereotyping, or bias) that may lead to disparate outcomes and/or may be considered discriminatory (Krieger, 2000; Reidpath et al., 2005; Smedley et al., 2003; van Ryn, 2002).

Servellen, Chang, Garcia, & Lombardi, 2002). Less is known, however, about the specific influence of discriminatory healthcare experiences and healthcare provider distrust on antiretroviral therapy adherence, or those attitudes and beliefs about antiretroviral therapy that are strong and consistent correlates of adherence. Therefore, the present study examined and modeled the relationships among racial/ethnic minority status, discriminatory healthcare experiences, healthcare provider distrust, attitudes and beliefs about antiretroviral therapy, and antiretroviral therapy adherence using data from a national cohort of HIV+ patients.

1.2. STUDY AIMS

The aims of the study were:

- To describe and examine the factors associated with discriminatory healthcare experiences
 and healthcare provider distrust among racial/ethnic minority and nonminority HIV+
 patients; and
- To test a causal model of the relationships among racial/ethnic minority status,
 discriminatory healthcare experiences, healthcare provider distrust, antiretroviral therapy
 attitudes and beliefs, and antiretroviral therapy adherence.

1.3. Organization of the Dissertation

This dissertation consists of six chapters. Chapter Two opens with a brief discussion of how interpersonal care quality may be influenced by stigma related to HIV infection and race/ethnicity, then reviews the literature on discriminatory healthcare experiences, healthcare provider distrust, and antiretroviral therapy adherence. Chapter Three describes the study's conceptual model, presents the research questions, and sets forth the hypotheses to be tested. Chapter Four details the study methodology, including research design, sample selection,

measurement construction, and analysis plan. Chapter Five presents the results of the analyses.

Chapter Six summarizes key study findings and makes recommendations for future research and practice.

CHAPTER TWO: LITERATURE REVIEW

This chapter presents the conceptual and empirical bases for the present study. The first section briefly describes how discriminatory healthcare experiences and healthcare provider distrust are the consequences of interpersonal care quality affected by the processes of stigma. The next two sections review findings from studies on discriminatory healthcare experiences and healthcare provider distrust, two potential consequences of stigma's effect on interpersonal care quality. The final section uses antiretroviral therapy adherence by HIV+ patients as a case study of how discriminatory healthcare experiences and healthcare provider distrust might help produce racial/ethnic healthcare disparities.

2.1. STIGMA AND INTERPERSONAL CARE QUALITY

Stigma, which arises from power imbalances within society, degrades interpersonal relations. Goffman's landmark work, *Stigma: Notes on the Management of a Spoiled Identity* (Goffman, 1963), defines stigma as "an attribute that is deeply discrediting within a particular social interaction" (p. 3). He describes three types: abominations of the body (physical deformities, illnesses); blemishes of individual character (e.g., prostitution, substance abuse, mental illness); and tribal stigma (race, gender, national origin). Some contemporary scholars have reconceptualized stigma as a process rather than a static trait of an individual by incorporating the idea of power differentials (Link & Phelan, 2001; Parker & Aggleton, 2003). Link and Phelan argue that the stigmatization process begins with members of groups with greater social, political, or economic

power labeling an observed difference among members of groups with less power as unfavorable (Link & Phelan, 2001). This labeling may then lead to negative stereotyping, exclusion, status loss, and discrimination of the labeled individual or group. These types of social interaction are perpetrated through such processes as racism, homophobia, classism, ageism or sexism (Parker & Aggleton, 2003). The present study focuses on two stigmatized characteristics of patients that may negatively affect the clinical encounter: racial/ethnic minority status, a type of tribal stigma (Goffman, 1963), and HIV infection, an incurable and threatening disease (abomination) that is often the consequence of "deviant" or "immoral" behaviors (blemish).

2.1.1. Racial/Ethnic Minority Status

For members of racial/ethnic minority groups, stigma manifests as various forms of racism. Jones describes three levels of racism: institutionalized racism, the differential access to power and resources by racial/ethnic minority status; personally-mediated racism, the prejudice and discrimination of individuals that is most commonly thought of as "racism"; and internalized racism, the negative self-worth exhibited by members of stigmatized races because of their acceptance of negative messages about their groups' abilities and worth(Jones, 2000). These different manifestations of racism directly and indirectly affect an individual's health. One pathway is through the experience of "inadequate or degrading" medical care (Krieger, 2003).

Concerns by members of racial/ethnic minority groups about the inequitable provision of care due to racism have their roots in historical, as well as present-day, experiences with the U.S. healthcare system (Corbie-Smith, 1999; Gamble, 1997; Jones, 2001; LaVeist, 1994; Williams, 1997). The Tuskeegee Syphilis Study is infamous (Jones, 1993), but the legally-entrenched racial segregation and disparate treatment that were in place until the passage of the Civil Rights Acts of 1964 (Smith, 2005) arguably had more pervasive effects on racial/ethnic minorities' attitudes about the healthcare system. The effects likely happened through both personal experiences and

beliefs about racism in medical care transmitted through social networks. For these reasons, racial/ethnic minority status may act as a proxy for beliefs, experiences, and expectations about racism in healthcare (LaVeist, 1994; Williams, 1997).

2.1.2. HIV Infection

HIV/AIDS seemingly came out of nowhere in the early 1980s, initially spreading quickly through largely unknown modes of transmission and considered an almost certain death sentence (Shilts, 1987). The disease was primarily associated with members of already-stigmatized groups such as homosexuals, injection drug users, and sex workers. Infants and individuals who were infected through blood transfusions, on the other hand, were considered innocent victims. The stigma of infection is thus bound to other stigmatized practices and personal characteristics (Reidpath & Chan, 2005). These characteristics of communicability, lethality, and association with other stigmatized groups mean that HIV/AIDS evokes powerful stigma (Herek et al., 1998; Madru, 2003; Reidpath & Chan, 2005; Weiner, Perry, & Magnusson, 1988).

People living with HIV/AIDS must contend with pervasive stigma and bias among the general population (Herek & Capitanio, 1993; Herek, Capitanio, & Widaman, 2002; Herek & Glunt, 1988). Studies conducted throughout the more than 25-year course of the epidemic consistently show that a substantial proportion of the general public feel that those infected with HIV "deserve" their illness, express discomfort being around those with the disease, and hold inaccurate beliefs about how the virus is spread (Centers for Disease Control and Prevention, 2000; Herek et al., 2002). Early studies found similar beliefs existed among some healthcare providers (Forrester & Murphy, 1992; Gerbert, Maguire, Bleeker, Coates, & McPhee, 1991; McCann, 1997; Robinson, 1998). The stigma experienced by people living with HIV/AIDS leads to physical and emotional trauma, indirectly promotes disease transmission, limits access to care,

and provides a barrier to self-care behaviors such as medication adherence (Madru, 2003; Sandelowski, Lambe, & Barroso, 2004; Taylor, 2001; UNAIDS, 2002).

2.1.3. The Effects of Stigma in the Clinical Encounter

Stigma arising from racial/ethnic minority and HIV status, among others, may produce poorer quality interpersonal care by affecting the attitudes, beliefs, and behaviors of healthcare providers and patients. Healthcare providers may have conscious or unconscious biases about patients with stigmatizing characteristics. In turn, these biases may affect providers' clinical decision-making or pattern of referrals (Reidpath & Chan, 2005; Smedley et al., 2003; van Ryn, 2002). HIV+ patients who are injecting drug users, for example, may receive less than optimal care from healthcare providers who hold negative stereotypes about people diagnosed with HIV/AIDS or who are injecting drug users, or both (Ding et al., 2005; Ware, Wyatt, & Tugenberg, 2005). Patients with stigmatizing characteristics may be more likely than those without such characteristics to perceive unfair treatment by healthcare providers (or discriminatory bealthcare experiences) and have lower expectations that providers will act in their best interests (or healthcare provider distrust). These attitudes, in turn, may influence patients' health-related behaviors such as medication adherence (Bogart et al., 2004; Smedley et al., 2003). The following sections describe these patient-level processes and pathways in further detail.

2.2. DISCRIMINATORY HEALTHCARE EXPERIENCES

As they do with other problematic healthcare experiences (Cleary, 1999; Edgman-Levitan & Cleary, 1996; Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993), patients identify *discriminatory healthcare experiences* through a process of awareness and interpretation of providers' behaviors. Discriminatory healthcare experiences are related to beliefs about healthcare bias or medical racism, global beliefs about the inequitable provision of care (LaVeist et al., 2000), but are based

on specific interactions patients have or have had with particular healthcare providers. Patients consider unfair acts or poor treatment by healthcare providers to be discriminatory when these acts are attributed to patients' memberships in stigmatized groups (Bird & Bogart, 2001; Bird, Bogart, & Delahanty, 2004; Krieger, 1999; Lillie-Blanton, Brodie, Rowland, Altman, & McIntosh, 2000; Schuster et al., 2005). This section presents a theoretical framework for understanding why patients may or may not perceive discriminatory healthcare experiences, as well as what is known about individual-level antecedents and consequences of discrimination in healthcare settings.

2.2.1. Attribution and Ambiguity in the Clinical Encounter

Attributions, individual perceptions of what causes others' behaviors, and the consequences of those perceptions are well-established phenomena within social psychology research.

Attributions can be formed through deliberate reflection or without conscious thought, and are shaped by information, beliefs, and motivation (Kelley & Michela, 1980). In turn, attributions may influence an individual's behaviors, emotions, and expectancies about future events (Harvey & Weary, 1984; Kelley & Michela, 1980). The process is not strictly linear, as the consequences of attribution become the antecedents of future judgments about causation (Kelley & Michela, 1980).

Attribution theory suggests that perceptions of discriminatory healthcare experiences are formed through the interactions between healthcare providers and patients' attitudes and behaviors. Many researchers believe that healthcare providers in general are not actively prejudiced against members of racial/ethnic minority groups (Ashton et al., 2003; Burgess et al., 2004; Smedley et al., 2003; van Ryn, 2002). Rather, discrimination may flow from more subtle processes: greater clinical uncertainty during encounters with minority patients; stereotypes about the health behaviors of minority patients; or greater difficulty in communicating with

minority patients (Ashton et al., 2003; Burgess et al., 2004; Smedley et al., 2003; van Ryn, 2002). Provider behaviors that patients may interpret as discriminatory range in their degree of ambiguity from those that are extreme and overtly manifest to those so subtle that their existence relies solely on an individual's judgment (Bird & Bogart, 2001; Schuster et al., 2005). Relatively unambiguous expressions of provider discrimination include treatment refusal or overt expressions of hostility. Healthcare providers' subtle expressions of discomfort or difficulties in communication may be interpreted as discrimination if patients believe that the problems are attributed to the patients' membership in stigmatized groups. The greater the ambiguity about healthcare providers' intentions, the more that perceptions of provider's behavior as discriminatory rely on patients' beliefs, motivations, and background experiences.

Once perceived, members of stigmatized groups must assess whether negative feedback received from members of non-stigmatized groups is valid, the result of bias, or represents other processes unrelated to bias, such as uncertainty or misinformation (Crocker & Major, 1989). Factors that may lead individuals to report discrimination in ambiguous contexts include: past experiences with discrimination, the desire to protect self-esteem or, at the extreme, hypervigilence (Allport, 1954; Crocker & Major, 1989; Pinel, 1999). Factors that may depress reporting of discrimination include fear of reprisals or being labeled by others as a troublemaker, a complainer, or paranoid; perception of greater discrimination against one's group than oneself; or, at the extreme, internalized stigma (Ruggiero & Taylor, 1995; Schnittker & McLeod, 2005; Sechrist, Swim, & Stangor, 2004; Stangor, Swim, Van Allen, & Sechrist, 2002; Taylor, Wright, Moghaddam, & Lalonde, 1990). Given these complexities when intentions and actions are ambiguous, it can be difficult to determine what is motivating a particular individual to report (or not report) discrimination (Ruggiero & Taylor, 1995).

2.2.2. Prevalence

Research suggests that up to one in five individuals report discriminatory healthcare experiences (Lillie-Blanton et al., 2000; Perez, 2005; Piette, Bibbins-Domingo, & Schillinger, 2006). For example, a national study found that Asians (20%), Hispanics (19%), and African Americans (14%) were more likely than whites (9%) to report being treated with disrespect or being looked down upon by their healthcare provider in the past two years (Lillie-Blanton et al., 2000). One study of a representative sample of non-institutionalized adults in California, however, found that only approximately 5% reported feeling discriminated against when receiving healthcare in the past year, ranging from 2.9% for Asians to 8.8% for American Indians (Trivedi & Ayanian, 2006). Issues of attribution and ambiguity, as well as access to care, may affect prevalence estimates of discriminatory healthcare experiences. The reported attributions made by members of racial/ethnic minority groups for discriminatory healthcare experiences are not exclusively, or even predominantly, related to racial/ethnic identity (Bird & Bogart, 2001; Lillie-Blanton et al., 2000; Piette et al., 2006; Trivedi & Ayanian, 2006). Discrimination in healthcare settings may be attributed to stigmatized characteristics other than racial/ethnic minority status, such as income level or insurance status (Lillie-Blanton et al., 2000), drug use behaviors (Ding et al., 2005; Ritson, 1999), same-gender sexual orientation (Hayter, 1996; Klitzman & Greenberg, 2002; Malebranche, Peterson, Fullilove, & Stackhouse, 2004), or HIV status (Cobb & De Chabert, 2002; Knussen & Niven, 1999; Robinson, 1998). These findings support the idea of stigma "layering," where multiple characteristics contribute to the effect of stigma on an individual (Reidpath & Chan, 2005).

The few studies that have measured the extent of discriminatory healthcare experiences among HIV+ patients do not find the same pattern of differences by racial/ethnic minority status as in the general population. Overall a quarter (26%) of the participants in the HIV Cost

and Services Utilization Study (HCSUS) conducted between 1996 and 1997, the data used for the present study, reported ever experiencing at least one of four types of discriminatory healthcare experiences (Schuster et al., 2005). Participants were asked whether any healthcare provider had ever been uncomfortable with them, treated them as inferior, preferred to avoid them, or refused them service since they had become HIV+; the perceived causes of this treatment were not reported. The most common response was that a healthcare provider had been uncomfortable with them (26%). White patients were more likely than other groups to report ever having at least one discriminatory healthcare experience. Possible explanations for this unexpected result include underreporting of discriminatory healthcare experiences by racial/ethnic minority patients or their selection of more welcoming healthcare settings (Schuster et al., 2005).

A later study, using a smaller convenience sample but a larger pool of items to measure discriminatory healthcare experiences, found a much higher prevalence of discriminatory experiences among participants recruited through one Midwestern AIDS service organization (Bird et al., 2004). Participants reported whether and how often (in qualitative, not numeric, terms) healthcare providers showed them less courtesy than other patients, acted afraid of them, and did not listen to them because of either their racial/ethnic minority or socioeconomic status. Discrimination scores did not vary by racial/ethnic minority status. The majority of participants (71%) reported ever suffering at least one of seven specific discriminatory experiences because of their race or socioeconomic status, and a quarter of the sample (26%) reported all seven types. The most common response attributed to both racial/ethnic and socioeconomic status was that a doctor or nurse did not listen to what the patient said (57%). While the lifetime prevalence of discriminatory healthcare experiences was high, participants reported that these experiences did not happen frequently. These studies suggest that, for HIV+ patients, the

prevalence of less ambiguously negative acts, such as treatment refusal, are much lower than are the more subtle difficulties experienced during patient-provider interactions. They also remind us that individuals may attribute such perceived discrimination to a number of stigmatized characteristics, such as an HIV infection, racial/ethnic minority status, or low socioeconomic status.

2.2.3. Antecedents and Consequences of Discriminatory Healthcare Experiences

Little is known about what factors are associated with reporting of discriminatory healthcare experiences. In unadjusted bivariate analyses, diabetic patients who reported discriminatory healthcare experiences were more likely to be members of racial/ethnic minority groups, female, and have lower annual income (Piette et al., 2006). Another exploratory study among African American adults found that higher educational attainment and stronger expectations of stereotyping by physicians were associated with discriminatory healthcare experiences (Bird & Bogart, 2001). Research among HIV+ patients suggests different correlates. An early study among homosexual and bisexual men in a clinical trial found that more advanced HIV infection was associated with more treatment refusals, which participants believed were based on their HIV status (Kass, Faden, Fox, & Dudley, 1992). Serostatus was the only characteristic considered by the researchers as a potential cause of discrimination, and results were not analyzed by racial/ethnic minority status. A later study found that discriminatory healthcare experiences were associated with depression, more AIDS-related symptoms, poor general health, and less satisfaction with the healthcare received (Bird et al., 2004). Both this and the previous study, however, only reported unadjusted bivariate associations. In multivariate analyses, Schuster and colleagues (2005) found that discriminatory healthcare experiences reported by participants in the HIV Cost and Services Utilization Study were independently associated with

being white, having greater than a high school education, having any health insurance other than private, and being diagnosed with HIV for a longer period of time.

Most studies find discriminatory healthcare experiences to be inversely associated with healthcare outcomes such as service use and health behaviors. This is consistent with attribution theory, which finds that perceptions of others' behaviors may influence one's own emotions, expectations, and behaviors. Discriminatory healthcare experiences have been independently associated in cross-sectional research with: greater numbers of hospital visits in the past year (Bird & Bogart, 2001); reduced likelihood of receiving age- and disease-appropriate preventive care (Trivedi & Ayanian, 2006); delay in filling pharmacy refills (Van Houtven et al., 2005); and less compliance with physician recommendations (Blanchard & Lurie, 2004). The two studies that have examined the consequences of discriminatory health experiences reported by HIV+ patients, one of which uses data considered in the present study, find associations with poorer access to care (Schuster et al., 2005) and lower ratings of medical care (Bird et al., 2004; Schuster et al., 2005). Previous studies have only examined the direct effect of discriminatory healthcare experiences on patient outcomes. Although some research suggests that discriminatory healthcare experiences are related to both treatment experience and treatment-related beliefs (Bird et al., 2004; Piette et al., 2006), no study to date has explicitly examined whether discriminatory healthcare experiences indirectly influence patient-level outcomes through treatment-related attitudes and beliefs.

2.3. HEALTHCARE PROVIDER DISTRUST

Interpersonal trust, a fundamental aspect of the patient-provider relationship, reflects patients' expectations that their healthcare providers will act in their best interests (Goold, 2002; Hall, Camacho, Dugan, & Balkrishnan, 2002; Thom, Hall, & Pawlson, 2004). Longstanding

paradigms in medical sociology describe the patient-provider relationship as asymmetrical but reciprocal, with each side having different expectations and responsibilities, as patients cede a degree of power to their healthcare providers when ill (Freidson, 1996; Parsons, 1951; Wolinsky, 1980). This asymmetry means that patients must evaluate to the extent possible providers' intentions, character, or values if they are to trust providers to work on their behalf (Goold, 2002; Parsons, 1951). *Healthcare provider distrust* occurs when patients' expectations that their providers will act in their best interests are not met. It differs from generalized distrust of the healthcare profession, institution, and payers because distrust is based on specific experiences with a particular provider (Goold, 2002; Keating et al., 2002; Pearson & Raeke, 2000). This section describes the factors that influence patients' trust in their healthcare provider, examines the level of healthcare provider distrust among patients with and without HIV infection, and summarizes the individual-level antecedents and consequences of healthcare provider distrust.

2.3.1. Domains of Trust

Patients' feelings of trust are based on holistic assessments of a provider's technical competency, interpersonal competency, agency, and confidentiality (Hall et al., 2002; Pearson & Raeke, 2000; Thom et al., 2004). Technical competency is the extent to which patients believe that providers have the requisite skills and use these appropriately. Interpersonal competency refers to patient assessments of provider communication and relationship-building skills. Agency means that patients expect their providers to act in their best interests, putting patients' health above cost or other considerations, such as research needs. Confidentiality, although included as a domain of interpersonal trust in some studies, appears to be a less important determinant among the general population (Hall et al., 2002; Thom & Campbell, 1997) but it may have increased relevance for patients living with HIV/AIDS or other stigmatizing illnesses (Hall et al., 2002; Roberts, 2002; Stone et al., 1998). These conceptual distinctions notwithstanding,

psychometric analyses of validated multi-item trust scales (Anderson & Dedrick, 1990; Kao, Green, Davis, Koplan, & Cleary, 1998; Safran et al., 1998) indicate that patients' assessment of any one domain of interpersonal trust affects their evaluation of all domains (Pearson & Raeke, 2000; Thom et al., 2004). Conversely, the multiple domains offer multiple ways for interpersonal trust of healthcare providers to be breached and distrust to occur.

2.3.2. Levels of Trust and Distrust

Distrust of individuals' own providers is relatively low (Balkrishnan, Dugan, Camacho, & Hall, 2003; Blendon & Benson, 2001; Kao et al., 1998; Safran et al., 1998) compared to distrust of the healthcare profession, institutions, and payers in general (Gamble, 1997; Goold, 2002; Kao, Green, Zaslavsky, Koplan, & Cleary, 1998; Kronenfeld, 2001). For example, Hall and colleagues (2002) found that, on average, trust in a specific physician was approximately 28% higher than global trust in physicians as a profession. African Americans and members of other racial/ethnic minority groups, however, generally report lower levels of trust in their own physicians than do whites (Boulware et al., 2003; Corbie-Smith, Thomas, & St George, 2002; Doescher et al., 2000; Schnittker, 2004; Taira et al., 2001), as well as less trust of physicians and the healthcare system in general (Brandon, Isaac, & LaVeist, 2005; LaVeist et al., 2000; Rose, Peters, Shea, & Armstrong, 2004).

As with the general population, studies of HIV+ patients report high levels of trust by these patients in their own healthcare providers (Altice, Mostashari, & Friedland, 2001; Brandon et al., 2005; Golin et al., 2002; Ingersoll & Heckman, 2005; Schneider et al., 2004; Whetten, Leserman, Whetten, & et al., 2006). For example, the average healthcare provider trust score in a large, cross-sectional study of HIV+ patients in the metropolitan Boston area was 84.8 on a 100-point scale (SD = 13.9), with almost a quarter of the sample at the ceiling (Schneider et al., 2004). Similarly, HIV+ patients at a university-based clinic in California averaged 4.5 on a 5-point scale

of trust in personal physician (Golin et al., 2002). Unlike the general population, HIV+ patients' trust in their own healthcare provider did not vary by racial/ethnic minority status (Altice et al., 2001; Golin et al., 2002; Whetten et al., 2006).

2.3.3. Antecedents and Consequences of Healthcare Provider Distrust

Many antecedents of healthcare provider distrust have been investigated, though not among HIV+ patients. Greater healthcare provider distrust is associated with racial/ethnic minority status (Boulware et al., 2003; Corbie-Smith et al., 2002; Doescher et al., 2000; Schnittker, 2004; Taira et al., 2001), lower annual income (Schnittker, 2004), not having a usual healthcare provider (Doescher et al., 2000), poorer health status (Doescher et al., 2000), and less education (Schnittker, 2004). Most previous studies of HIV+ patients, however, have not explored potential antecedents of healthcare provider distrust beyond racial/ethnic minority status. The present study explored sociodemographic, health, psychosocial, and service use factors associated with healthcare distrust by HIV+ patients.

One potential psychosocial factor is discriminatory healthcare experiences. Each interaction within a clinical encounter helps to shape patients' expectation of future care (Goold, 2002; Keating et al., 2002), and thus past discriminatory healthcare experiences may increase patients' healthcare provider distrust. Some indirect evidence of an association between discriminatory healthcare experiences and healthcare provider distrust can be found in research examining the relationship between problematic healthcare experiences and healthcare provider distrust.

Among respondents enrolled in managed care plans in three metropolitan areas, for example, each problematic experience (e.g., physicians did not always give understandable answers to questions or involve patients in decisions as much as desired) was associated with lower trust in personal physicians after controlling for both trust in the health plan and general trust in others, as well as other sociodemographic and care characteristics (Keating et al., 2002). Only two

studies to date, however, have directly examined the potential relationship between healthcare provider distrust and discriminatory healthcare experiences. Using the same dataset as does the present study, Schuster and colleagues (2005) found that HIV+ patients who reported ever experiencing healthcare discrimination trusted their current doctor less than those who did not report experiencing any discrimination, even after controlling for respondent characteristics. Past poor treatment by doctors reported by HIV+ inmates in a Connecticut prison was associated with greater healthcare provider distrust (Altice et al., 2001). The few studies that have examined the relationship between healthcare provider distrust and behavioral outcomes find lower compliance with physician recommendations among the general population (Safran et al., 1998; Thom & Campbell, 1997) and greater delay in initiating care by HIV+ patients in the HIV Cost and Services Utilization Study (Turner et al., 2000). Previous research has not explored the extent to which healthcare provider distrust influences the treatment-related attitudes and beliefs that directly affect patient-level behavioral outcomes. Therefore, the present study examined the direct and indirect effects of discriminatory healthcare experiences and healthcare provider distrust on antiretroviral therapy adherence, a critical behavioral outcome for HIV+ patients.

2.4. DISCRIMINATORY HEALTHCARE EXPERIENCES, HEALTHCARE PROVIDER DISTRUST, AND ANTIRETROVIRAL THERAPY ADHERENCE BY HIV+ PATIENTS

Antiretroviral therapy, which produced dramatic reductions in HIV/AIDS morbidity and mortality after its introduction in 1996 (Centers for Disease Control and Prevention, 2003), requires near-perfect and lifelong adherence to produce optimal health benefits (Palella et al., 1998; Paterson et al., 2000). *Antiretroviral therapy adherence* means not missing any doses of prescribed medication (Chesney, 2000). This patient-controlled outcome often varies by racial/ethnic minority status, with racial/ethnic minority HIV+ patients having poorer

adherence than white patients (Gifford et al., 2000; Golin et al., 2002; Gordillo, del Amo, Soriano, & Gonzalez-Lahoz, 1999; van Servellen et al., 2002; Wenger et al., 1999). Few researchers, however, have explicitly considered potential mediators, such as discriminatory healthcare experiences or healthcare provider distrust, of the relationship between racial/ethnic minority status and antiretroviral therapy adherence. The following section presents an overview of antiretroviral therapy adherence and its determinants, and also examines the potential role of discrimination and distrust in producing racial/ethnic disparities in antiretroviral therapy adherence.

2.4.1. Antiretroviral Therapy and the Importance of Adherence

Of the approximately 529,000 people in the United States living with HIV/AIDS in 2002, over 80% had been prescribed antiretroviral therapy^{2,3} (Centers for Disease Control and Prevention, 2003). Regimens consist of two or more antiretroviral agents from three different drug classes (protease inhibitors, nonnucleoside reverse transcriptase inhibitors, and nucleoside reverse transcriptase inhibitors); Highly Active Anti-Retroviral Therapy (HAART) is a specific combination of medications that is considered the gold standard of HIV/AIDS care (Centers for Disease Control and Prevention, 2002). Many antiretroviral therapy regimens require multiple pills at multiple dosing intervals with specific food requirements and may cause a number of adverse side effects, such as diarrhea, nausea, and vomiting (Centers for Disease

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² Use of antiretroviral therapy is lower among racial/ethnic minority HIV+ patients, especially African Americans, even after controlling for health status, access to healthcare services, and sociodemographic variables (Crystal et al., 2001; Gebo et al., 2005; Palacio et al., 2002; Wong et al., 2003). Access to antiretroviral therapy – and thus the potential for adherence – implies the existence of a source of care, joint provider-patient decision making regarding its use, and an expectation of regular follow-up care (Giordano, 2006). To the extent that discriminatory healthcare experiences and healthcare provider distrust play a role in actual access to and use of antiretroviral therapy (which is largely unknown), the present study considers these factors as a potential source of selection bias as well as potential determinants of adherence.

³ The data used in the present study was collected between 1996 and 1997. The Centers for Disease Control and Prevention (1997) reported that 641,086 individuals were living with AIDS by December 1997. The previous year had witnessed a 25% reduction in deaths from AIDS-related illnesses, the first time in the United States epidemic, attributed to the increased use of antiretroviral therapy (CDC, 1997).

Control and Prevention, 2002). The treatment prolongs life by reducing patients' viral loads to undetectable levels (<50 copies/mL). High levels of HIV impair the immune system and lead to the opportunistic infections characteristic of an AIDS diagnosis. HIV+ patients must take at least 95% of prescribed medication every day for the rest of their lives to maintain life-prolonging viral suppression (Paterson et al., 2000).

No matter how it is measured (e.g., patient self-report, pill counts, pharmacy records, HIV viral load, electronic pill cap monitors, or a combination) however, poor adherence to antiretroviral therapy is common. Studies suggest that up to half of HIV+ patients who are prescribed antiretroviral therapy do not consistently adhere to their medication directions (Deeks et al., 1999; Lucas, Chaisson, & Moore, 1999). This estimate is similar to medication adherence rates for other chronic diseases (McDonald, Garg, & Haynes, 2002; Sackett & Haynes, 1976). In the case of antiretroviral therapy, however, those who miss even a few doses may see steep declines in immune system functioning, and consequently face a greater likelihood of HIV/AIDS-related morbidity and mortality (Lucas et al., 1999; McNabb et al., 2001; Montaner et al., 1996; Palella et al., 1998; Paterson et al., 2000; Powderly et al., 1999; Valdez et al., 1999). In addition, inconsistent medication use may encourage the development of drugresistant strains of HIV (Durant et al., 1999; Sethi, Celentano, Gange, Moore, & Gallant, 2003). Improving antiretroviral therapy adherence is thus a major strategy for reducing the impact of the HIV/AIDS epidemic (Amico et al, 2006; Giordano, 2006).

2.4.2. Determinants of Antiretroviral Therapy Adherence

The reasons for poor adherence to antiretroviral therapy are multiple and complex (Chesney, 2003; Ickovics & Meade, 2002). Patients commonly report forgetfulness, being busy, being away from home, changing daily routine, experiencing medication side effects, and being depressed or ill as barriers to adherence (Chesney, 2003). Drawing upon the treatment adherence literature for

chronic diseases and empirical studies of HIV+ patients, Ickovics and Meade (2002) proposed a model that considers antiretroviral therapy adherence to be the result of the dynamic interplay of multilevel factors. Patient factors include knowledge of the disease and treatment regimen, health beliefs about the disease and treatment, perceptions (e.g., perceived threat of illness and perceived benefits of treatment), self-efficacy regarding one's ability to adhere, coping skills, and stress. Treatment regimen factors include the existence and severity of side effects, as well as the complexity of the treatment regimen. Socioenvironmental factors include availability of social support and access to care. Practioner factors include patient-provider communication patterns, the nature of the relationship with the provider, and the level of patient participation in medical decision-making – all of which are components of interpersonal care quality.

High quality interpersonal care may facilitate adherence to antiretroviral therapy adherence. Better adherence is associated with different measures of interpersonal care such as greater satisfaction with care (Russell et al., 2004; Schneider et al., 2004), higher engagement with healthcare providers (Bakken et al., 2000; Demmer, 2003), better treatment by clinic staff (van Servellen et al., 2002), and better physician-patient relationship quality (Ingersoll & Heckman, 2005; Schneider et al., 2004). These findings are supported by qualitative studies of antiretroviral therapy adherence (Laws, Wilson, Bowser, & Kerr, 2000; Malcolm, Ng, Rosen, & Stone, 2003; Roberts, 2002; Stone et al., 1998), and complement research on adherence and patient-provider interactions conducted in the pre-HAART era of HIV/AIDS care (Stall et al., 1996).

2.4.3. Discrimination, Distrust, and Antiretroviral Therapy Adherence

Less is known, however, about the extent to which discriminatory healthcare experiences and healthcare provider distrust influence adherence to antiretroviral therapy. Only one study to date has examined the relationship between discriminatory healthcare experiences and antiretroviral therapy adherence. Among clients of a Midwestern AIDS service organization,

perceived discrimination that was attributed to socioeconomic status, but not race, was negatively associated with medication adherence (Bird et al., 2004). In terms of distrust, the process of negotiation with healthcare providers may influence compliance with medical recommendations (Carr, 2001). Previous studies, which examine the issue in terms of trust rather than distrust, find some support for that view. Trust in one's physician was independently associated with self-reported antiretroviral therapy adherence in a large, cross-sectional study of HIV+ patients in the Boston area (Schneider et al., 2004). Another study found that trust was significantly associated with acceptance of and adherence to antiretroviral therapy among participants in a prison-based, directly-observed therapy program (Altice et al., 2001), although the sample and setting reduces generalizability to the broader population of HIV+ patients. In contrast, trust was not associated in multivariate analyses with a composite adherence measure in a prospective study of Los Angeles county HIV clinic patients (Golin et al., 2002).

The relative lack of information in this area makes it difficult to determine whether, and if so how, discriminatory healthcare experiences and healthcare provider distrust negatively influence antiretroviral therapy adherence by HIV+ patients. As with research using other measures of interpersonal care quality, the combination of convenience sampling and small sample sizes used in many studies increases the possibility of selection bias and threatens the validity of the findings. In addition, existing research has only examined the direct effects of discriminatory healthcare experiences and healthcare provider distrust on antiretroviral therapy adherence.

HIV+ patients' beliefs about and attitudes toward antiretroviral therapy are some of the most consistent and proximate determinants of adherence (Chesney, 2003; Ickovics & Meade, 2002; Richter, Sowell, & Pluto, 2002; Viswanathan, Anderson, & Thomas, 2005). Negative feelings towards healthcare providers that manifest as, or result from, discriminatory healthcare experiences and healthcare provider distrust may lead HIV+ patients to doubt the efficacy and

worth of antiretroviral therapy, and thus make them less likely to adhere to their prescribed medication.

2.4.4. Does Racial/Ethnic Minority Status Play a Role?

Racial/ethnic minority status is inconsistently associated with antiretroviral therapy adherence by HIV+ patients. Many studies find that racial/ethnic minority patients have poorer adherence than white patients (Gifford et al., 2000; Golin et al., 2002; Gordillo et al., 1999; van Servellen et al., 2002; Wenger et al., 1999), while others show no difference (Paterson et al., 2000; Wutoh et al., 2001). The relationship between racial/ethnic minority status and antiretroviral therapy adherence sometimes disappears after controlling for key predictors of adherence such as depression, active alcohol and drug use, or low health literacy (Stone, 2006). It is worth asking, however, what racial/ethnic minority status may be acting as a proxy for when an association is observed, as well as what factors may explain such a relationship.

Existing research on antiretroviral therapy adherence and interpersonal care quality has not specifically investigated racial/ethnic differences, and studies generally have not been designed to detect moderate or small effects. Research that is not specifically conceptualized or designed to make comparisons by racial/ethnic minority status may come to erroneous *post hoc* conclusions about the meaning of both significant and nonsignificant study findings (Corbie-Smith, Moody-Ayers, & Thrasher, 2004; Kagawa-Singer, 2000; LaVeist, 1994). Indeed, studies on interpersonal care quality and antiretroviral therapy adherence seldom report analyses by racial/ethnic group. The only published study with a large, diverse sample that examined racial/ethnic differences in the quality of interpersonal HIV/AIDS care and self-reported antiretroviral therapy adherence found no differences in quality or adherence (Bakken et al., 2000; Wilson, 2005). Unpublished analyses in another study with a large, diverse sample also found no racial/ethnic differences in either interpersonal care quality or antiretroviral therapy

adherence (Schneider et al., 2004; Wilson, 2005). However, neither study incorporated measures of discriminatory healthcare experiences nor did they consider the potential indirect effects of interpersonal care quality on antiretroviral therapy adherence.

The present study considered racial/ethnic minority status as a crude indicator of patients' beliefs, experiences, and expectations about racism in healthcare. Following attribution theory, experiencing discrimination from healthcare providers and/or having greater distrust in one's own healthcare provider may reduce the likelihood that racial/ethnic minority HIV+ patients comply with treatment. Furthermore, experiences and expectations of racism in healthcare settings may increase the skepticism and lack of confidence some racial/ethnic minority HIV+ patients have in the treatments that are offered. To date, however, no study has explored whether and how discriminatory healthcare experiences and healthcare provider distrust affect patients' attitudes and beliefs about antiretroviral therapy. Therefore, the present study used data from a large, multiethnic cohort of HIV+ patients to specifically examine the relationships among racial/ethnic minority status, discriminatory healthcare experiences, healthcare provider distrust, attitudes and beliefs about antiretroviral therapy, and adherence.

CHAPTER THREE: CONCEPTUAL MODEL, RESEARCH QUESTIONS, AND HYPOTHESES

The theoretical perspectives and empirical findings on discrimination, distrust, and antiretroviral therapy adherence described in Chapter 2 informed the conceptual model for the present study. This chapter defines the constructs in that model and their relationships with each other, as well as sets forth the study research questions and hypotheses.

3.1. CONCEPTUAL MODEL

3.1.1. Definitions

Racial/ethnic minority status refers to an individual's self-classification in the United States into one of the Office of Management and Budget categories other than Caucasian: African American; Hispanic ethnicity (any race); American Indians or Native American; Asian American; Pacific Islander and Native Hawaiian. Self-classification in multiple categories is also possible (Mays, Ponce, Washington, & Cochran, 2003). Many researchers have described racial/ethnic minority designation in the United States as representing a subordinate social status. The designation often serves as a proxy for lower socioeconomic position, having less education, "different" (non-majority) cultural practices, a history of oppression, or experience of discrimination (Krieger, 1999; LaVeist, 1994; Williams, 1997). In the present study, racial/ethnic minority status is conceptualized as a proxy for beliefs, experiences, and expectations about

racism in healthcare, including general distrust of the healthcare system (Gamble, 1997; LaVeist, 1994; Williams, 1997).

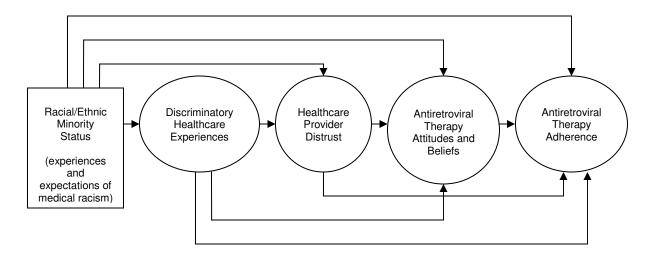
Discriminatory healthcare experiences refer to perceived unfair acts or poor treatment by healthcare providers toward members of lower status socially-defined groups such as racial/ethnic minorities (Krieger, 1999). This definition assumes that individuals accorded such treatment perceive the unfairness as a type of discrimination attributable to their subordinate status in a hierarchical society.

Healthcare provider distrust is the negative expectation held by patients of their providers' intentions and behaviors. This occurs when patients' feel that their healthcare providers lack technical or interpersonal competency, will not act in their best interests, or will not keep their information confidential.

Antiretroviral therapy attitudes and beliefs are those feelings and opinions HIV+ patients have about taking their medication or about the therapy itself. The specific components of the construct were identified through exploratory factor analysis (see Chapter 4): psychological burden of medications, concerns about the physical and emotional effects of being on antiretroviral therapy as barriers to adherence; difficulty accessing medications, how hard it is for patients to obtain their prescribed medication; difficulty scheduling medications, changes in routine as barriers to adherence; and medication efficacy beliefs, how effective and important patients feel antiretroviral therapy to be.

The degree of *antiretroviral therapy adherence* is the extent to which HIV+ patients take their medication as prescribed (Chesney et al., 2000). It is considered on a continuum from no or poor adherence to better or perfect adherence.

Figure 3.1. Conceptual Model



3.1.2 Description

The conceptual model (Figure 3.1) hypothesizes that discriminatory healthcare experiences, healthcare provider distrust, and antiretroviral therapy attitudes and beliefs mediate the relationship between racial/ethnic minority status and antiretroviral therapy adherence. It is adapted from existing models of antiretroviral therapy adherence (Golin et al., 2002; Ickovics & Meade, 2002) described in the literature review. In the present study, the patient factors of interest were racial/ethnic minority status, discriminatory healthcare experiences (exposure from past healthcare providers), and antiretroviral therapy attitudes and beliefs. The provider factor of interest was healthcare provider distrust. The authors of existing models of antiretroviral therapy adherence posited direct effects of patient and provider factors on antiretroviral therapy adherence as well as bidirectional effects between patient and provider factors (Golin et al., 2002; Ickovics & Meade, 2002). That is, patient factors may affect provider factors and vice versa. These feedback loops are important, but the present study teased apart those bidirectional effects to consider specific pathways by which patient factors indirectly influence adherence via provider factors and provider factors indirectly influence adherence via patient factors. Control

variables were selected from existing models for their association with antiretroviral therapy adherence: age, gender, year first diagnosed as HIV+, education, annual income, insurance status, AIDS diagnosis, viral load, CD4 count, self-reported physical and mental health, depression, dysthymia, type of illicit drug used, number of medications in regimen, social support, and adherence self-efficacy. Other potential covariates may be associated with discriminatory healthcare experiences or healthcare provider distrust (sexual orientation, HIV risk exposure, having a usual provider).

These factors, however, are not expected to completely explain the relationship between racial/ethnic minority status and antiretroviral therapy adherence by HIV+ patients. The fundamental cause theory (Link & Phelan, 1995) posits that the health effects of social and economic inequality cannot be eliminated by addressing the mechanisms that appear to link them to disease. Fundamental causes, which influence multiple risk factors and multiple disease outcomes, have an enduring effect on health outcomes because the effect of one mechanism emerges or becomes more prominent as another declines (Link & Phelan, 1995). Therefore, I hypothesized that racial/ethnic minority status (as a crude proxy for experiences and expectations of racism in healthcare) will affect antiretroviral therapy adherence indirectly through more reports of discriminatory healthcare experiences (regardless of whether or not the unfair treatment is attributed to racial/ethnic minority status), increased healthcare provider distrust, and more negative antiretroviral therapy attitudes and beliefs. However, the relationship between racial/ethnic minority status and adherence will not be completely mediated by these proposed factors.

Of secondary interest in this study are relationships among the hypothesized mediators.

More discriminatory healthcare experiences may lead to greater healthcare provider distrust, and thus to poorer adherence. The hypothesized relationships with antiretroviral therapy attitudes

and beliefs are largely exploratory. Previous research suggests that racial/ethnic minority HIV+ patients may report different psychosocial barriers toward or hold more negative attitudes about antiretroviral therapy adherence than white patients (Ferguson et al., 2002). Thus I hypothesized that racial/ethnic minority HIV+ patients would have greater difficulty accessing antiretroviral medication and more negative beliefs about the efficacy of the treatment. In addition, antiretroviral therapy attitudes and beliefs may mediate the relationship between discriminatory healthcare experiences, healthcare provider distrust, and adherence. These potential pathways are not included in the following list of research questions and hypotheses, however.

3.2. RESEARCH QUESTIONS AND HYPOTHESES

Aim 1: To describe and examine the factors associated with discriminatory healthcare experiences and healthcare provider distrust among racial/ethnic minority and nonminority HIV+ patients.

- 1.1 What is the prevalence of discriminatory healthcare experiences among HIV+ patients?
- 1.2 Does the prevalence of discriminatory healthcare experiences among HIV+ patients vary by racial/ethnic minority status?

 (H 1.2) Minority HIV+ patients will report more discriminatory healthcare experiences than nonminority HIV+ patients.
- 1.3 What factors are associated with discriminatory healthcare experiences by HIV+ patients?
- 1.4 Do the factors associated with discriminatory healthcare experiences by HIV+ patients vary by racial/ethnic minority status?
- 1.5 What is the prevalence of healthcare provider distrust among HIV+ patients?
- 1.6 Does the prevalence of healthcare provider distrust among HIV+ patients vary by racial/ethnic minority status?

 (H 1.4) More minority HIV+ patients will distrust their healthcare providers than nonminority HIV+ patients.
- 1.7 What factors are associated with healthcare provider distrust by HIV+ patients?

1.8 Do the factors associated with healthcare provider distrust by HIV+ patients vary by racial/ethnic minority status?

Aim 2: To test a causal model of the relationships among racial/ethnic minority status, discriminatory healthcare experiences, healthcare provider distrust, antiretroviral therapy attitudes and beliefs, and antiretroviral therapy adherence.

- 2.1 Is racial/ethnic minority status associated with antiretroviral therapy adherence? (H 2.1.1.) Racial/ethnic minority HIV+ patients will have poorer adherence to antiretroviral therapy than nonminority HIV+ patients.
- 2.2 Do discriminatory healthcare experiences partially mediate the relationship between racial/ethnic minority status and antiretroviral therapy adherence?

 (H 2.2.1) As discriminatory healthcare experiences increases, adherence to antiretroviral therapy decreases.

 (H 2.2.2) Minority HIV+ patients will have more discriminatory healthcare experiences and, in turn, poorer adherence to antiretroviral therapy than nonminority HIV+ patients.
- 2.3 Does healthcare provider distrust partially mediate the relationship between racial/ethnic minority status and antiretroviral therapy adherence? (H 2.3.1) As healthcare provider distrust increases, adherence to antiretroviral therapy decreases. (H 2.3.2) Minority HIV+ patients will have greater distrust in their healthcare providers and, in turn, poorer adherence to antiretroviral therapy than nonminority HIV+ patients.
- 2.4 Do antiretroviral therapy attitudes and beliefs partially mediate the relationship between racial/ethnic minority status and antiretroviral therapy adherence?

 (H 2.4.1) As (a) psychological burden of medication, (b) difficulty accessing medication, (c) difficulty scheduling medication, and (d) negative beliefs about medication efficacy increase, antiretroviral therapy adherence decreases.

 (H 2.4.2) Minority HIV+ patients will have greater difficulty accessing medication and, in turn, poorer adherence to antiretroviral therapy than nonminority HIV+ patients.

CHAPTER FOUR: METHODS

The present study is a secondary analysis of completed survey data from a national cohort of HIV+ patients. This chapter presents the: (1) research design of the original data source; (2) eligibility criteria for the secondary analysis; (3) construction and operationalization of study variables; and (4) analytical strategies by study aim.

4.1. DATA SOURCE

The HIV Cost and Services Utilization Study (HCSUS) was the first study to collect information on a national sample of HIV+ individuals in care (Frankel et al., 1999; Shapiro et al., 1999). The eligibility criteria for HCSUS were residence in the 48 contiguous states, aged 18 and over, known HIV infection, and receipt of medical care in facilities other than emergency departments, the military, or prisons. HCSUS used a panel design, with a baseline in-person interview conducted in January-February 1996 and follow-up interviews conducted 6 and 12 months afterwards. The interviews assessed service access and utilization, cost and quality of care, quality of life, unmet service needs, social support, satisfaction with medical care, and knowledge of HIV therapies.

4.1.1. Sampling Strategy

HCSUS used multistage population-proportion-to-size (PPS) sampling for urban areas and purposive sampling for rural areas (Frankel et al., 1999; Shapiro et al., 1999). The PPS sampling

was completed in three stages: (1) urban areas were randomly sampled proportional to numbers of AIDS cases reported; (2) providers within these areas were sampled proportional to their caseload using estimates obtained through provider surveys; and (3) HIV+ patients were sampled within practices, taking into account the possibility that individuals might obtain care from more than one site. Providers in rural areas were identified by a colleague-recruitment strategy. This complex sampling design required the use of analytic weights to correct for the inflated variance caused by clustering (Duan et al., 1999; Frankel et al., 1999; Shapiro et al., 1999). Unless otherwise noted, all analyses were conducted with weighted data.

4.1.2. Data Collection and Instrumentation

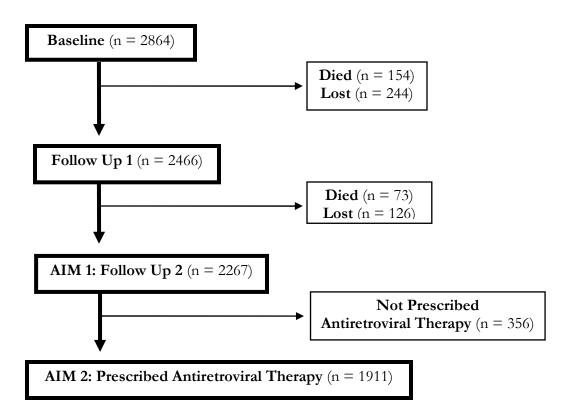
Researchers surveyed 4042 HIV+ persons receiving care in 28 urban areas and 24 clusters of rural counties in the contiguous United States (Duan et al., 1999; Frankel et al., 1999; Shapiro et al., 1999). Of those surveyed, field interviewers completed full in-person structured interviews at baseline with 2864 (68%) individuals. Information on individuals too ill to complete the long-form interview was collected from short-form in-person interviews or interviews with the participants' medical provider. Similar methods were used for the first (6 month) and second (12 month) follow-up interviews. All structured interviews were conducted using computer-assisted personal interview instruments.

4.1.3. Study Sample

Figure 4.1 presents the sampling strategy for the present study, which considered participants as "lost" if they did not complete the full interview or were otherwise lost to follow up (e.g., refusal). For Aim 1, eligible participants are those who completed the long-form HCSUS survey at all three waves (n = 2267, 79% of those completing the full interview at baseline). For Aim 2, participants were excluded if they were not prescribed antiretroviral therapy by the second follow up interview (n = 356). The final sample of 1911 for Aim 2

represents 67% of baseline and 84% of the second follow-up. The present study was deemed exempt from full review by the Institutional Review Board of the University of North Carolina School of Public Health.

Figure 4.1. Sample Selection



Note: For the purposes of this study, participants who are "lost" are those who did not complete the full inperson interview, refused to participate, or were unable to be contacted.

Sources: Duan et al., 2001; Frankel et al., 1999; Shapiro et al., 1999

4.2. DATA PREPARATION

The following section describes the data preparation activities for the current study.

4.2.1. Missing Values

The public use version of the HCSUS dataset imputed missing data on some variables with the hot-deck method (Duan et al., 1999). This method uses a matching process to identify observations to provide values for records with missing values. Variables used in the present study with 5% or more missing values are noted in Section 4.3, Measures. Section 4.4.2, Analyses for Aim 2, describes how missing values were handled during model testing.

4.2.2. Measurement Construction and Assessment

I used two methods, exploratory and confirmatory factor analysis, to develop all key study constructs.

Exploratory factor analysis. Exploratory factor analysis (EFA) determined which items, selected based on face validity, defined the latent variables (unobserved variables or factors) that represent the study constructs (DeVellis, 2003). I conducted EFA to determine whether items held together without a priori constraints, which was important as many of the measures were newly developed for the present study. First, I identified factors using principal axis factor analysis with varimax rotation to seek items that substantially loaded on only one factor. To increase interpretability, I retained individual items that had loadings over 0.5 and did not have crossloadings on other factors of greater than 0.3 (DeVellis, 2003). I then retained factors with eigenvalues greater than 1.0 (Nunnally, 1978). Next, I examined item means and variances for variability and assessed reliability using inter-item correlations and item-total correlations.

Finally, I computed the internal consistency of each factor using Cronbach's alpha, which was deemed acceptable if above .70 (DeVellis, 2003). The final measures are described in Section 4.3, Measures; details of the exploratory factor analyses are presented in Appendix A.

Confirmatory factor analysis. Confirmatory factor analysis (CFA) confirms or disconfirms hypotheses about the relationships between a set of indicators and their respective factors (DeVellis, 2003; Netemeyer, Bearden, & Sharma, 2003). CFA produces the measurement model used for structural equation modeling (SEM) for Aim 2 and is described in Section 4.4.2, Analyses.

4.2.3. Screening

I first examined the univariate descriptive statistics (e.g., distributions, means, measures of dispersion, residuals) for evidence of non-normal distributions. I then created bivariate scatter plots to determine linearity and checked for outliers; no influential cases were found. All key study variables exhibited floor and ceiling effects, being skewed and kurtotic.

4.2.4. Attrition Analysis and Selection Bias

I conducted t-tests, chi-square, Mann-Whitney U-tests (depending on variable type and normality of distribution), and multivariate regression to assess whether the individuals who died or were lost to follow up (n = 597) differed from those who remained in the study (n = 2267). In multivariate analyses, participants who completed all three waves of data collection (n = 2267) were less likely to be a member of a racial/ethnic minority group, have an AIDS diagnosis, and use heroin or cocaine in the past year than those who did not complete all waves (n = 597). Participants who completed all waves were more likely to be exposed to HIV through male-to-female sexual contact and to have higher social support than those who did not complete all waves. Details of the attrition analysis are found in Appendix B.

I also used these tests to see if participants who were prescribed antiretroviral medication at the second follow-up (n = 1911) differed on both the explanatory and control variables from those who were not prescribed antiretroviral therapy (n = 356). In multivariate analyses, participants who were on antiretroviral therapy (n = 1911) had higher viral loads and less distrust

of their healthcare provider than those who were not on antiretroviral therapy (n = 356). Participants who were on antiretroviral therapy were also more likely to have a higher income and an AIDS diagnosis than those who were not on antiretroviral therapy. Details of the selection bias analysis are found in Appendix B.

4.3 MEASURES

Table 4.1 describes the indicators, response format, and alpha of key study variables. All measures demonstrated acceptable to good internal consistency. Six of the seven measures used data collected at the second follow-up, making the research design for the present study primarily cross-sectional. Further description of the study measures are provided below.

4.3.1. Dependent Variable

Antiretroviral Therapy Adherence included five indicators obtained at the second follow up. For each medication participants reported taking, they were asked the number of days in the last seven that they forgot to take a dose, deliberately skipped a dose, took less medication than prescribed, and took all medication as prescribed. The value of each indicator was the mean days across medications, with the first three (FORGOT, SKIP, LESS) reverse coded. The fifth global indicator assessed the extent to which participants believed they took their antiretroviral medications exactly as prescribed in the last 30 days (1 = none of the time to 6 = all of the time). The items were summed and averaged to create a composite score. Higher scores meant better adherence.

Table 4.1. Key Study Measures

Construct	Wave*	Item	Response Format	Alpha
Antiretroviral Therapy Adherence	В	 #Days in last 7 forgot to take a dose (reverse) #Days in last 7 purposely skipped dose (reverse) #Days in last 7 took lesser amount (reverse) #Days in last 7 took as prescribed Took meds exactly as prescribed in the last 30 days 	0 - 7 1 = none of the time, 6 = all of the time	.82
Discriminatory Healthcare Experiences	B B FU 1 FU 1 FU 1	 Exhibited hostility or a lack of respect to participant Gave less attention to participant than to other patients Refused service to participant Was uncomfortable with participant Treated participant as inferior Preferred to avoid participant 	0 = no, 1 = yes	.84
Healthcare Provider Distrust	FU 2	 Trust to offer quality care Trust to know best treatments Trust to give enough information Trust to keep personal information private Trust to treat patient nonjudgmentally Trust to offer high quality care regardless of insurance coverage Trust to put patient needs ahead of 	1= completely, 5 = not at all	.92

Construct	Wave*	Item	Response Format	Alpha
		research goals		
Psychological Burden of Medication	FU 2	 Too many pills to take Wanted to avoid side effects Reminded self of HIV status Health wasn't improving Worried about becoming immune Took a "drug holiday" Felt depressed or overwhelmed 	1 = often, 4 = never	.85
Difficulty Accessing Medication	FU 2	 Hard to get HIV medications Easy to get HIV prescriptions (reverse) Takes a lot of time and effort to get HIV medication HIV medication would be hard to get if it runs out 	1 = strongly agree,4 = strongly disagree	.71
Difficulty Scheduling Medication	FU 2	Away from homeToo busy or forgotChange in daily routine	1 = often, 4 = never	.76
Medication Efficacy Beliefs *B = becaling: ELL1 = 1st follow	FU 2	 HIV medications make people live longer HIV medications improve the quality of people's lives 	1 = strongly agree,4 = strongly disagree	.72

^{*}B = baseline; FU 1 = 1st follow up; FU 2 = 2nd follow up

4.3.2. Independent Variables

Discriminatory Healthcare Experiences had three dichotomous indicators obtained at baseline and three at the first follow up interview. Participants reported at baseline whether, since they had become HIV+, any healthcare provider had ever exhibited hostility or disrespect to them, paid

less attention to them than other patients, or refused them service. At the first follow-up interview, participants reported whether any healthcare provider had ever been uncomfortable around them, treated them as inferior, or preferred to avoid them since becoming HIV+. Even though the data were collected in two waves, the items were considered as a group as retrospective indicators of separate experiences. The items were summed and averaged to create a composite score. Higher scores meant more experiences with discrimination in healthcare settings.

Healthcare Provider Distrust had seven indicators obtained at the second follow up interview assessing the extent to which participants trusted their current primary provider of HIV/AIDS care. On a 5-point scale (1 = completely to 5 = not at all), participants reported the degree that they trusted their healthcare provider to offer quality care, know the best treatments, provide enough information, keep personal information confidential, treat them in a nonjudgmental manner, offer high quality care regardless of insurance status, and put participant needs ahead of research goals. The items were summed and averaged to create a composite score. Higher scores meant greater distrust in healthcare providers.

Four factors captured participants' attitudes and beliefs about antiretroviral therapy, with all indicators obtained at the second follow up interview:

- Psychological Burden of Medication had eight indicators of the degree to which participants had worries and concerns about taking antiretroviral therapy (e.g., too many pills to take, reminded self of HIV status, concern about developing immunity), with higher scores meaning greater psychological burden. Each indicator was measured on a 4-point scale (1 = never to 4 = often).
- Difficulty Accessing Medication had four indicators assessing the degree to which participants felt that obtaining antiretroviral therapy was difficult (e.g., hard to get HIV medications,

takes a lot of time and effort to get HIV medications), with higher scores meaning greater difficulty. Each indicator was measured on a 4-point scale (1 = strongly disagree to 4 = strongly agree).

- Difficulty Scheduling Medication had three indicators assessing the extent to which changes in participants' routines impeded their adherence to antiretroviral therapy (e.g., being away from home, too busy or forgot), with higher scores meaning greater difficulty.

 Each indicator was measured on a 4-point scale (1 = never to 4 = often).
- *Medication Efficacy Beliefs* had two indicators assessing the extent to which participants believed antiretroviral therapy promoted longer and better quality lives, with higher scores meaning more positive beliefs about the efficacy of antiretroviral therapy. Each indicator was measured on a 4-point scale (1 = strongly disagree to 4 = strongly agree).

The items for each construct were summed and averaged to create a composite score.

Racial/Ethnic Minority Status was dummy coded as 0 if participants self-classified as White race, non-Hispanic ethnicity and 1 otherwise. I did not use alternate coding schemes to test for differences among racial/ethnic groups because of inadequate sample sizes of the Hispanic (n = 272) and "other" group (n = 65) samples among participants who completed all waves of data collection and were prescribed antiretroviral therapy (n = 1911).

4.3.3. Control Variables

The control variables used in these analyses, chosen for their potential for confounding the relationships between racial/ethnic minority status and adherence, were selected from derived variables created by the HCSUS research team (Duan et al., 2001):

• The original responses for Age at baseline were 1 for 18-29 years, 2 for 30-34, 3 for 35-39, 4 for 40-44, 5 for 45-49, and 6 for 50 years and over. This variable was recoded to its category's midpoint to approximate a continuous scale.

- *Gender*, assigned by the interviewer at baseline, was an indicator with 0 for male and 1 for female.
- Sexual Orientation was a nominal variable obtained at baseline, coded as 1 for homosexual,
 2 for heterosexual, and 3 for bisexual. Two dummy variables for heterosexual and
 bisexual orientation, with homosexual as the reference category, were used in multivariate analyses.
- HIV Risk Exposure described the manner in which the participant became infected with HIV. Obtained at baseline, this nominal variable was coded as 1 for injection drug use, 2 for male-to-male sexual contact, 3 for male-to-female sexual contact, and 4 for other (e.g., blood transfusion). When more than one possible transmission was selected (e.g., men having sex with men/injection drug use), the first method listed was selected. Three dummy variables were used for multivariate analyses with male-to-male sexual contact as the reference category.
- The Year First Diagnosed as HIV+ was a continuous variable ranging from 1978 to 1996, with 11.8% (n = 337) missing values. The earlier the year, the longer participants had known their HIV status.
- Education at baseline was the highest degree obtained by the participant, with responses ranging from 1 for less than a high school degree to 4 for a bachelor's degree or higher. Three dummy variables were used for multivariate analyses, with less than high school as the reference category.
- The original responses for *Annual Income*, participant's individual earnings in 1995, ranged from 1 for \$0 \$5000 to 5 for \$40000 or more. This variable was recoded to its category's midpoint to approximate a continuous scale.

- At baseline, primary *Insurance Status* in the past six months was derived using hierarchical assignment. First, participants with Medicare were assigned to the Medicare category regardless of other insurance. Next, if the Medicare data were not missing and participants had private insurance or CHAMPUS (private managed care for military), they were assigned to the private insurance category. Then, if participants had Medicaid or Veterans Administration coverage (publicly financed health benefits for military) and no missing data on Medicare, private insurance, or CHAMPUS, then they were assigned to the Medicaid category. Otherwise, participants were categorized as having no insurance. Multivariate analyses used three dummy variables for Medicare, private, and Medicaid insurance, with no insurance as the reference category.
- *AIDS Diagnosis* was an indicator variable with 0 for no and 1 for yes if, at baseline, participants had either a CD4 count of less than 200 or a clinical diagnosis of AIDS.
- The most recent *Viral Load* at second follow up was categorized as 1 for undetectable to 7 for 100,000 or more copies/ml. This variable was recoded to its category's midpoint to approximate a continuous scale. The lower the viral load, the healthier the participant was considered to be. There were 15.6% (n = 354) missing values.
- The lowest ever reported *CD4 Count* at baseline was categorized as 1 for 0 49 and 4 for 500 or more. This variable was recoded to its category's midpoint to approximate a continuous scale. The higher the CD4 count, the healthier the participant was considered to be. There were 16.6% (n = 376) missing values.
- The *Physical Health Composite* and *Mental Health Composite* scores were standardized measures of Health-Related Quality of Life subscales of the Medical Outcomes Study Short Form Health Survey (SF-36) (Hays et al., 2000) obtained at baseline. Higher scores indicated better physical and mental health.

- Depression is a disabling episode that is characterized by such symptoms as persistent sadness, feelings of hopelessness and pessimism, and decreased energy (NIMH, 2000).
 The number of *Depression Symptoms*, measured at baseline, was a count variable with the range 0 8.
- Dysthymia is a less severe form of depression but one that was long-term and chronic (NIMH, 2000). The number of *Dysthymia Symptoms*, measured at baseline, is a count variable with the range 0 – 4.
- At baseline, *Type of Drug Used in Past Year* was derived using hierarchical assignment (Tucker et al., 2003). Participants who did not use any illicit drug in the past year were assigned to the no use category. Participants who reported any illicit drug use were assigned to one of three additional categories. The first category was those who reported using marijuana and analgesics, but no other illicit drugs. The second category was those who reported any use of inhalants, hallucinogens, sedatives, and amphetamines, but not heroin or cocaine. The third category was those who reported any use of heroin and cocaine. Three dummy variables were used for multivariate analyses, with no use as the reference category.
- At the second follow up, participants reported the *Number of Antiretroviral Medications* that they were prescribed.
- Usual Provider at baseline was an indicator variable (0 = no, 1 = yes) for whether participants usually saw the same healthcare provider for their HIV/AIDS care.
- Social Support was defined as functions performed by others that are intended to be helpful (Fleishman et al., 2000). This was a standardized composite variable (range 0 100) measuring at baseline the degree to which participants felt they had someone who

- could give them money, help with daily chores, and love them. The higher the score, the more perceived social support the participant had.
- Adherence Self-Efficacy was an ordinal variable assessing the extent to which participants believed they would be able to take their antiretroviral therapy exactly as prescribed over the next month (1 = strongly agree to 4 = strongly disagree).

4.4. DATA ANALYSIS

I performed the analysis in three stages. First, I conducted descriptive and bivariate analyses. Second, I used multiple regression to determine the independent associations between the dependent and six explanatory variables. These first two stages were performed using Intercooled STATA, version 8.2 (STATA Corporation, 2003), which incorporates the analytic weights required by the complex sampling design used in the HCSUS dataset. Third, I used structural equation modeling (SEM) to identify the direct and indirect effects of the study measures on antiretroviral therapy adherence. The SEM analyses were performed using MPlus, version 3.11 (Muthen & Muthen, 2004), which can handle categorical data, non-normally distributed data, and analytic weights. Below, I describe these strategies in more detail.

4.4.1. Analyses for Aim 1

Descriptive statistics. The first aim was to describe and examine discriminatory healthcare experiences, healthcare provider distrust, and their determinants among HIV+ patients. The sample for Aim 1 included all participants who had completed all three waves of data collection (n = 2267). I generated descriptive statistics (e.g., proportions or means, standard deviations, confidence intervals) for each variable, stratified by racial/ethnic minority status. For the key study measures, I used mean composite scores based on construct indicators instead of factor scores to increase data interpretability; the correlation between the two types of variables was

greater than .99 for all measures. Simple linear regression was conducted to determine the unadjusted bivariate associations among the control variables, discriminatory healthcare experiences, and healthcare provider distrust. The significance level for all analyses was set at probability value of less than or equal to .05 but variables with a probability value of .20 or less in bivariate analyses were included in the multivariate models. This liberal cut off point was used because of the exploratory nature of the analysis.

Regression analyses. I used multivariate linear regression to identify independent associations between discriminatory healthcare experiences, healthcare provider distrust, and the control variables. To assess whether the factors associated with discriminatory healthcare experiences and healthcare provider distrust varied by minority status, interaction terms were added to each regression equation. Interaction terms with a probability value greater than .05 were then dropped from the full model so that the main effects could be interpreted.

4.4.2. Analyses for Aim 2

Descriptive statistics. The second aim was to test causal models of the relationships among racial/ethnic minority status, discriminatory healthcare experiences, healthcare provider distrust, antiretroviral therapy attitudes and beliefs, and antiretroviral therapy adherence. The sample for Aim 2 included all participants who had completed three waves of data collection and who were taking antiretroviral medications at the time of the second follow up interview (n = 1911). I generated descriptive statistics for each variable, stratified by racial/ethnic minority status. Next, I conducted simple linear regression to determine the unadjusted bivariate associations between the explanatory variables, control variables, and antiretroviral therapy adherence. The significance level for all analyses was set at probability value less than or equal to .05 but variables with a probability value of .20 or less in bivariate analyses were included in the structural equation models.

Model testing. I tested hypotheses regarding mediators of the relationship between racial/ethnic minority status and antiretroviral therapy adherence using structural equation modeling. SEM proposes a set of relations between variables and evaluates the degree of model fit with observed data (Bollen, 1989; Hoyle & Smith, 1994; Kline, 1998; MacCallum & Austin, 2000). SEM is considered an efficient means of testing mediation because it: (1) controls for measurement error; (2) allows for computation of direct effects through inclusion of third variables; and (3) allows estimation of models with multiple mediators or mediation/moderation combinations (Hoyle & Smith, 1994). This technique does not allow researchers to identify a "true" model. Rather, multiple models may fit the data and researchers must use their own judgment to determine whether a given model corresponds with reality (Bollen, 1989; Hoyle & Smith, 1994; Kline, 1998; MacCallum & Austin, 2000).

The general structural equation model consists of the measurement model and structural model (Bollen, 1989; Hoyle & Smith, 1994). The measurement model is a set of hypotheses about the relationship between observed and latent variables (i.e., the confirmatory factor analysis described earlier). Measurement error is represented as a latent variable in the measurement model because it is inferred, not directly assessed. To provide a unit scale for each latent variable, the factor loading of one indicator was constrained to 1.0 (Bollen, 1989; Kline, 1998). The structural model is a set of hypotheses about the relationships between independent and dependent variables, whether observed or latent (Bollen, 1989; Hoyle & Smith, 1994). I produced model parameters using weighted least square mean- and variance-adjusted estimation (WLSMV), a robust method that accounts for the non-independent, non-normal observations and is used when at least one categorical variable is incorporated in the model (Muthen & Muthen, 2004).

I imputed missing data using the MISSING command in MPlus, which is a missing at random (MAR) maximum likelihood data method (Muthen & Muthen, 2004). This means that the missing data can be modeled as a function of observed covariates and observed outcomes. This strategy cannot be used for exogenous variables, however. The control variable Viral Load was thus dropped from the SEM analysis because the large amount of missing data (n = 354, 15.6%) produced unstable estimates. The other control variables with large amounts of missing data, year first diagnosed as HIV+ and lowest ever CD4 count, were not significantly associated with antiretroviral therapy adherence in bivariate analyses and thus not included in multivariate analyses.

I used a model-generating strategy to build a good-fitting model (Kline, 2005). This strategy allows the researcher to add or delete parameters to improve model fit based on both researcher's content knowledge and modification indices (Lagrange multiplier and Wald statistics) calculated by the SEM program. In all cases, however, theoretical plausibility trumps modification indices when deciding what paths to add to an existing model. Nonsignificant paths were dropped in the final model. Following Hu and Bentler (1998), models were considered to have a good fit if: (1) the ratio of χ^2 to degrees of freedom (CMINDF) was less than 3.0⁴; (2) the root mean square error of approximation (RMSEA) was .06 or less; (3) and the Tucker-Lewis (TLI) and Comparative Fit (CFI) indices were .95 or greater (Hu & Bentler, 1998). Because the models included categorical indicators, I used the weighted root mean residual (Muthen & Muthen, 2004) instead of the recommended standardized root mean residual (SRMR). WRMR should have a score of 1.00 or less (Muthen, 2004).

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⁴ The chi-square statistic is a basic model fit index, with nonsignificant results demonstrating good fit. However, the chi-square statistic is sensitive to large sample sizes (Bollen, 1989; Kline, 2005), which is the case for the present study. Therefore I reported the normed chi-square (ratio of chi square to degrees of freedom) instead.

I assessed statistical significance of unstandardized parameter estimates based on the absolute value of the critical ratio test statistic (estimate divided by its standard error; considered as a *t* score), whose absolute value should be greater than 1.96 for a probability value of .05 or less. I also checked whether the parameter estimate had the hypothesized sign and assessed the magnitude of the standardized estimates according to Cohen's (1988) typology of small (.10 or less), medium (around .30), and large (.50 or more) effects. All models controlled for the effects of sociodemographic and psychosocial factors associated with antiretroviral therapy adherence.

Finally, I conducted an effects decomposition using the MODEL INDIRECT command of MPlus (Muthen & Muthen, 2004). This produces the total, direct, and indirect effects of study constructs on the outcome (in this case, antiretroviral therapy adherence). The direct effect is the parameter estimate of the relationship between one construct and the outcome. Indirect effects are parameter estimates of mediating pathways. The total effect is the sum of the direct and indirect effects. The strongest evidence for mediation comes when there is a pattern of significant indirect effects but nonsignificant direct effects (Kline, 2005).

CHAPTER FIVE: RESULTS

This chapter reports study findings by research aim. Each aim includes sample characteristics and bivariate analyses. Aim 1 includes multivariate regression models and Aim 2 includes structural equation models. The chapter concludes with a summary of the support for the study hypotheses.

5.1. AIM 1

To describe and examine the factors associated with discriminatory healthcare experiences and healthcare provider distrust, two consequences of stigma in interpersonal care quality, among racial/ethnic minority and nonminority HIV+ patients.

5.1.1. Sample Description

Table 5.1 presents descriptive statistics for the sample for Aim 1 (n = 2267) stratified by racial/ethnic minority status. Of the minority sample (n = 1109), 64% were African American (non-Hispanic), 29% were Hispanic/Latino, and 7% reported another racial/ethnic category. The minority sample differed from the nonminority sample on most sociodemographic characteristics. Compared to nonminorities, minority participants were more likely to be female, younger, have less than a high school degree, earn less than \$25,000 annually, to have been on Medicaid, identify as heterosexual, report exposure to HIV through injection drug use or male-to-female sexual contact. Minority participants also were more likely to have a more recent HIV diagnosis, and to have used heroin or cocaine in the past year. Minorities were less likely than nonminorities to identify as homosexual, have private insurance, or to have an AIDS diagnosis.

Minority participants reported fewer symptoms of depression, more symptoms of dysthymia, and less social support than did nonminority participants.

Table 5.1. Sample Characteristics for Aim 1 by Minority Status

	Minority (n = 1109), % or Mean (SD)	Nonminority (n = 1158), % or Mean (SD)	p
Female	34.1	12.4	<.001
< 35 Years Old	35.8	3.3	.016
< High School Degree	36.5	12.5	<.001
< \$25,000 Annual Income	84.4	56.4	<.001
Insurance in Last 6 Months			
None	19.9	15.6	<.001
Medicaid	16.7	4.8	
Medicare	2.9	18.5	
Private	2.8	46.8	
Sexual Orientation			
Homosexual	28.8	68.0	<.001
Heterosexual	62.4	24.8	
Bisexual	8.9	7.1	
Risk Exposure			
Injection Drug Use	27.0	2.3	<.001
Male-to-Male Sexual Contact	32.4	65.6	
Male-to-Female Sexual Contact	29.8	8.6	
Other	1.8	5.5	
Year Diagnosed HIV+	1992 (3.1)	1990 (3.4)	<.001
Has AIDS Diagnosis	54.3	62.1	.009
Viral Load 1000 copies/ml or less	15.5	24.7	<.001
Lowest Ever CD4 Count < 200	11.3	16.6	<.001
Self-Perceived Physical Health	49.8 (1.2)	49.6 (1.1)	.600

	Minority (n = 1109), % or Mean (SD)	Nonminority (n = 1158), % or Mean (SD)	p
Self-Perceived Mental Health	49.7 (1.1)	49.9 (1.3)	.709
Depression Symptoms	1.6 (2.9)	2.0 (3.1)	.003
Dysthymia Symptoms	1.1 (1.6)	.8 (1.5)	<.001
Used Heroin or Cocaine in Past Year	18.6	12.6	<.001
Has Usual HIV Provider	91.2	92.0	.677
Social Support	62.6 (28.0)	68.1 (28.7)	<.001

5.1.2. Prevalence

- 1.1 What is the prevalence of discriminatory healthcare experiences among HIV+ patients?
- 1.2 Does the prevalence of discriminatory healthcare experiences among HIV+ patients vary by racial/ethnic minority status?

 (H 1.2) Minority HIV+ patients will have more discriminatory healthcare experiences than nonminority HIV+ patients.

More than one-third of participants (41%) reported ever experiencing at least one type of discrimination in healthcare settings since they were diagnosed with HIV. Table 5.2 shows the proportion of minority and nonminority participants who reported ever having each type of discriminatory healthcare experience. The most common experience reported across groups was that healthcare providers exhibited hostility or lack of respect towards the participant (27%), followed by providers giving less attention to participants than to other patients (21%) and providers being uncomfortable with patients (20%). The mean number of experience types reported by minorities was lower than that reported by nonminorities (.8 [CI₉₅: .7, .9] vs. 1.5 [CI₉₅: 1.4, 1.6], Mann-Whitney χ [1878] = 7.17, p < .01) and the prevalence of all types of

discrimination was lower among minorities than nonminorities. Thus, Hypothesis 1.2 was not supported.

Table 5.2. Prevalence of Discriminatory Healthcare Experiences by Minority Status

	% Ever Experienced Discrimination		
Type of Experience	Minority (95% CI)	Nonminority (95% CI)	p
Exhibited hostility, lack of respect to patient	19.8 (16.5, 23.5)	33.5 (29.7, 37.5)	<.001
Gave less attention than to other patients	14.7 (11.4, 18.9)	25.8 (22.1, 3.1)	<.001
Been uncomfortable with patient	12.3 (1.5, 14.5)	27.1 (22.7, 31.9)	<.001
Treated patient as inferior	11.8 (9.3, 15.0)	22.7 (18.2, 27.9)	.002
Preferred to avoid patient	11.7 (1.2, 13.3)	24.7 (2.3, 29.8)	<.001
Refused service to patient	1.1 (8.2, 12.5)	5.9 (4.3, 8.0)	.013

Note. Because of missing data across items, the minority sample size ranges from 1106 to 1109 and the nonminority sample size ranges from 1147 to 1158.

Participants most commonly attributed discriminatory healthcare experiences to their HIV status (79%), followed by their sexual orientation (31%) and race (13%)⁵. Minority participants were significantly less likely than nonminorities to attribute these experiences to their HIV status (74% vs. 83%, χ^2 [1, 687] = 8.1, p = .010) or sexual orientation (19% vs. 40%, χ^2 [1, 676] = 34.4, p < .001). Minority participants were more likely than nonminorities to attribute discriminatory healthcare experiences to their race (27% vs. 5%, χ^2 [1, 696] = 7.1, p < .001). There were no differences in attributions to gender or drug use.

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⁵ Descriptive statistics on attributions to discrimination were computed without weights because a stratum with only one population sampling unit was detected.

- 1.3 What is the prevalence of healthcare provider distrust among HIV+ patients?
- 1.4 Does the prevalence of healthcare provider distrust among HIV+ patients vary by racial/ethnic minority status?

 (H 1.4) More minority HIV+ patients will distrust their healthcare provider than nonminority HIV+ patients.

Across domains, low proportions of participants distrusted their healthcare providers (Table 5.3). The proportion of those who did not completely or almost completely trust their healthcare provider did not vary by minority status except for the domain regarding research goals (10.7% Minority vs. 8.0% Nonminority, χ^2 [1, 2267] = 23.94, p < .001). Hypothesis 1.4 was thus largely unsupported. Using a more conservative definition that considered as distrustful only participants who did not completely trust their healthcare provider increased the proportion of the sample considered distrustful by approximately 10% across domains, but the difference by minority status for research goals was no longer significant (22.3% Minority vs. 23.4% Nonminority, χ^2 [1, 2267] = 4.09, p = .231). Racial/ethnic minority and nonminority participants also did not differ in the degree of healthcare provider distrust in an unadjusted bivariate analysis (Mann-Whitney χ [2263] = .05, p = .963).

Table 5.3. Prevalence of Healthcare Provider Distrust by Minority Status

	% Who Do Not Trust Their Healthcare Provider Completely or Almost Completely		
Trust Domain	Minority (95% CI)	Nonminority (95% CI)	p
Put patient needs ahead of research goals	10.7 (8.7, 13.0)	8.0 (6.6, 9.7)	<.001
Offer high quality care regardless of insurance	7.3 (5.6, 9.4)	6.7 (5.0, 9.0)	.13
Give enough information	5.5 (4.3, 7.1)	6.3 (5.3, 7.5)	.96
Offer quality care	5.1 (4.0, 6.5)	4.3 (3.3, 5.6)	.08
Respond in a caring and nonjudgmental way	5.1 (4.0, 6.6)	5.7 (4.4, 7.3)	.84
Know best treatments	4.6 (3.7, 5.6)	3.9 (3.0, 5.0)	.09
Keep personal information private	4.1 (3.0, 5.5)	3.1 (2.3, 4.2)	.07

Note. Because of missing data, the minority sample size ranges from 1045 to 1107 and the nonminority sample ranges from 1119 to 1154 across items.

5.1.3. Sociodemographic and Psychosocial Factors

- 1.5 What factors are associated with exposure to discriminatory healthcare experiences by HIV+ patients?
- 1.6 Do the factors associated with discriminatory healthcare experiences by HIV+ patients vary by racial/ethnic minority status?

Table 5.4 shows the unadjusted bivariate associations⁶ between discriminatory healthcare experiences and potential sociodemographic and psychosocial factors. Higher discrimination scores were associated with nonminority status, higher education level, having Medicare or no insurance, homosexual orientation, having HIV risk exposure through male-to-male sexual contact, longer HIV infection, having an AIDS diagnosis, poorer physical and mental health,

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 $^{^6}$ Unstandardized betas (β) are regression coefficients that represent the amount of change in the dependent variable given a 1-unit change in the independent variable. By definition, these coefficients cannot be compared across variables as they are not standardized.

more symptoms of depression and dysthymia, taking any illicit drug in the past year, and less social support.

Table 5.4. Bivariate Associations between Discriminatory Healthcare Experiences and Potential Sociodemographic and Psychosocial Factors

	Discriminatory Healthcare Experiences	
	β (95% CI)	p
	• • • • • • • • • • • • • • • • • • • •	
Minority	72 (-1.06,39)	<.001
Female	14 (31, .01)	.064
Age	03 (07, .01)	.150
Education		
High School	.34 (.11, .57)	.005
Less than College	.75 (.41, 1.09)	<.001
College or Higher	.40 (.19, .62)	<.001
Less than High School	(reference)	
Annual Income	.03 (04, .10)	.358
Insurance Status		
Medicaid	.14 (18, .45)	.384
Medicare	.65 (.47, .83)	<.001
Private	58 (79,37)	<.001
None	(reference)	
Sexual Orientation		
Heterosexual	29 (43,15)	<.001
Bisexual	19 (60, .24)	.386
Homosexual	(reference)	
Risk Exposure		
IDU	.06 (14, .27)	.542
Male-to-Female Sexual Contact	32 (54,11)	.004
Other	30 (58,02)	.036
Male-to-Male Sexual Contact	(reference)	
Year Diagnosed HIV+	09 (12,06)	<.001
AIDS Diagnosis	.37 (.21, .53)	<.001

	Discriminatory Healthcare Experiences	
	β (95% CI)	p
Viral Load	03 (06, .00)	.086
Lowest Ever CD4 Count	07 (15, .01)	.084
Self-Reported Physical Health	04 (05,04)	<.001
Self-Perceived Mental Health	04 (05,03)	<.001
Depression Symptoms	.12 (.09, .15)	<.001
Dysthymia Symptoms	.15 (.10, .20)	<.001
Type of Drug Used in Past Year		
Marijuana or Analgesics	.54 (.35, .75)	<.001
Inhalants, Hallucinogens, Sedatives, or Amphetamines	.63 (.40, .86)	<.001
Heroin or Cocaine	.34 (.12, .57)	.004
No Use	(reference)	
Usual HIV Provider	01 (34, .31)	.941
Social Support	01 (01, .00)	<.001

Note. Because of missing data, the sample sizes across items range from 1864 to 2232.

Multivariate associations between discriminatory healthcare experiences and baseline sociodemographic characteristics are shown in Table 5.5. To assess whether the factors associated with discriminatory healthcare experiences varied by minority status, interaction terms were added to the original regression equation. Interaction terms with a *p*-value greater than .05 were then dropped from the full model so the main effects could be interpreted. In the reduced model (Table 5.5), significant interaction effects were found between minority status and depression symptoms. That is, minority HIV+ patients with fewer symptoms of depression had higher discrimination scores than minority HIV+ patients with more symptoms of depression. Significant interaction effects were also found between minority status and HIV risk exposure.

That is, minority HIV+ patients who were exposed to HIV through male-to-male sexual contact had higher discrimination scores than minority HIV+ patients who were exposed to HIV in other ways (e.g., injection drug use, male-to-female sexual contact). For both minority and nonminority patients, higher discrimination scores were associated with having less than a college degree, being diagnosed with HIV earlier, having an AIDS diagnosis, ever having a CD4 count less than 200, poorer physical health, using any illicit drug in the past year except heroin or cocaine, and having less social support. The two interaction terms explained less than an additional 1% of the variance in discriminatory healthcare experiences.

Table 5.5. Final Reduced Model of the Interaction between Minority Status and Factors Associated with Discriminatory Healthcare Experiences (n = 1840)

	Discriminator Healthcare Experi	•
	β (95% CI)	p
Minority	32 (58,05)	.020
Female	02 (25, .21)	.855
Age	05 (10, .01)	.086
High School	.25 (01, .51)	.063
Less than College	.60 (.27, .93)	.001
College	.25 (05, .55)	.100
Medicare	.15 (16, .47)	.336
Private Insurance	27 (63, .09)	.141
Heterosexual Orientation	.09 (08, .26)	.305
Male-to-Female Sexual Contact	.08 (15, .30)	.487
Other Risk Exposure	.60 (04, 1.24)	.067
Year Diagnosed HIV+	07 (10,04)	<.001

	Discriminator Healthcare Exper	•
	β (95% CI)	p
AIDS Diagnosis	.29 (.12, .46)	.001
Viral Load	.00 (05, .04)	.885
Lowest Ever CD4 Count	17 (28,06)	.005
Self-Reported Physical Health	03 (04,02)	<.001
Self-Reported Mental Health	.00 (02, .01)	.533
Depression Symptoms	.08 (.04, .12)	<.001
Dysthymia Symptoms	.05 (01, .10)	.076
Used Marijuana or Analgesics in Past Year	.31 (.14, .47)	<.001
Used Inhalants, Hallucinogens, Sedatives, or Amphetamines in Past Year	.21 (.04, .38)	.016
Used Heroin or Cocaine in Past Year	.09 (15, .33)	.441
Social Support	.00 (01, .00)	.041
Minority x Other Risk Exposure	78 (15,06)	.035
Minority x Depression Symptoms	08 (13,04)	<.001
$R^2 = .14$		

Note. Nonsignificant interactions are not included in the final model.

- 1.7 What factors are associated with healthcare provider distrust by HIV+ patients?
- 1.8 Do the factors associated with healthcare provider distrust by HIV+ patients vary by racial/ethnic minority status?

Table 5.6 shows the unadjusted bivariate associations between healthcare provider distrust and potential sociodemographic and psychosocial factors. Higher distrust scores were associated with younger age, having completed college, less annual income, being exposed to HIV through

injection drug use, higher viral load, poorer physical and mental health, more symptoms of depression and dysthymia, using any type of illicit drug in the past year, less social support, and more discriminatory healthcare experiences.

Table 5.6. Bivariate Associations between Healthcare Provider Distrust and Potential Sociodemographic and Psychosocial Factors

	Healthcare Provider	Distrust
	β (95% CI)	p
Minority	.05 (05, .15)	.288
Female	02 (09, .05)	.639
Age	04 (06,02)	<.001
Education High School Less than College College or Higher Less than High School	03 (09, .03) .07 (03, .17) 08 (17, .00)	.373 .144 .046
Annual Income	04 (06,02)	<.001
Insurance Status Medicaid Medicare Private None	.04 (05, .13) 06 (13, .01) 01 (09, .06) (reference)	.339 .098 .715
Sexual Orientation Heterosexual Bisexual Homosexual	02 (09, .04) .02 (07, .13) (reference)	.483 .563
Risk Exposure IDU Male-to-Female Sexual Contact Other Male-to-Male Sexual Contact	.10 (.02, .17) 04 (10, .03) 01 (14, .12) (reference)	.016 .256 .841

	Healthcare Provider	Distrust
	β (95% CI)	p
Year Diagnosed HIV+	.00 (01, .01)	.871
AIDS Diagnosis	03 (12, .05)	.472
Viral Load	.03 (.02, .04)	<.001
Lowest Ever CD4 Count	.02 (02, .07)	.253
Self-Perceived Physical Health	01 (02,01)	<.001
Self-Perceived Mental Health	02 (02,01)	<.001
Depression Symptoms	.02 (.01, .03)	<.001
Dysthymia Symptoms	.05 (.04, .07)	<.001
Type of Drug Used in Past Year Marijuana or Analgesics Inhalants, Hallucinogens, Sedatives, or Amphetamines Heroin or Cocaine No Use	.10 (.03, .17) .11 (.02, .19) .17 (.07, .27) (reference)	.004 .018 .001
Usual HIV Provider	11 (25, .04)	.139
Social Support	.00 (01, .00)	<.001
Discriminatory Healthcare Experiences	.06 (.04, .08)	<.001

Note. Because of missing data, the sample sizes across items range from 1890 to 2263.

Multivariate associations between healthcare provider distrust, baseline sociodemographic characteristics, and discriminatory healthcare experiences are shown in Table 5.7. Because distrust scores did not vary by minority status, an interaction analysis was not performed. Higher distrust scores were associated with younger age, having some college education, higher viral load, poorer physical and mental health, using any illicit drug in the past year except heroin and cocaine, and less social support. More discriminatory healthcare experiences were also

independently associated with greater healthcare provider distrust, so Hypothesis 1.8 was supported. These variables explained 12% of the variance in distrust scores.

Table 5.7. Multivariate Model of Healthcare Provider Distrust (n = 1866)

	Healthcare Provider	Distrust
	β (95% CI)	p
Age	04 (07,01)	.009
Less than College	.12 (.03, .21)	.012
College	.05 (06, .16)	.363
Annual Income	.01 (02, .03)	.572
Medicare	04 (10, .03)	.261
IDU Risk Exposure	.05 (03, .13)	.180
Viral Load	.02 (.00, .03)	.022
Self-Reported Physical Health	.00 (01, .00)	.042
Self-Reported Mental Health	01 (01,01)	<.001
Depression Symptoms	.00 (02, .01)	.573
Dysthymia Symptoms	01 (03, .01)	.203
Used Marijuana or Analgesics in Past Year	.07 (01, .14)	.071
Used Inhalants, Hallucinogens, Sedatives, or Amphetamines in Past Year	.09 (.01, .16)	.024
Used Heroin or Cocaine in Past Year	.08 (04, .19)	.190
Usual HIV Provider	03 (16, .09)	.617
Social Support	.00 (.00, .00)	<.001
Discriminatory Healthcare Experiences	.04 (.02, .06)	.001
$R^2 = .12$		

5.2. AIM 2

To test a causal model of the relationships among racial/ethnic minority status, discriminatory healthcare experiences, healthcare provider distrust, antiretroviral therapy attitudes and beliefs, and antiretroviral therapy adherence.

5.2.1. Sample Description

Table 5.8 presents descriptive statistics for the sample for Aim 2 (n = 1911) stratified by racial/ethnic minority status. Compared to nonminorities, minority participants were more likely to be female, have less than a high school degree, earn less than \$25,000, have no insurance or Medicaid, have been exposed to HIV through male-to-female sexual contact, have used heroin or cocaine in the past year. Minorities were less likely than nonminorities to identify as homosexual and have an AIDS diagnosis. Minority participants also reported less social support than nonminority participants. Compared to minorities, nonminority participants had been diagnosed with HIV infection longer, had a lower viral load, and were less likely to ever have a CD4 count less than 200. Nonminority participants also had more symptoms of depression but fewer symptoms of dysthymia, and took more antiretroviral medications; the magnitude of those differences, however, was small.

Table 5.8. Sample Characteristics for Aim 2 by Minority Status

	Minority (n=918), % or Mean (SD)	Nonminority (n=993), % or Mean (SD)	p
Female	32.8	12.1	<.001
< 35 Years Old	24.5	29.8	.064
< High School Degree	35.0	11.8	<.001
< \$25,000 Annual Income	83.7	53.5	<.001
Insurance in Last 6 Months None Medicaid Medicare Private	19.1 39.8 18.8 22.4	14.3 16.4 2.7 48.7	<.001
Sexual Orientation Homosexual Heterosexual Bisexual	28.3 62.3 8.9	68.7 24.9 6.3	<.001
Risk Exposure Injection Drug Use Male/Female Sexual Contact Male-to-male sexual contact Other	25.7 33.4 3.2 1.7	18.7 66.5 9.2 5.6	<.001
Year First Tested HIV-Positive	1992 (3.1)	1990 (3.4)	<.001
Has AIDS Diagnosis	56.8	64.1	.017
Viral Load < 1000 copies/ml	27.9	38.9	<.001
Lowest Ever CD4 Count < 200	28.8	21.2	<.001
Self-Perceived Physical Health	5.1 (9.8)	5.1 (9.8)	.895
Self-Perceived Mental Health	5.3 (1.0)	5.3 (9.8)	.960
Depression Symptoms	1.6 (2.8)	1.9 (3.0)	.005
Dysthymia Symptoms	1.0 (1.6)	.7 (1.4)	<.001

	Minority (n=918), % or Mean (SD)	Nonminority (n=993), % or Mean (SD)	p
Used Heroin or Cocaine in Past Year	17.7	11.5	<.001
Number of Antiretroviral Medications	2.8 (.7)	3.0 (.7)	<.001
Has Usual HIV Provider	91.8	91.9	.967
Social Support	62.8 (27.8)	68.8 (28.3)	<.001

5.2.2. Statistics Describing Antiretroviral Therapy Adherence

Almost half of the participants (45.7%, n = 888) reported perfect adherence to antiretroviral therapy in the past week. Minority participants were less likely to report perfect adherence than nonminority participants (40.3% [CI₉₅: 35.9%, 44.7%] vs. 45.3% [CI₉₅: 46.1%, 54.5%], χ^2 [1, 54] = 31.5, p < .001). Table 5.9 presents regression coefficients representing the unadjusted bivariate associations between the degree of antiretroviral therapy adherence and its covariates. Better antiretroviral adherence was associated with older age, having a high school degree or more, higher income, better physical and mental health, taking more antiretroviral medications, and greater social support. Poorer adherence was associated with minority status, female gender, having Medicaid, heterosexual orientation, exposure to HIV through injecting drug use or male-to-female sexual contact, higher viral load, more symptoms of depression and dysthymia, and using heroin or cocaine in the past year. These variables were used as covariates in subsequent analyses.

⁷ Further analyses did not identify problems with collinearity among the proposed covariates.

Table 5.9. Bivariate Associations among Antiretroviral Therapy Adherence and Control Variables (n = 1911)

	Antiretrovira	
	Therapy Adhera β (95% CI)	p p
Minority	32 (42,22)	<.001
Female	31 (40,23)	<.001
Age	.01 (.01, .01)	<.001
Highest Degree		
High School/GED	.28 (.14, .42)	<.001
Associate's	.22 (.04, .41)	.020
Bachelor's or Higher	.40 (.25, .56)	<.001
Less than High School	(reference)	
Annual Income	.09 (.06, .12)	<.001
Insurance Status		
Medicaid	31 (46,16)	<.001
Medicare	02 (15, .10)	.730
Private	.11 (02, .25)	.093
None	(reference)	
Sexual Orientation		
Heterosexual	26 (37,16)	<.001
Bisexual	07 (18, .04)	.197
Homosexual	(reference)	
Risk Exposure		
IDU	20 (32,08)	.002
Male-to-Female Sexual Contact	30 (43,18)	<.001
Other	05 (18, .09)	.484
Male-to-Male Sexual Contact	(reference)	
Year Diagnosed HIV+	.00 (01, .01)	.943
AIDS Diagnosis	.07 (02, .15)	.112
Viral Load	05 (09,02)	.003
Lowest Ever CD4 Count	.04 (.03, .11)	.290
Self-Perceived Physical Health	.02 (.01, .02)	<.001

	Antiretroviral Therapy Adherence		
	β (95% CI)	p	
Self-Perceived Mental Health	.02 (.01, .02)	<.001	
Depression Symptoms	02 (04,01)	.009	
Dysthymia Symptoms	09 (13,04)	<.001	
Type of Illicit Drugs Used in Past Year Marijuana or Analgesics Inhalants, Hallucinogens, Sedatives, or Amphetamines Heroin or Cocaine No Use	10 (21, .01) 14 (30, .02) 20 (32,08) (reference)	.085 .094 .002	
Number of Antiretroviral Medications	.12 (.05, .20)	.003	
Usual HIV Provider	.16 (04, .37)	.117	
Social Support	.00 (.00, .00)	.002	

5.2.3. Structural Equation Models

I tested hypotheses regarding mediators of the relationship between racial/ethnic minority status and antiretroviral therapy adherence using structural equation modeling (SEM). The measurement model for SEM, created by confirmatory factor analysis, is the hypothesized relationships between observed indicators and factors. The structural model for SEM produces estimates (beta weights) of the strength and direction of relationships among factors. The overall fit of a proposed model to data is assessed through fit indices, whose results are compared to published guidelines. Model fit is improved by adding or deleting paths based on content knowledge and modification indices reported by the MPlus statistical program. When the model fit was satisfactory, I trimmed nonsignificant paths from the model. The following sections provide the results of this process.

5.2.3.1. Measurement Model

Confirmatory factor analysis (CFA) established the measurement models for subsequent analyses, i.e., confirmed the hypothesized structure of study constructs (latent variables). CFA was conducted separately for discriminatory healthcare experiences, healthcare provider distrust, antiretroviral therapy attitudes and beliefs, and antiretroviral therapy adherence. Table 5.11 presents the factor loading estimates and squared multiple correlations of construct indicators. Factor loading estimates are regression coefficients, with their standardized form interpretable as Pearson correlation coefficients between indicators and constructs (Kline, 2005). The critical ratios for factor loadings were all above 1.96 and therefore statistically significant at $p \le .05$. The standardized factor loadings were all greater than .50, a large effect according to Cohen's (1988) typology. The squared multiple correlations of the indicators denote the proportion of variance explained by the construct (Kline, 2005). Two indicators had squared multiple correlations of .40 or less: refused service (REFUSE; .34) and number of days took lesser amount of medication than prescribed (rLESS; .35). These indicators were retained, however, because of their conceptual importance.

Table 5.10 also presents the fit indices for the final measurement models of the key study variables. As a reminder, both measurement and structural models are considered to have a good fit if: the ratio of χ^2 to degrees of freedom (CMINDF) is 3.0 or less; the weighted root mean residual (WRMR) is 1.00 or less; the root mean square error of approximation (RMSEA) is .06 or less; and the Tucker-Lewis (TLI), and Comparative Fit (CFI) indices are .95 or greater. The fit indices generally suggest that the measurement models demonstrated adequate to good fit. The ratios for χ^2 to degrees of freedom (CMINDF) are well over the preferred score of 3.0 for

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 $^{^{8}}$ Observations with missing data on multiple construct indicators were dropped from further analysis (n = 25).

⁹ Model fit is assessed in the context of values from a set of indices and no one index provides a gold standard.

Healthcare Provider Distrust, Antiretroviral Therapy Attitudes and Beliefs, and Antiretroviral Therapy Adherence, which indicate poor fit. The values for the other four goodness-of-fit indices, however, described earlier meet the suggested guidelines. Therefore, I deemed the measurement models satisfactory and proceeded to test the structural model (relationships among constructs).

Table 5.10. Confirmatory Factor Analyses of Study Constructs (n = 1886)

Construct	Indicator (Label)	Unstd Factor Loading	Std Factor Loading	\mathbb{R}^2
Discriminatory Healthcare	Exhibited hostility or a lack of respect to participant (HOSTILE)*	1.00	.65	.43
Experiences	Gave less attention to participant than to other patients (LESSATTEN)	1.01	.66	.44
	Refused service to participant (REFUSE)	.89	.58	.34
	Was uncomfortable with participant (UNCOMF)	1.40	.91	.84
	Treated participant as inferior (INFERIOR)	1.46	.96	.92
	Preferred to avoid participant (AVOID)	1.50	.98	.96
	Model Fit: $\chi^2 = 8.91$, df = 3, $p = .030$; CMINDF = 2.97; CFI = 1.00; TLI = 1.00; RMSEA = .03; WRMR = .48			
Healthcare Provider	Trust to offer quality care (QUALITY)*	1.00	.90	.81
Distrust	Trust to know best treatments (BEST)	.88	.80	.63
	Trust to give enough information (INFO)	.99	.89	.80
	Trust to keep personal information private (PRIVATE)	.86	.78	.60
	Trust to treat patient nonjudgmentally (NOTJUDGE)	.95	.86	.74

Construct	Indicator (Label)	Unstd Factor Loading	Std Factor Loading	\mathbb{R}^2
	Trust to offer high quality care regardless of insurance coverage (INSUR)	.95	.86	.74
	Trust to put patient needs ahead of research goals (RESEARCH)	.92	.83	.68
	Model Fit: $\chi^2 = 47.29$, df = 4, $p = .000$; CMINDF = 11.82; CFI = .99; TLI = .99; RMSEA = .08; WRMR = .92			
Antiretroviral The	erapy Attitudes and Beliefs**			
Psychological Burden of	Too many pills to take (PILLS)*	1.00	.79	.51
Medication	Wanted to avoid side effects (EFFECT)	1.04	.82	.75
	Reminded self of HIV status (HIV)	.88	.69	.57
	Health wasn't improving (HEALTH)	1.00	.78	.62
	Felt the drug was too toxic (TOXIC)	1.07	.84	.62
	Worried about becoming immune (IMMUNE)	1.01	.80	.67
	Took a "drug holiday" (HOLIDAY)	.97	.76	.48
	Felt depressed or overwhelmed (DEPRESS)	1.02	.81	.61
Difficulty	Hard to get HIV medications (HARD)*	1.00	.74	.67
Accessing Medication	Easy to get HIV prescriptions (EASY)	.93	.69	.71
	Takes a lot of time and effort to get HIV medication (TIME)	1.03	.76	.64
	HIV medication would be hard to get if it runs out (RUNOUT)	.87	.64	.58
Difficulty	Away from home (AWAY)*	1.00	.75	.65
Scheduling Medication	Too busy or forgot (BUSY)	1.05	.79	.54

Construct	Indicator (Label)	Unstd Factor Loading	Std Factor Loading	\mathbb{R}^2
	Change in daily routine (CHANGE)	.87	.64	.47
Medication Efficacy Beliefs	HIV medications make people live longer (LONGER)*	1.00	.71	.57
	HIV medications improve the quality of people's lives (IMPROVE)	1.22	.87	.41
	Model Fit: $\chi^2 = 42.93$, df = 9, $p = .000$; CMINDF = 4.77; CFI = .99; TLI = .98; RMSEA = .05; WRMR = 1.29			
Antiretroviral Therapy Adherence	#Days forgot to take a dose – reverse (rFORGOT)*	1.00	.71	.50
Adherence	#Days purposely skipped dose – reverse (rSKIP)	.88	.58	.33
	#Days took lesser amount – reverse (rLESS)	.85	.60	.36
	#Days took as prescribed (PERFECT)	2.10	.86	.74
	Took meds exactly as prescribed (GLOBAL)	1.07	.67	.45
	Model Fit: $\chi^2 = 27.19$, df = 2, $p = .000$; CMINDF = 13.60; CFI = .98; TLI = .98; RMSEA = .08; WRMR = .54			

^{*}These parameters were constrained to 1.00 to scale the constructs.

Note: All factor loadings were significant at $p \le .05$; however, constrained indicators were not tested.

Figures 5.1, 5.2, and 5.3 present the final measurement models. *Circles* represent constructs (factors, or latent variables). *Squares* represent indicators (or observed variables). *Single-headed arrows* from constructs (circles) to indicators (squares) represent standardized factor loadings. Single-headed arrows into indicators (squares) represent residual variance, or error. *Double-headed arrows* between constructs (circles) represent covariances; and double-headed arrows between the residual variances of indicators (single-headed arrows into squares) represent correlated measurement error that I suggest is due to similar item wording.

^{**}The constructs that comprise Antiretroviral Therapy Attitudes and Beliefs were tested as a group because they were hypothesized to covary.

Figure 5.1. Standardized Measurement Model of Discriminatory Healthcare Experiences, All Factor Loadings Significant at $p \le .05$

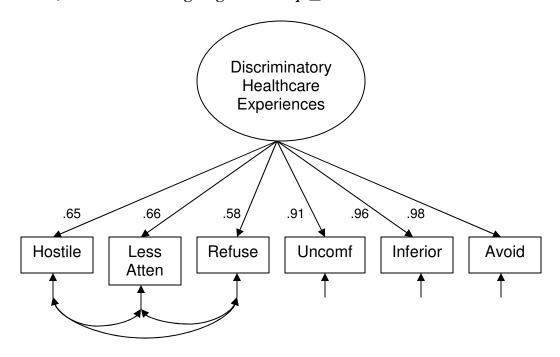


Figure 5.2. Standardized Measurement Model of Healthcare Provider Distrust, All Factor Loadings Significant at $p \le .05$

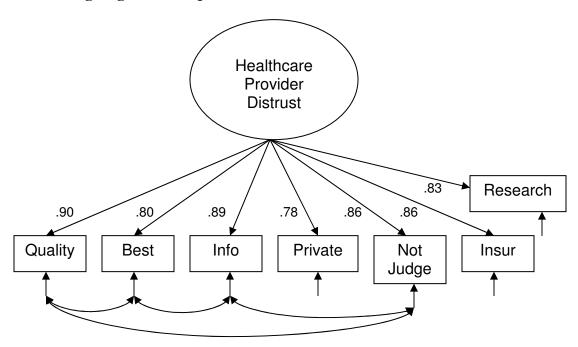


Figure 5.3. Standardized Measurement Model of Antiretroviral Therapy Beliefs and Attitudes, All Factor Loadings Significant at $p \le .05$

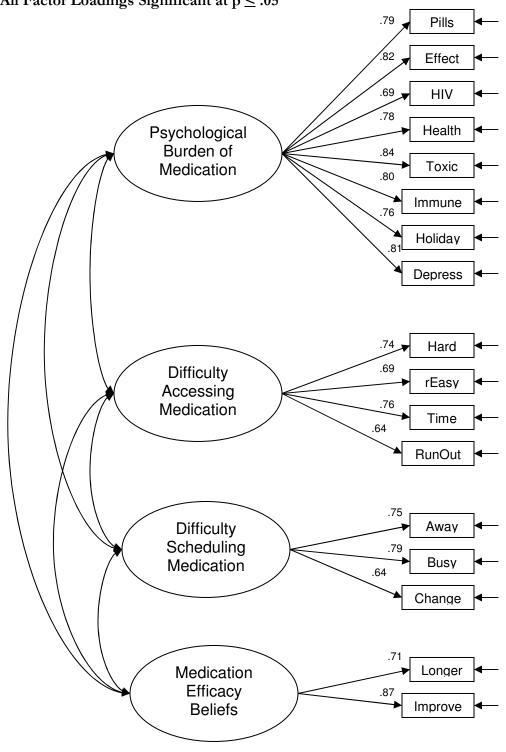


Figure 5.4. Standardized Measurement Model of Antiretroviral Therapy Adherence, All Factor Loadings Significant at $p \le .05$

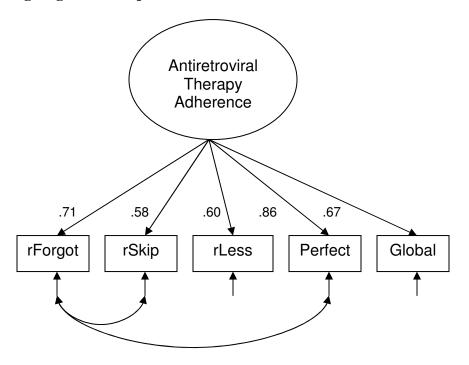


Table 5.11 presents bivariate correlations, means, and standard deviations of the study constructs produced with the composite variables used in Aim 1. Poorer antiretroviral therapy adherence was associated with greater healthcare provider distrust and all antiretroviral therapy attitudes and beliefs. Discriminatory healthcare experiences were not associated with poorer adherence. Both discriminatory healthcare experiences and healthcare provider distrust were associated with greater psychological burden of medication, difficulty accessing medications, difficulty scheduling medications, and more negative beliefs about medication efficacy.

Table 5.11. Correlations, Means, and Standard Deviations (n = 1886)

	1	2	3	4	5	6	7
1. Antiretroviral Therapy Adherence							
2. Discriminatory Healthcare Experiences	03 .198						
3. Healthcare Provider Distrust	09 <.001	.16 <.001					
4. Psychological Burden of Medication	47 <.001	.11 <.001	.22 <.001				
5. Difficulty Accessing Medication	10 <.001	.06 .011	.12 <.001	.15 <.001			
6. Difficulty Scheduling Medication	43 <.001	.09 <.001	.16 <.001	.43 <.001	.14 <.001		
7. Medication Efficacy Beliefs	15 <.001	.10 <.001	.20 <.001	.25 <.001	.16 <.001	.13 <.001	
Mean	6.40	1.19	1.46	1.37	2.18	1.91	1.53
S.D.	.92	1.8	.60	.55	.39	.78	.52

5.2.3.2. Structural Model

Table 5.12 summarizes the fit indices of the original and modified mediation models. By all of the goodness-of-fit indices except for the root mean square error of approximation (RMSEA), the original mediation model presented in Figure 5.5 ($\chi^2 = 76.02$, df = 12, p = .000) was a poor fit for the data. Guided by modification indices and conceptual plausibility, I sequentially added parameters to improve the fit of the model.

No literature directly supports the following modifications that add paths among antiretroviral therapy attitudes and beliefs, but the new paths can be justified logically. First, I

added a direct path from Psychological Burden of Disease to Difficulty Scheduling Medication (Mod 1). It is possible that patients who have concerns about or negative associations with antiretroviral therapy may have more difficulty incorporating the medication into their daily routine. Second, I added a direct path from Medication Efficacy Beliefs to Difficulty Accessing Medication (Mod 2). It is possible that patients who believe antiretroviral therapy is less important to their health may believe that the difficulty they go through to obtain the medication is more trouble than it's worth. Third, I added a direct path from Medication Efficacy Beliefs to Psychological Burden of Medication (Mod 3). It is possible that patients who believe antiretroviral therapy is less important to their health may also have more concerns about or negative associations with the medication. Finally, I allowed the errors of all of the Antiretroviral Therapy Adherence indicators except for GLOBAL to covary (i.e., to have a relationship) because of possible measurement error due to similar wording.

The built up model presented in Figure 5.6 ($\chi^2 = 40.87$, df = 12, p = .000) demonstrated good fit across the CFI, TLI, and RMSEA indices and adequate fit for CMINDF and WRMR. The model was then trimmed to remove nonsignificant paths; these included paths from: Minority Status to Difficulty Accessing Medication; Discriminatory Healthcare Experiences to Antiretroviral Therapy Adherence; and Difficulty Accessing Medication to Antiretroviral Therapy Adherence. Figure 5.7 presents the final trimmed model ($\chi^2 = 40.48$, df = 12, p = .000) with standardized parameters; additional details about parameter estimates follows.

Table 5.12. Measures of Overall Fit for Original and Modified Structural Models

	χ^2 (df, p)	CMINDF	CFI	TLI	RMSEA	WRMR
Original	76.02 (12, .000)	6.34	.92	.91	.05	1.94
Mod 1: Added path from Psychological Burden to Difficulty Scheduling	53.20 (12, .000)	4.43	.95	.94	.04	1.61
Mod 2: Added path from Medication Efficacy to Difficulty Accessing	47.68 (12, .000)	3.97	.96	.95	.04	1.52
Mod 3: Added path from Medication Efficacy to Psychological Burden	45.68 (12, .000)	3.81	.96	.95	.04	1.48
Mod 4: Added error covariances among Adherence indicators	40.87 (12, .000)	3.41	.97	.96	.04	1.39
Final: Dropped nonsignificant paths	40.48 (12, .000)	3.37	.97	.96	.04	1.40

Note. CMINDF = ratio of χ^2 to degrees of freedom; CFI = Comparative Fit Index; TLI = Tucker-Lewis Index; RMSEA = root means square error of approximation; WRMR = weighted root mean residual

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Figure 5.5. Original Structural Model

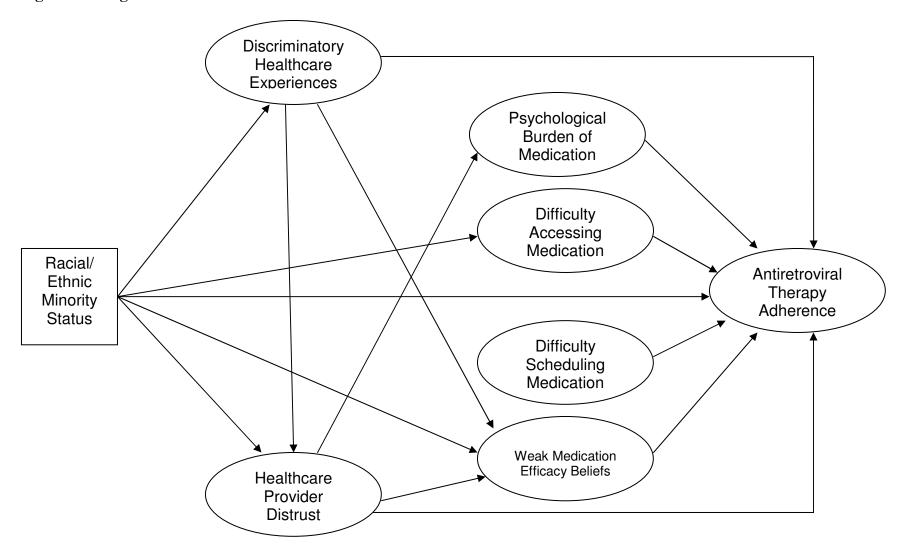


Figure 5.6. Structural Model after Modifications

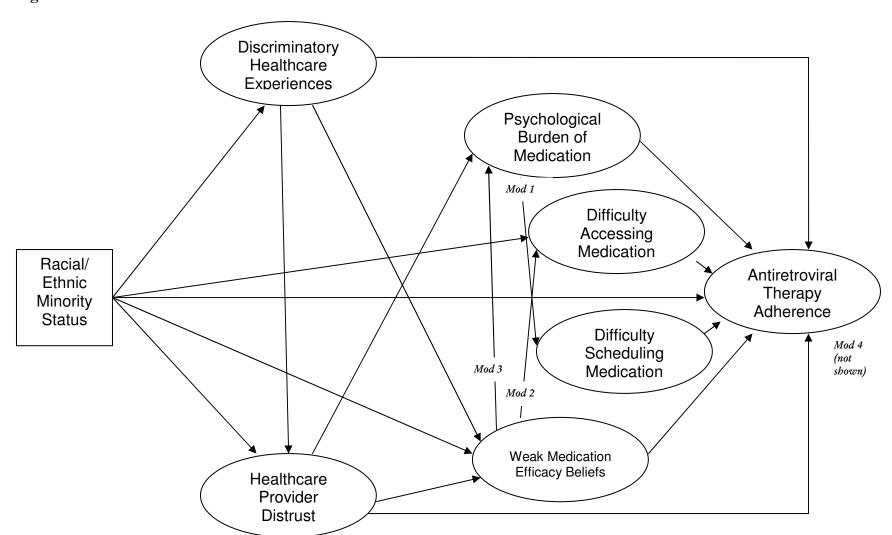
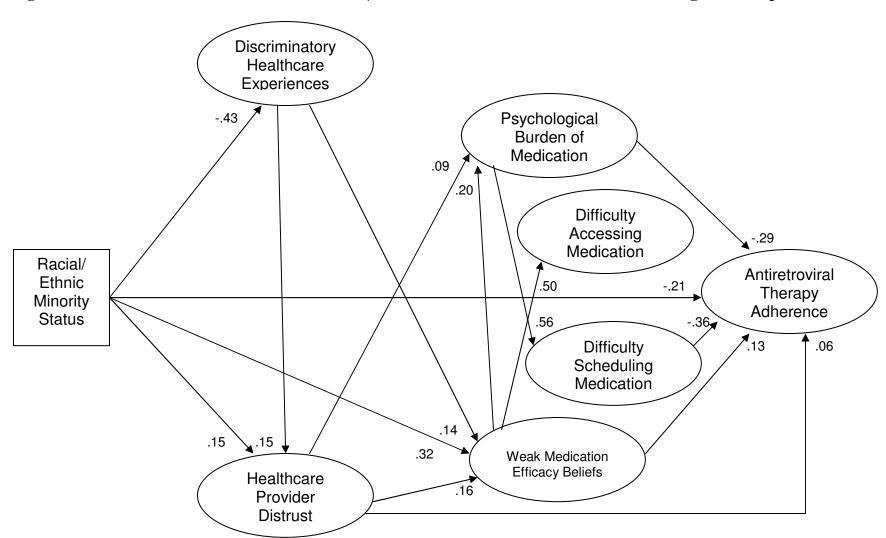


Figure 5.7. Final Trimmed Structural Model with Adjusted Standardized Parameter Estimates, All Significant at $p \le .05$



The next section reviews evidence that discriminatory healthcare experiences, healthcare provider distrust, and antiretroviral therapy attitudes and beliefs mediate the relationship between racial/ethnic minority status and antiretroviral therapy adherence.

2.1 Is racial/ethnic minority status associated with antiretroviral therapy adherence?

(H 2.1.1.) Racial/ethnic minority HIV+ patients will have poorer adherence to antiretroviral therapy than nonminority HIV+ patients.

2.2 Do discriminatory healthcare experiences partially mediate the relationship between racial/ethnic minority status and antiretroviral therapy adherence?

(H 2.2.1) As discriminatory healthcare experiences increases, adherence to antiretroviral therapy decreases.

(H 2.2.2) Minority HIV+ patients will have more discriminatory healthcare experiences and, in turn, poorer adherence to antiretroviral therapy than nonminority HIV+ patients.

2.3 Does healthcare provider distrust partially mediate the relationship between racial/ethnic minority status and antiretroviral therapy adherence?

(H 2.3.1) As healthcare provider distrust increases, adherence to antiretroviral therapy decreases

(H 2.3.2) Minority HIV+ patients will have greater distrust in their healthcare providers and, in turn, poorer adherence to antiretroviral therapy than nonminority HIV+ patients.

2.4 Do antiretroviral therapy attitudes and beliefs partially mediate the relationship between racial/ethnic minority status and antiretroviral therapy adherence?

(H 2.4.1) As (a) psychological burden of medication increases, (b) difficulty accessing medication, (c) difficulty scheduling medication, and (d) negative beliefs about medication efficacy increases, antiretroviral therapy adherence decreases.

(H 2.4.2) Minority HIV+ patients will have more difficulty accessing medication and, in turn, poorer adherence to antiretroviral therapy than nonminority HIV+ patients. (H 2.4.3) Minority HIV+ patients will have more negative beliefs in medication efficacy and, in turn, poorer adherence to antiretroviral therapy than nonminority HIV+ patients.

Table 5.13 presents the regression weights, covariances, and residual variances of the final model (Figure 5.7) along with the squared multiple correlations for the latent variables. The reported standardized parameter estimates (b) are adjusted for factors associated with

antiretroviral therapy adherence. As a reminder, these estimates are significant at the $p \le .05$ level when the absolute value of the critical ratio (t) is greater than 1.96. In the table, the regression weight under the "Parameter" column represents the coefficient estimates of the path through which the first factor affects the second factor. For example, "Minority \rightarrow Discriminatory Healthcare Experiences" indicates the direct effect of racial/ethnic minority status on discriminatory healthcare experiences. The covariances represent nondirectional associations between item error terms. The residual variances are error terms for both the factors and items. The R^2 of each factor is listed under "Residual Variances" as well.

Hypothesis 2.1.1 was supported; racial/ethnic minority patients had poorer antiretroviral adherence than nonminority patients (β = -.12, t = -3.29). Hypothesis 2.2.1 was not supported; discriminatory healthcare experiences were not associated with adherence, and thus were not included in the final trimmed model. Hypothesis 2.3.1 was not supported as HIV+ patients who were more distrustful of their healthcare providers had better antiretroviral adherence than patients who were less distrustful of their healthcare providers (β = .04, t = 2.88), which was contrary to the hypothesized direction. Most antiretroviral therapy attitudes and beliefs had direct effects on antiretroviral therapy adherence. The exception was Difficulty Accessing Medication, whose path was dropped in the final model and therefore Hypothesis 2.4.1b was not supported. The parameter estimate for Medication Efficacy Beliefs had a positive instead of negative sign. Therefore, Hypothesis 2.4.1d was also not supported (nor Hypothesis 2.4.3 by extension; but see discussion of indirect effects).

As reported for Aim 1, racial/ethnic minority HIV + patients reported fewer discriminatory healthcare experiences than nonminority patients ($\beta = -.39$, t = -3.95). There was no direct effect of racial/ethnic minority status on Difficulty Accessing Medication, whose path was dropped in the final model. Thus the hypothesized mediating effects of Discriminatory Healthcare

Experiences and Difficulty Accessing Medication on the relationship between racial/ethnic minority status and antiretroviral therapy adherence were not supported (Hypothesis 2.2.2 and 2.4.2). Contrary to the results from the unadjusted bivariate analyses of Aim 1, racial/ethnic minority patients had greater distrust for their healthcare providers than nonminority patients in this multivariate analysis ($\beta = .14$, t = 2.14). Racial/ethnic minority patients also had more negative beliefs about the efficacy of antiretroviral therapy than did nonminority patients ($\beta = .25$, t = 4.67).

There were other unhypothesized direct effects among study constructs, such as the path from Discriminatory Healthcare Experiences to Medication Efficacy Beliefs (β = .12, t = 3.94), and the path from Healthcare Provider Distrust to Medication Efficacy Beliefs (β = .13, t = 3.18). The final trimmed model explained almost half the variance of antiretroviral therapy adherence (R^2 = .49), with the squared multiple correlations of individual constructs ranging from .15 for Healthcare Provider Distrust to .58 for Psychological Burden of Medication.

Table 5.13. Variance-Adjusted Weighted Least Squares Parameter Estimates of the Final Structural Model (n = 1867)

Parameter	Unstd Estimate*	Std Error	Std Estimate*	t
Regression Weights				
Minority → Discriminatory Healthcare Experiences	39	.10	43	-3.95
Minority → Healthcare Provider Distrust	.14	.07	.15	2.14
Minority → Medication Efficacy Beliefs	.25	.05	.32	4.67
Minority → Antiretroviral Therapy Adherence	12	.04	21	-3.29
Discriminatory Healthcare Experiences → Healthcare Provider Distrust	.15	.04	.14	3.84

Parameter	Unstd Estimate*	Std Error	Std Estimate*	t
Discriminatory Healthcare Experiences → Medication Efficacy Beliefs	.12	.03	.14	3.94
Healthcare Provider Distrust → Psychological Burden of Medication	.08	.02	.09	3.30
Healthcare Provider Distrust → Medication Efficacy Beliefs	.13	.04	.16	3.18
Healthcare Provider Distrust → Antiretroviral Therapy Adherence	.04	.01	.06	2.88
Psychological Burden of Medication → Difficulty Scheduling Medication	.52	.03	.56	15.59
Psychological Burden of Medication → Antiretroviral Therapy Adherence	18	.02	29	-8.69
Difficulty Scheduling Medication → Antiretroviral Therapy Adherence	25	.02	36	-16.25
Medication Efficacy Beliefs → Psychological Burden of Medication	.22	.04	.20	5.94
Medication Efficacy Beliefs → Difficulty Accessing Medication	.49	.06	.50	8.34
Medication Efficacy Beliefs → Antiretroviral Therapy Adherence	.09	.04	.13	2.34
Covariances				
Antiretroviral Therapy Adherence: Error (rSKIP) ↔ Error (rFORGOT)	11	.01	11	-8.00
Antiretroviral Therapy Adherence: Error (rSKIP) ↔ Error (PERFECT)	.21	.02	.21	10.09
Antiretroviral Therapy Adherence: Error (rLESS) ↔ Error (rFORGOT)	.07	.01	.07	7.90
Residual Variances				
Discriminatory Healthcare Experiences ($R^2 = .18$)	.67	.04	.83	17.51

Parameter	Unstd Estimate*	Std Error	Std Estimate*	t
Healthcare Provider Distrust $(R^2 = .15)$.79	.01	.85	55.03
Psychological Burden of Medication $(R^2 = .39)$.48	.03	.61	16.66
Difficulty Accessing Medication $(R^2 = .33)$.40	.03	.67	11.84
Difficulty Scheduling Medication $(R^2 = .46)$.37	.02	.54	18.27
Medication Efficacy Beliefs $(R^2 = .37)$.38	.04	.63	9.54
Antiretroviral Therapy Adherence $(R^2 = .49)$.16	.01	.51	15.39
Antiretroviral Therapy Adherence: Error (rFORGOT)	.44	.01	.44	37.77
Antiretroviral Therapy Adherence: Error (rSKIP)	.56	.02	.56	32.70
Antiretroviral Therapy Adherence: Error (rLESS)	.55	.01	.55	38.93
Antiretroviral Therapy Adherence: Error (PERFECT)	.88	.04	.88	24.44

^{*}Controlling for gender, age, education, annual income, insurance status, HIV risk behavior, self-reported physical and mental health, depression, dysthymia, type of illicit drug used in the past year, number of antiretroviral medications, social support, and adherence self-efficacy.

The total, direct, and indirect effects of racial/ethnic minority status on antiretroviral therapy adherence are presented in Table 5.14. The direct effect is the parameter estimate of the relationship between one construct and the outcome. Indirect effects are parameter estimates of mediating pathways. The total effect is the sum of the direct and indirect effects. In the table, the first two lines note the total and direct effects of racial/ethnic minority status on antiretroviral therapy adherence. The labels in the "Mediating Path" column represent the indirect effects of racial/ethnic minority status on antiretroviral therapy adherence. For example, "Discriminatory Healthcare Experiences \rightarrow Healthcare Provider Distrust" indicates the path from racial/ethnic minority status to discriminatory healthcare experiences to healthcare provider distrust to antiretroviral therapy adherence.

There were a total of nine significant indirect effects of racial/ethnic minority status on antiretroviral therapy adherence: six via Discriminatory Healthcare Experiences; one via Healthcare Provider Distrust; and two via Medication Efficacy Beliefs. The strongest indirect effects came through Medication Efficacy Beliefs (β = .02, t = 2.06) and the path between Medication Efficacy Beliefs and Psychological Burden of Medication (β = -.01, t = -3.29). These two indirect effects also accounted for the largest proportion of the total effect of racial/ethnic minority status on antiretroviral therapy adherence (11.7%). Although these indirect pathways were statistically significant, the magnitudes of these effects were negligible. The direct effect is essentially the same as the total effect, indicating lack of mediation from the hypothesized factors. Therefore, I consider Hypotheses 2.3.2 and 2.4.3 to be unsupported.

Table 5.14. Direct, Total, and Indirect Effects of Racial/Ethnic Minority Status on Antiretroviral Therapy Adherence via Hypothesized Mediators (n = 1867)

Mediating Path	Unstd Estimate*	Std Error	Std Estimate*	t
Total Effect of Minority Status	111	.031	199	-3.57
Direct Effect of Minority Status	117	.036	209	-3.29
Via Discriminatory Healthcare Experiences				
Discriminatory Healthcare Experiences → Healthcare Provider Distrust	002	.001	004	-3.07
Discriminatory Healthcare Experiences → Medication Efficacy Beliefs	004	.002	008	-1.91
Discriminatory Healthcare Experiences → Healthcare Provider Distrust → Psychological Burden of Medication	.001	<.001	.001	2.44
Discriminatory Healthcare Experiences → Medication Efficacy Beliefs → Psychological Burden of Medication	.002	.001	.003	2.14

Mediating Path	Unstd Estimate*	Std Error	Std Estimate*	t
Discriminatory Healthcare Experiences → Healthcare Provider Distrust → Medication Efficacy Beliefs	001	<.001	001	-1.52
Discriminatory Healthcare Experiences → Healthcare Provider Distrust → Medication Efficacy Beliefs → Psychological Burden of Medication	<.001	<.001	.001	2.07
Discriminatory Healthcare Experiences → Healthcare Provider Distrust → Psychological Burden of Medication → Difficulty Scheduling Medication	.001	<.001	.001	2.15
Discriminatory Healthcare Experiences → Medication Efficacy Beliefs → Psychological Burden of Medication → Difficulty Scheduling Medication	.001	.001	.002	1.92
Discriminatory Healthcare Experiences → Healthcare Provider Distrust → Medication Efficacy Beliefs → Psychological Burden of Medication → Difficulty Scheduling Medication	<.001	<.001	<.001	2.19
Subtotal: % of Total Effect:	002 1.8			
Via Healthcare Provider Distrust				
Healthcare Provider Distrust	.005	.003	.009	1.62
Healthcare Provider Distrust → Psychological Burden of Medication	002	.001	004	-1.60
Healthcare Provider Distrust → Medication Efficacy Belief	.002	.001	.003	1.29
Healthcare Provider Distrust → Medication Efficacy Belief → Psychological Burden of Medication	001	<.001	001	-1.64
Healthcare Provider Distrust → Psychological Burden of Medication →	007	.003	013	-2.90

Mediating Path	Unstd	Std	Std	t
G	Estimate*	Error	Estimate*	
Difficulty Scheduling Medication				
Healthcare Provider Distrust → Medication Efficacy Beliefs → Psychological Burden of Medication → Difficulty Scheduling Medication	001	<.001	001	-1.84
Subtotal:	004			
% of Total Effect:	3.6			
Via Medication Efficacy Beliefs				
Medication Efficacy Beliefs	.023	.011	.042	2.06
Medication Efficacy Beliefs → Psychological Burden of Medication	010	.003	019	-3.29
Subtotal:	.013			
% of Total Effect:	11.7			

^{*}Controlling for gender, age, education, annual income, insurance status, HIV risk behavior, self-reported physical and mental health, depression, dysthymia, type of illicit drug used in the past year, number of antiretroviral medications, social support, and adherence self-efficacy.

5.3 SUMMARY

This chapter presented the results of multiple regression and SEM analyses examining the relationships among racial/ethnic minority status, discriminatory healthcare experiences, healthcare provider distrust, antiretroviral therapy attitudes and beliefs, and antiretroviral therapy adherence. Table 5.15 summarizes the support for study hypotheses provided by these results. In the final chapter, I discuss the findings in the context of existing research and consider potential next steps for research and practice.

Table 5.15. Summary of Support for Study Hypotheses

Hypothesis	Support
(H 1.2) Minority HIV+ patients will have more discriminatory healthcare experiences than nonminority HIV+ patients.	No
(H 1.4) More minority HIV+ patients will distrust their healthcare provider than nonminority HIV+ patients.	No
(H 2.1.1.) Racial/ethnic minority HIV+ patients will have poorer adherence to antiretroviral therapy than nonminority HIV+ patients.	Yes
(H 2.2.1) As discriminatory healthcare experiences increases, adherence to antiretroviral therapy decreases.	No
(H 2.2.2) Minority HIV+ patients will have more discriminatory healthcare experiences and, in turn, poorer adherence to antiretroviral therapy than nonminority HIV+ patients.	No
(H 2.3.1) As healthcare provider distrust increases, adherence to antiretroviral therapy decreases.	No
(H 2.3.2) Minority HIV+ patients will have greater distrust in their healthcare providers and, in turn, poorer adherence to antiretroviral therapy than nonminority HIV+ patients.	Partial
(H 2.4.1) As (a) psychological burden of medication,	Yes
(b) difficulty accessing medication,	No
(c) difficulty scheduling medication, and(d) negative beliefs about medication efficacy increase, antiretroviral therapy adherence decreases.	Yes No
(H 2.4.2) Minority HIV+ patients will have more difficulty accessing medication and, in turn, poorer adherence to antiretroviral therapy than nonminority HIV+ patients.	No
(H 2.4.3) Minority HIV+ patients will have more negative beliefs in medication efficacy and, in turn, poorer adherence to antiretroviral therapy than nonminority HIV+ patients.	No

CHAPTER SIX: DISCUSSION

In this study I assessed the prevalence and factors associated with discriminatory healthcare experiences and healthcare provider distrust, two indicators of interpersonal care quality, and their effects on antiretroviral adherence by HIV+ patients. The first two sections of the chapter interpret key findings by study aim in the context of existing research. The third section describes the study's limitations, strengths, and significance. The chapter concludes with suggestions for future research and implications for practice.

6.1. SUMMARY OF AIM 1

Given the dearth of research in this area, the study's first aim was to describe the prevalence and factors associated with discriminatory healthcare experiences and healthcare provider distrust among HIV+ patients.

6.1.1. Discriminatory Healthcare Experiences

Prevalence. Almost half (41%) the HIV+ patients studied reported ever experiencing discrimination in healthcare settings. This is a 60% higher prevalence than the 26% prevalence reported by Schuster and colleagues (2005) using the same HIV Cost and Services Utilization Study (HCSUS) dataset. The discrepancy in rates could be due to differences in the operationalization of discrimination. Schuster and colleagues (2005) measured discrimination with four indicators of discriminatory healthcare experiences at the first follow-up interview (been uncomfortable with the patient, treated the patient as an inferior, preferred to avoid the

patient, or refused service to the patient). The present study measured discrimination using six indicators, three from the baseline (exhibited hostility or lack of respect towards patient, gave less attention than to other patients, refused service to patient) and three from the first follow-up interview (been uncomfortable with the patient, treated the patient as an inferior, preferred to avoid the patient). This expanded measure was used to capture more domains of discriminatory healthcare experiences than those used in the Schuster study.

The wider range of potential types of discrimination may have increased the likelihood that HIV+ patients surveyed had experienced at least one of those situations. Bird and colleagues (2004), for example, reported a much higher prevalence of discriminatory healthcare experiences (71%) among HIV+ individuals who responded to a list of seven potentially discriminatory experiences: treated patient with less courtesy than shown to other people; treated patient with less respect than other people; provided poorer service than to others; thought patient was not smart; acted as if afraid of patient; acted as if better than patient; did not listen to what patient was saying. Participants were asked whether they attributed being a recipient of these negative experiences to their race and/or socioeconomic status, for a total of 14 potential discriminatory healthcare experiences. The present study, on the other hand, did not separately consider discrimination by reported stigmatizing characteristic (e.g., HIV status, sexual orientation) in because of the small sample sizes associated with characteristics other than HIV status. In addition, the indicators used in the study by Bird and colleagues (2004) referred to interactions with HIV+ patients' current healthcare providers (specifically their physician), while indicators used in the present study referred to any interaction with a healthcare provider (e.g., physician, nurse, dentist) since the time the patient had been diagnosed with HIV. The exposure variables used in the present study may have been more liable to recall bias and thus less sensitive

indicators of the prevalence of discriminatory healthcare experiences than variables that referred to interactions with a current provider.

In both this and the Schuster (2005) study, white HIV+ patients reported more discriminatory healthcare experiences than did racial/ethnic minority HIV+ patients in a national sample. In contrast, Bird and colleagues (2004) found no differences in discrimination by racial/ethnic minority status among HIV+ individuals. Research on non-HIV specific samples generally finds that racial/ethnic minority participants report more unfair treatment by healthcare providers than do whites, regardless of the perceived cause (Lillie-Blanton et al., 2000; Perez, 2005; Piette et al., 2006). One study using a national sample found that racial/ethnic differences in perceived disrespect and condescension from physicians were explained after adjusting for patient characteristics, source of care, and patient-physician communication measures (Johnson et al., 2004). Possible explanations for the unexpected findings reported here, and in the previous study using the HCSUS data (Schuster et al., 2005), are several. First, white participants had been diagnosed with HIV longer than their racial/ethnic minority peers, thus providing the white sample with more opportunities to experience, remember, and report healthcare discrimination. Second, racial/ethnic minority participants experiencing discrimination may have minimized or taken perceived prejudicial treatment for granted. On the contrary, white male participants, who were predominantly gay in this sample, may not have been open about their sexual orientation before 1996, and hence not exposed to any discrimination their homosexuality may have evoked from their healthcare providers prior to their HIV diagnosis (Hayter, 1996; Klitzman & Greenberg, 2002).

Factors. Many factors associated with discriminatory healthcare experiences by HIV+ patients were related to these participants' health status, consistent with other research on discriminatory healthcare experiences among HIV+ patients (Bird et al., 2004; Kass et al., 1992; Schuster et al.,

2005). These factors – earlier diagnosis of HIV, poorer self-reported health, having an AIDS diagnosis, and ever having a CD4 count less than 200 – suggest that sicker individuals may be more likely to experience the effects of HIV/AIDS stigma in healthcare settings. Early in the epidemic several visible indicators of advanced HIV infection, such as the dark lesions of Karposi's sarcoma or wasting syndrome, signaled AIDS to the general public (Shilts, 1987; Weiner et al., 1988). Physical manifestations of disease are classic markers of stigma, exposing people to more frequent discrimination (Goffman, 1963; Weiner et al., 1988). Furthermore, the longer individuals have been diagnosed with HIV or the more often they have been sick, the more opportunities they have to experience, and report, discrimination.

Other factors associated with discriminatory healthcare experiences by HIV+ patients included younger age, having some college education, use of any type of illicit drug in the past year except heroin or cocaine, and reporting less social support. Besides education, earlier studies of discriminatory healthcare experiences among HIV+ patients have not investigated these factors. In this study, racial/ethnic minority status interacted with two other factors, HIV risk exposure and depression symptoms, of discriminatory healthcare experiences. However, these interaction terms did not increase the explanatory power of the discriminatory healthcare experience multivariate model. In fact, the sociodemographic factors in this study explained only a small proportion of the variance of discriminatory healthcare experiences. Future research should explore other psychosocial factors (e.g., stigma consciousness, group identity, coping) and contextual variables (e.g., high poverty, low physician to population ratio) unavailable in this dataset that may be more strongly associated with discrimination.

6.1.2. Healthcare Provider Distrust

Prevalence. Although discriminatory healthcare experiences were common in this study, healthcare provider distrust was not. Across domains, few participants expressed distrust of their

healthcare providers. The overall level of healthcare provider distrust in this sample did not vary by racial/ethnic minority status, contrary to the study hypothesis. Other researchers have also found high levels of trust in personal healthcare providers by HIV+ patients (Altice et al., 2001; Golin et al., 2002; Ingersoll & Heckman, 2005; Schneider et al., 2004; Whetten et al., 2006). The lack of racial/ethnic difference in healthcare provider distrust is consistent with previous smaller studies of HIV+ patients, but not with national studies on provider distrust conducted in the general population (Boulware et al., 2003; Corbie-Smith et al., 2002; Doescher et al., 2000; Schnittker, 2004; Taira et al., 2001). In the present study, the only racial/ethnic difference across trust domains was concern that healthcare providers would place research goals above participants' personal interests. This finding is consistent with other research which has reported African Americans in particular to be skeptical of medical researchers' intentions and the benefits of medical research to them personally and as a group (Allen et al., 2005; Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999). The difference in healthcare provider distrust between racial/ethnic groups on this domain was small, however, with overlapping confidence intervals and thus may not be of great importance in understanding differences that occur when individual HIV+ patients interact with individual healthcare providers. In the face of a lifethreatening illness, both racial/ethnic minority and white HIV+ patients may simply trust more instinctively those who provide critical medical care.

Factors. The factors associated with healthcare provider distrust among HIV+ patients overlap some with those of discriminatory healthcare experiences. Both psychosocial constructs are associated with younger age, having attained some college education, poorer self-reported health, drug use in the past year, and less social support. In addition, greater healthcare provider distrust was also associated with higher viral load, poorer mental health, and experiencing more discrimination in healthcare settings. Previous studies of HIV+ patients have not explored

factors associated with healthcare provider distrust, so comparisons with such studies are not possible. However, research with non-HIV specific samples did not find or has not examined associations between healthcare provider distrust and age, drug use, or social support, but did find relationships with poorer health status and less education (Doescher et al., 2000; Schnittker, 2004). The inclusion of drug use (a stigmatizing behavior) and social support are psychosocial stressors and buffers that may affect HIV+ patients' expectations about their healthcare providers. As with discriminatory healthcare experiences, the hypothesized sociodemographic factors of distrust supported by these analyses explained little of the variance of healthcare provider distrust among HIV+ patients. Also, potentially important psychosocial and contextual factors of healthcare provider distrust were not available in the public use HCSUS dataset.

6.1.3. Racial/Ethnic Minority Status and Interpersonal HIV/AIDS Care Quality

The extent of discriminatory healthcare experiences and healthcare provider distrust in this sample does not provide evidence of racial/ethnic disparities in the quality of interpersonal HIV/AIDS care. Earlier research in the general population has suggested that experiences, expectations, and beliefs about racism in healthcare would lead racial/ethnic minority patients to perceive more discrimination (regardless of the source to which they attributed the discrimination), as well as report more distrust in their healthcare providers. Either these effects do not exist among minority participants, or they are being overshadowed by the effects of HIV/AIDS stigma shared by all participants.

6.2. SUMMARY OF AIM 2

The study's second aim was to test a model of the direct and indirect effects of racial/ethnic minority status, discriminatory healthcare experiences, and healthcare provider distrust on antiretroviral adherence by HIV+ patients. Many studies, although not all, have found that

racial/ethnic minority HIV+ patients report poorer antiretroviral therapy adherence than white HIV+ patients (Bogart et al., 2004; Gifford et al., 2000; Golin et al., 2002; Gordillo et al., 1999; van Servellen et al., 2002). Thus, the primary objective was to examine possible mediators of an observed relationship between racial/ethnic minority status and adherence. The full model with covariates explained almost half (49%) the variance found in participants' self-reported adherence to antiretroviral therapy.

6.2.1. Racial/Ethnic Minority Status

Contrary to the study's hypotheses, the observed relationship between racial/ethnic minority status and antiretroviral therapy adherence was not mediated by discriminatory healthcare experiences, healthcare provider distrust, or antiretroviral therapy attitudes and beliefs. The structural equation modeling analyses identified several statistically significant pathways involving one or more of the hypothesized mediators (specifically discriminatory healthcare experiences, healthcare provider distrust, and medication efficacy beliefs), but the magnitude of each indirect effect was negligible (generally less than .01) and the sum of these effects was not statistically significant. The fact that racial/ethnic minority status remained, in multivariate models, significantly associated with adherence in the present study can be understood in the context of fundamental cause theory. That theory posits that the effects of social and economic inequity cannot be eliminated by addressing the mechanisms that appear to link them to disease (Link & Phelan, 1995). If true, the direct effect of racial/ethnic minority status (a crude proxy for the effects of racism) on antiretroviral therapy adherence would not be completely mediated by discrimination, distrust, or medication beliefs. However, I had hypothesized that there would be evidence of partial mediation. One explanation for the lack of either partial mediation may be that important factors (e.g., housing stability, shared decisionmaking) have been left out of the

analysis. Given the large number of included covariates, however, it is unlikely that the bias from one or two potential omitted variables would dramatically affect the findings reported here.

6.2.2. Discriminatory Healthcare Experiences

The effect of discriminatory healthcare experiences on antiretroviral therapy adherence in this sample was entirely indirect, contrary to study hypotheses. The indirect effects occurred when participants' distrust of their healthcare providers increased and their beliefs in the worth of antiretroviral therapy weakened. Discriminatory healthcare experiences may subtly color HIV+ patients' perspectives on their care providers and the treatment they recommend. This finding contrasts with the findings of the only other study to examine these relationships (Bird et al., 2004). Bird and colleagues (2004) found that discrimination based on socioeconomic status, but not on racial/ethnic minority status, was associated with antiretroviral therapy adherence. That analysis was conducted on a small convenience sample (n = 110) of participants recruited through an AIDS service organization in the Midwest and examined only bivariate correlates of adherence. The current study had a large national sample, did not differentiate between the attributions made for discriminatory healthcare experiences (e.g., HIV status versus racial/ethnic minority status), and controlled for multiple covariates of antiretroviral therapy adherence. On the basis of the larger sample size and multivariate analysis, the present study offers stronger evidence that discriminatory healthcare experiences do not directly influence antiretroviral therapy adherence.

6.2.3. Healthcare Provider Distrust

As hypothesized, healthcare provider distrust has both direct and indirect effects on antiretroviral therapy adherence. The relationship between distrust and adherence is consistent with multivariate findings in previous studies of antiretroviral therapy adherence (Altice et al., 2001; Schneider et al., 2004), but the direction of the effect was unexpected. In focus groups and

interviews, HIV+ patients have drawn connections between the trust they have in their healthcare providers and their willingness to comply with treatment recommendations (Roberts, 2002; Stone et al., 1998): "If you don't trust your doctor, you won't trust (and take) your meds" (Roberts, 2002). The results of the present study seem to indicate the opposite: that negative expectations of their healthcare providers may increase HIV+ patients' resolve and determination to comply with a demanding treatment regimen. In a related study, Ford (2005) found that African American STD clinic patients who perceived more racism were more likely to get tested for HIV. HIV+ patients in the present study, as in Ford's, may feel that their healthcare providers are not looking out for their best interests. Hence, they must be extra vigilant about the care that they receive.

The indirect effects of healthcare provider distrust occurred as a result of increases in participants' psychological distress about having to take antiretroviral therapy and of weakened beliefs in the worth of antiretroviral therapy. Previous research has not specifically examined the extent to which healthcare provider distrust influences treatment-related attitudes and beliefs. Because the indicators of healthcare provider distrust and antiretroviral therapy attitudes and belief used in this analysis were measured at the same point in time, it is possible that the effect occurred in the opposite direction. That is, participants' negative feelings about antiretroviral therapy may have increased their distrust in their healthcare providers for encouraging use of the regimen in the first place. Both interpretations are plausible.

6.2.4. Other Effects

Other findings of note relate to the associations, or lack thereof, among hypothesized mediators. First, the difficulty participants had fitting antiretroviral therapy into their daily lives showed the strongest direct effect on self-reported antiretroviral therapy non-adherence. Being able to take ones' medications despite disruptions is a key task for HIV+ patients, and is

consistently associated with antiretroviral therapy adherence (Chesney, 2003). Second, contrary to the study hypothesis, participants' perceptions that antiretroviral therapy is difficult to obtain was not significantly associated with adherence in the final model. The inclusion of financial resources (indicated by annual income and insurance status) and social support as control variables may explain this finding. Finally, being a member of a racial/ethnic minority group was associated with greater healthcare provider distrust in the structural equation model explaining variation in antiretroviral therapy adherence but not in the multiple regression model of healthcare provider distrust in Aim 1 that included primarily sociodemographic factors. This unexpected finding may indicate a suppressor effect, where an independent variable is significantly associated with the outcome variable only in the presence of a third variable (MacKinnon, Lockwood, Hoffman, West, & Sheets, 2002). In this case, racial/ethnic differences in healthcare provider distrust may only appear when controlling for the effects of other psychosocial factors, in this case antiretroviral therapy attitudes and beliefs.

6.2.5. Alternative Model

Although a strong conceptual and empirical rationale underlies the proposed mediation model, it is possible that racial/ethnic minority status might, instead, moderate the relationships among other study constructs. A moderation model would suggest that the stigma of racial/ethnic minority status (racism) produces different contexts for antiretroviral therapy adherence among racial/ethnic minority and nonminority HIV+ patients. That is, the effect of discriminatory healthcare experiences and healthcare provider distrust on antiretroviral therapy attitudes, beliefs, and adherence may be stronger among racial/ethnic minority patients than nonminority patients. These relationships may also be affected by the different environments in which the two groups of HIV+ patients in the present study live, demonstrated by the sociodemographic characteristics of the sample. For example, racial/ethnic minority patients in

this sample were younger, less educated, poorer, and more likely to have been exposed to HIV through injection drug use or male/female sexual contact than were nonminority participants. The two groups may have had different priorities, concerns, and resources when it came to antiretroviral therapy adherence. In this alternative explanation, racial/ethnic minority status is a contextual, rather than an exogenous, variable in models of antiretroviral therapy adherence.

6.2.6. Stigma, Interpersonal Care Quality, and Antiretroviral Therapy Adherence

These findings offer partial support for the relationships, based on attribution theory, posited among discriminatory healthcare experiences, healthcare provider distrust, and antiretroviral therapy adherence. Racial/ethnic minority status, as a proxy for expectations and experiences with racism in healthcare, was negatively associated with healthcare provider distrust but not discriminatory healthcare experiences. Discriminatory healthcare experiences were positively associated with healthcare provider distrust, but only indirectly influenced the behavioral outcome of adherence. Distrust, the negative expectations of healthcare providers, was unexpectedly associated with antiretroviral therapy adherence. These results generally support other research that has found subtle effects of patient-provider relationships on treatment adherence (DiMatteo & DiNicola, 1982; Hall, Roter, & Katz, 1988; Roter & Hall, 1993).

6.3. STUDY LIMITATIONS, STRENGTHS, AND SIGNIFICANCE

6.3.1. Limitations

Context of the Sample. The present study's findings are the product of data collected over 10 years ago, and as such, are probably less generalizable to HIV+ individuals in care today. The HIV Cost and Services Utilization Study was conducted when antiretroviral therapy was just coming into widespread use. Previously considered a death sentence, these medications ushering

in a new era of the HIV/AIDS epidemic in the United States and produced great optimism among people living with HIV at the time (Kagawa-Singer, 2000; Kelly & Kalichman, 2002; Kelly, Otto-Salaj, Sikkema, Pinkerton, & Bloom, 1998). While such an optimistic context may have positively influenced participants' attitudes and beliefs about antiretroviral therapy, and thus motivation to adhere, the regimens at the time were very complex. Although the number of antiretroviral medications taken has sometimes been associated with poorer adherence (Chesney, 2003; Fogarty et al., 2002), it was not a significant factor in the present study. In the years since the HCSUS data was conducted new medications that have been developed, including simpler twice-daily and even single-dose regimens (Giordano, 2006). The differences in both general patient optimism and complexity of available medication regimens may lessen the generalizeability of these study findings to the current population of HIV+ patients.

Attrition and Selection Biases. Certain characteristics of the study sample may influence the interpretation and generalizability of these findings. Participants who completed all three waves of data collection were more likely than those who did not do so to have been white, exposed to HIV through male/female sexual contact, not have an AIDS diagnosis, not be heroin or cocaine users, and have more social support¹⁰. In addition, participants who were prescribed antiretroviral therapy at the second follow-up interview were more likely than those who were not to have had higher incomes, higher viral loads, an AIDS diagnosis, and distrust their healthcare providers less. These attrition and selection biases produced a more homogeneous study sample compared to the full HCSUS sample and may reduce the generalizability of the findings to the general population of HIV+ individuals in care. These biases may also have

¹⁰ Almost all of the sociodemographic variables were collected at baseline, but all of the indicators of healthcare provider distrust used in the present study were collected at the second follow-up interview. Thus only participants who completed all three waves of data collection answered these questions.

underestimated the effect of discriminatory healthcare experiences and healthcare provider distrust on antiretroviral therapy adherence (only assessed at the second follow-up interview).

Social Desirability and Recall Biases. HIV+ patients may under-report the number of times they fail to take their medications as prescribed because of a desire to appear compliant (and hence socially acceptable) in the eyes of their physicians (Chesney, 2003; Liu et al., 2001; Miller & Hays, 2000; Turner, 2002). On the other hand, Wagner and Miller (2004) found that poor memory, not concern about provider reactions, was the main reason that HIV+ patients in a pilot study did not disclose missing medications. Indeed, four of the five adherence indicators were based on a mean score across up to 14 medications. The effect of either social desirability or recall bias may be to underestimate the relationships between study constructs and antiretroviral adherence.

Measurement Issues. Except for healthcare provider distrust (Kao et al., 1998), key measures were newly developed for the present study and thus not previously validated. They were not formally tested for invariance (psychometric equivalence) by racial/ethnic minority status, but they demonstrated good reliability and other satisfactory psychometric properties across groups (data not shown). Another limitation is the degree to which other researchers might agree about how these measures were constructed or interpreted. For example, Williams and colleagues (2003) point toward the stress literature to argue that inventories of discriminatory experiences should not be considered as indicators of the underlying construct, and that high internal consistency suggests redundancy or wording bias, not validity. For these researchers, the fact that a person experiences one type of discrimination does not necessarily imply the likelihood of having another. In contrast, I would argue that theories of attribution (Harvey & Weary, 1984; Kelley & Michela, 1980) as well as other social psychological constructs such as cognitive schemas support an underlying factor related to the way that individuals perceive and interpret

problematic interpersonal interactions. The proper interpretation of the measures, as well as their validity, will not be settled in one study.

Temporality. The HIV Cost and Services Utilization Study collected three waves of data over approximately a 12 month period; the present study used measures from each wave. However, the indicators for healthcare provider distrust, antiretroviral therapy attitudes and beliefs, adherence, and a few covariates were only collected at the second follow-up interview. In this way, therefore, the design is primarily cross-sectional and cannot establish causality among these constructs. The research design leaves unclear whether healthcare provider distrust precedes negative attitudes towards antiretroviral therapy or vice versa.

The indicators for discriminatory healthcare experiences were obtained at baseline and the first follow-up interview and thus have some claim on temporal order. How recent these experiences occurred, however, is unknown as participants were asked to recall incidents "since they had HIV"— which could be one month to ten years prior to the study. This variability would have the effect of reducing the strength of association between discriminatory healthcare experiences and the other factors.

Between versus Within Group Analysis. I categorized all members of racial/ethnic minority groups as part of one group for these analyses because sample sizes among some subpopulations (Asian/Pacific Islanders and Native Americans) would be too small to analyze. I did not exclude these groups because the focus of the study was the ways that interpersonal care quality and healthcare outcomes were affected by racism (stigma). Membership in a racial/ethnic minority group indicates a subordinate social status in the U.S. which, through the processes of stigma (Link & Phelan, 1995), implies a history of oppression or experience of discrimination (Jones, 2001; LaVeist, 1994; Williams, 1997). The small sizes of some subpopulations in HCSUS are likely to have made little difference to the study findings had these groups been excluded.

However, the different racial/ethnic minority groups undoubtedly have unique life experiences and circumstances that may or may not affect their healthcare and health outcomes (Williams, 1997). Subgroup analyses might have revealed different prevalences, predicators, and patterns of associations among discriminatory healthcare experiences, healthcare provider distrust, and antiretroviral therapy adherence. For example, members of Asian and Pacific Islander groups often report significantly poorer interpersonal care from healthcare providers than do members of other groups, but these experiences are not generally associated with poorer healthcare outcomes (Ngo-Metzger, Legedza, & Phillips, 2004; Taira et al., 2001). Future examination of how these processes work within subpopulations may lead to a more nuanced understanding of what differentiates those who have better and worse outcomes (Corbie-Smith et al., 2004; Kagawa-Singer, 2000).

6.4.2. Strengths and Significance

Choice of Dataset. Although the unique temporal context of the HIV Cost and Services

Utilization Study may have reduced the generalizability of my conclusions, several characteristics of the sample make it useful for research on interpersonal care quality and healthcare outcomes. It remains the only large, multiethnic national study of which I am aware of that includes measures of both discriminatory healthcare experiences and healthcare provider distrust. In addition, the large sample allowed for the detection of small effects that may be important at the population, if not at the individual, level.

Analytic Technique. Another strength of this analysis is the use of structural equation modeling. Although the technique does not establish the right or "true" model, it does allow for the testing of hypotheses about direct and indirect effects. Multiple and multi-part pathways for mediators have not been explicitly considered in previous research on antiretroviral therapy adherence. In addition, the analysis of latent variables takes measurement error and bias from

omitted variables into account, producing estimates that are less biased than regression analyses of observed variables which assume that independent variables are measured without error.

Examined Potential Mechanisms of Racial/Ethnic Healthcare Disparities. This research contributes to the emerging literature on racism and healthcare, as opposed to health, outcomes. In this study, I attempted to address the recommendations of earlier investigators who call for more research into the potential pathways by which racial/ethnic healthcare disparities are produced (Corbie-Smith et al., 2004; Lurie, 2002; Smedley et al., 2003). I used social psychological and sociological theories to conceptualize relationships among the key study constructs. Although the results did not fully support my hypotheses, this research adds to our understanding of how individual-level sociodemographic and psychosocial factors influence healthcare outcomes by racial/ethnic minority and nonminority HIV+ patients.

6.5. Areas of Future Research and Implications for Practice

There is no cure for the disease, but receipt of appropriate, timely, and high quality medical care can reduce HIV/AIDS-related morbidity and mortality (Bozzette et al., 2000; Centers for Disease Control and Prevention, 2002). Current quality improvement efforts among federally-funded HIV/AIDS treatment programs focus on clinical indicators such as increased use of antiretroviral therapy and controlled HIV viral loads (Bozzette et al., 2000; Landon et al., 2004; McKinney et al., 2002). Experts recognize, however, that the quality of interpersonal HIV/AIDS care medical personnel provide may affect achievement of desired healthcare outcomes (McKinney et al., 2002). Specifically, increasing the quality of care and improving outcomes for racial/ethnic minority HIV+ patients, as well as white HIV+ patients, will require more attention to interpersonal care issues (Stone, 2004). The next sections present possible areas of future research and potential implications for practice that are suggested by this study's findings.

6.5.1. Future Research

Refinement and further assessment of study measures are critical areas for future research. First, research on how these measures are understood by participants and perform psychometrically will help to establish their validity. Qualitative, formative work, such as cognitive interviewing might clarify to what extent HIV+ patients identify and differentiate between categories of discriminatory experiences, domains of healthcare provider (dis)trust, and types of antiretroviral therapy attitudes and beliefs. Second, researchers should conduct confirmatory factor analyses with samples of HIV+ patients and the general public to corroborate the form of the measures used in this study, as well as assess psychometric differences across racial/ethnic groups (invariance). Finally, researchers could compare the predictive power of lifetime experiences of healthcare experiences to measures of discriminatory experiences with patients' current providers.

Improvements and extensions to the study design and analyses are other fruitful areas of future research. First, designing longitudinal studies with the temporality of measures in mind will help to better tease apart the direction of effect among hypothesized psychosocial factors and adherence, the behavioral outcome. Second, researchers should refine and extend the model proposed in this study. Instead of using racial/ethnic minority status as a proxy for experiences and expectations of racism in healthcare, for example, analyses should incorporate measures of beliefs in medical racism and generalized healthcare distrust. In addition, the current analyses controls for, as opposed to parceling out, provider-level effects on HIV+ patients' assessments of interpersonal care quality. Multilevel modeling would allow researchers to explore the extent that provider factors such as racial/ethnic minority status, gender, and experience/expertise both working with HIV patients and in medicine overall contribute to the variability in discriminatory healthcare experiences, healthcare provider distrust and, ultimately, antiretroviral

therapy adherence. Finally, as described earlier, future research should compare the mediation model proposed in this study with one that considers racial/ethnic minority status as a moderator, or contextual, factor. These areas of future research will further our understanding of both racial/ethnic disparities in interpersonal care quality as well as in antiretroviral therapy adherence.

6.5.2. Practice Implications

The findings of this study raise questions about whether and how healthcare providers take their patients' racial/ethnic minority status into account within the clinical encounter. Evidence exists that healthcare providers are more likely to stereotype racial/ethnic minority patients as nonadherent to treatment regimens than they do white patients (Balsa & McGuire, 2003; Bogart, Catz, Kelly, & Benotsch, 2001; Lutfey & Ketcham, 2005). That is, providers have a priori beliefs that racial/ethnic minority patients will not adhere to treatment recommendations more frequently than white patients. Such beliefs may influence clinical decision making and, consciously or not, worsen the quality of interpersonal care (Smedley et al., 2003; van Ryn, 2002). Early stereotypes about nonadherence may have affected treatment patterns of racial/ethnic minority HIV+ patients (Bogart et al., 2001; Stone, 2006). As a result some researchers discourage the use racial/ethnic minority status as a heuristic for predicting of antiretroviral therapy adherence by HIV+ patients (Chesney, 2003; Stone, 2004; Stone, 2006l Turner, 2002). The present study and others, however, did not find that the relationship between racial/ethnic minority status and antiretroviral therapy adherence was explained by patient-level sociodemographic or psychosocial factors. How can these divergent points of view be reconciled?

One possible approach may include increased patient-centeredness by healthcare providers that acknowledges, but does not prioritize, the possible role of racial/ethnic minority status as an

influence on interpersonal care quality. Patient-centered healthcare providers must manage a delicate balance between considering their patients' beliefs, needs, and choices and understanding the social context in which those individual circumstances occur. For racial/ethnic minority patients, this context may produce experiences and expectations of racism in healthcare that may influence judgment about their care and care providers. Members of other stigmatized groups such as HIV+ individuals may similarly have experiences or expectations of discrimination in healthcare settings. This study's patient-level analysis implies patient-level interventions such as education and empowerment strategies. The interaction between patients and providers that produces patient assessments of interpersonal care quality, however, suggests a need to intervene at the provider level as well. As each clinical encounter produces expectations of the next (Goold, 2002; Keating et al., 2002; LaVeist et al., 2000), such interventions should target both generic clinical and cross-cultural communication skills. Better communication and relationships between HIV+ patients and their healthcare providers may help improve antiretroviral therapy adherence for all patients and also help reduce disparities by racial/ethnic minority status.

APPENDIX A: EXPLORATORY FACTOR ANALYSES

Antiretroviral Therapy Adherence

Table A.1. Indicators of Antiretroviral Therapy Adherence: Descriptive Statistics

Variable	Mean	Std Dev	Min	Max
Perfect	6.15	1.52	0	7
rForgot	6.57	.90	0	7
rSkip	6.75	.91	0	7
rLess	6.70	.92	0	7
Global	5.18	1.19	1	6

Table A.2. Indicators of Antiretroviral Therapy Adherence: Varimax Rotation of Factor Loadings

Variable	Loading	Uniqueness
Perfect	.86	.27
rForgot	.63	.61
rSkip	.61	.62
rLess	.60	.63
Global	.70	.50

Table A.3. Indicators of Antiretroviral Therapy Adherence: Item-Total and Inter-Item Correlations

Variable	Item-Total	Inter-Item
Perfect	.88	.40
rForgot	.72	.50
rSkip	.71	.51
rLess	.72	.50
Global	.78	.46

Discriminatory Healthcare Experiences

• Descriptive statistics for these dichotomous indicators are found in Chapter 5, Results.

Table A.4. Indicators of Discriminatory Healthcare Experiences: Varimax Rotation of Factor Loadings

Variable	Loading	Uniqueness
Hostile	.62	.60
LessAtten	.64	.58
Refuse	.50	.75
Uncomf	.71	.49
Inferior	.75	.44
Avoid	.80	.36

Table A.5. Indicators of Discriminatory Healthcare Experiences: Item-Total and Inter-Item Correlations

Variable	Item-Total	Inter-Item
Hostile	.76	.06
LessAtten	.74	.06
Refuse	.62	.07
Uncomf	.76	.06
Inferior	.78	.06
Avoid	.80	.06

Healthcare Provider Distrust

Table A.6. Indicators of Healthcare Provider Distrust: Descriptive Statistics

Variable	Mean	Std Dev	Min	Max
Quality	1.49	.77	1	5
Best	1.50	.76	1	5
Info	1.54	.83	1	5
Private	1.34	.74	1	5
NotJudge	1.49	.81	1	5
Insur	1.53	.86	1	5
Research	1.66	.93	1	5

Table A.7. Indicators of Healthcare Provider Distrust: Varimax Rotation of Factor Loadings

Variable	Loadings	Uniqueness
Quality	.84	.29
Best	.82	.33
Info	.83	.32
Private	.67	.54
NotJudge	.80	.35
Insur	.75	.43
Research	.77	.40

Table A.8. Indicators of Healthcare Provider Distrust: Item-Total and Inter-Item Correlations

Variable	Item-Total	Inter-Item
Quality	.85	.41
Best	.83	.42
Info	.85	.40
Private	.73	.45
NotJudge	.84	.41
Insur	.81	.41
Research	.83	.40

Table A.9. Indicators of Antiretroviral Therapy Attitudes and Beliefs: Descriptive Statistics

Variable	Mean	Std Dev	Min	Max
Pills	3.64	.03	1	4
Effect	3.53	.06	1	4
HIV	3.64	.03	1	4
Health	3.78	.02	1	4
Toxic	3.59	.03	1	4
Immune	3.64	.02	1	4
Holiday	3.57	.04	1	4
Depress	3.57	.04	1	4
Hard	3.48	.03	1	4
rEasy	1.59	.04	1	4
Time	3.13	.04	1	4
RunOut	3.10	.03	1	4
Away	3.06	.05	1	4
Busy	2.96	.05	1	4
Change	3.23	.04	1	4
Longer	1.41	.02	1	4
Improve	1.64	.04	1	4

Table A.10. Indicators of Antiretroviral Therapy Attitudes and Beliefs: Varimax Rotation of Factor Loadings

Variable	Psychological Burden of Medication	Difficulty Accessing Medication	Difficulty Scheduling Medication	Medication Efficacy Beliefs	Uniqueness
Pills	.57	04	25	06	.61
Effect	.65	02	15	10	.55
HIV	.59	06	11	.00	.63
Health	.61	06	06	14	.60
Toxic	.73	06	11	13	.44
Immune	.64	09	11	04	.56
Holiday	.54	.01	25	12	.63
Depress	.66	07	21	04	.51
Hard	.11	60	01	11	.61
rEasy	11	.54	.00	.19	.65
Time	.09	 57	18	07	.63
RunOut	.05	53	07	11	.70
Away	.23	11	60	.05	.57
Busy	.19	03	69	.03	.48
Change	.31	04	59	00	.56
Longer	12	.18	.01	.54	.66
Improve	19	.12	.04	.64	.54

Note: These indicators are the final remaining after conducting a factor analysis on a set of 35 items. The strongest factor loading of the retained item is bolded.

Table A.11. Indicators of Psychological Burden of Medication: Item-Total and Inter-Item Correlations

Variable	Item-Total	Inter-Item
Pills	.69	.43
Effect	.72	.42
HIV	.65	.44
Health	.68	.43
Toxic	.76	.41
Immune	.71	.42
Holiday	.68	.43
Depress	.74	.41

Table A.12. Indicators of Difficulty Accessing Medication: Item-Total and Inter-Item Correlations

Variable	Item-Total	Inter-Item
Hard	.75	.36
rEasy	.71	.40
Time	.75	.36
RunOut	.72	.38

Table A.13. Indicators of Difficulty Scheduling Medication: Item-Total and Inter-Item Correlations

Variable	Item-Total	Inter-Item
Away	.83	.50
Busy	.84	.46
Change	.80	.57

• Medication Efficacy had two indicators, with an inter-item correlation of .56.

APPENDIX B: ATTRITION AND SELECTION BIASES

Table B.1. Differences between Participants Who Did and Did Not Complete the Second Followup Interview: Bivariate Associations

	Completed 2 nd FU (n = 2267) % or Mean (SE)	Did Not Complete 2 nd FU (n = 597) % or Mean (SE)	p
	, ,	,	
Minority	46.5	57.3	<.001
Male Gender	77.5	77.3	.940
< 35 Years Old	33.0	36.7	.171
< High School Degree	23.6	28.6	.225
< \$25,000 Annual Income	69.4	77.9	.003
Insurance in Last 6 Months			
None	17.6	17.7	.003
Medicaid	27.9	36.1	
Medicare	19.8	20.6	
Private	34.7	25.6	
Sexual Orientation			
Homosexual	49.9	41.2	.018
Heterosexual	42.1	51.2	
Bisexual	7.9	7.7	
Risk Exposure			
Injection Drug Use	23.4	28.2	<.001
Male-to-Male Sexual Contact	50.1	42.2	
Male-to-Female Sexual Contact	18.5	15.0	
Other	8.0	14.6	
Year First Tested HIV+	1991 (.07)	1991 (.13)	.051
Has AIDS Diagnosis	58.5	66.9	.006
Depression Symptoms	1.8 (.06)	2.0 (.13)	.168
Dysthymia Symptoms	.9 (.03)	1.1 (.07)	.019

	Completed 2 nd FU (n = 2267) % or Mean (SE)	Did Not Complete 2 nd FU (n = 597) % or Mean (SE)	p
Used Heroin or Cocaine in Past Year	15.3	25.8	<.001
Has Usual HIV Provider	91.6	89.6	.210
Perceived Social Support	65.4 (.60)	59.9 (1.23)	<.001
Discriminatory Healthcare Experiences	1.2 (.04)	1.3 (.14)	.371

Table B.2. Characteristics of Participants Who Completed the Second Followup Interview: Multivariate Associations

	Completed 2^{nd} FU (n = 2829)	
	OR (95% CI)	p
Minority	.75 (.60, .94)	.012
Age	1.07 (.99, 1.15)	.103
Annual Income	1.04 (.93, 1.16)	.519
Medicaid	.90 (.69, 1.16)	.408
Medicare	.98 (.73, 1.31)	.877
Private Insurance	1.12 (.77, 1.64)	.534
Heterosexual Orientation	.77 (.50, 1.19)	.230
Bisexual Orientation	1.02 (.70, 1.49)	.932
Injection Drug Use Risk Exposure	1.04 (.68, 1.59)	.851
Male-to-Female Sexual Contact	1.56 (1.01, 2.41)	.047
Other Risk Exposure	.64 (.41, 1.01)	.054
Year Diagnosed HIV+	.98 (.95, 1.01)	.266
AIDS Diagnosis	.68 (.52, .89)	.006

	Completed 2^{nd} FU (n = 2829)	
	OR (95% CI)	p
Depression Symptoms	.99 (.95, 1.02)	.495
Dysthymia Symptoms	.98 (.91, 1.05)	.513
Used Heroin or Cocaine in Past Year	.87 (.79, .96)	.008
Social Support	1.00 (1.00, 1.01)	.009

Table B.3. Differences between Participants Who Were and Were Not Prescribed Antiretroviral Therapy at the Second Followup Interview: Bivariate Associations

	On ART at 2 nd FU	Not on ART at 2 nd FU	
	(n = 1911)	(n = 356)	
	% or Mean (SE)	% or Mean (SE)	p
Minority	45.7	51.1	.200
Male Gender	78.5	71.8	.023
< 35 Years Old	32.0	39.1	.023
< High School Degree	32.0	39.1	.001
< \$25,000 Annual Income	67.3	82.3	<.001
Insurance in Last 6 Months			
None	16.5	24.5	.002
Medicaid	27.1	33.0	
Medicare	19.8	19.4	
Private	36.7	23.1	
Sexual Orientation			
Homosexual	50.4	47.0	.231
Heterosexual	42.1	42.6	
Bisexual	7.5	10.4	
Risk Exposure			
Injection Drug Use	21.9	32.7	.003
Male-to-Male Sexual Contact	51.4	42.7	
Male-to-Female Sexual Contact	18.8	16.5	
Other	8.0	8.1	

	On ART at 2 nd FU	Not on ART at 2 nd FU	
	(n = 1911) % or Mean (SE)	(n = 356) % or Mean (SE)	р
Year First Tested HIV+	1991 (.08)	1991 (.18)	.456
Has AIDS Diagnosis	60.8	44.8	<.001
Viral Load ≤1000 copies/ml	43.0	21.5	<.001
CD4 Count < 200	27.2	32.3	.070
Self-Perceived Physical Health	50.1 (.22)	47.5 (.61)	<.001
Self-Perceived Mental Health	50.3 (.23)	47.1 (.61)	<.001
Depression Symptoms	1.8 (.07)	2.2 (.17)	.005
Dysthymia Symptoms	.9 (.03)	1.2 (.09)	<.001
Used Heroin or Cocaine in Past Year	14.4	21.3	.013
Has Usual HIV Provider	91.0	90.0	.241
Perceived Social Support	65.9 (.64)	62.6 (1.58)	.040
Discriminatory Healthcare Experiences	1.2 (.04)	1.4 (.11)	.124*
Healthcare Provider Distrust	1.5 (.01)	1.8 (.05)	<.001*

^{*}p value based on Wilcoxon rank sum test

Table B.4. Characteristics of Participants Who Were Prescribed Antiretroviral Therapy at the Second Followup Interview: Multivariate Associations

	On ART at 2 nd	On ART at 2 nd FU	
	OR (95% CI)	p	
Minority	1.18 (.74, 1.89)	.479	
Male Gender	1.33 (.83, 2.14)	.224	
Age	1.06 (.97, 1.15)	.172	
Education	1.07 (.88, 1.31)	.468	

	On ART at 2 nd FU	
	OR (95% CI)	p
Annual Income	1.18 (1.02, 1.36)	.028
Medicaid	1.26 (.74, 2.15)	.384
Medicare	.99 (.61, 1.63)	.980
Private Insurance	1.34 (.71, 2.52)	.355
Injection Drug Use Risk Exposure	.97 (.57, 1.65)	.904
Male-to-Female Sexual Contact	1.56 (.94, 2.60)	.083
Other Risk Exposure	.99 (.48, 2.05)	.986
AIDS Diagnosis	2.44 (1.44, 4.16)	.001
Viral Load	.83 (.77, .89)	<.001
Lowest Ever CD4 Count	.96 (.73, 1.25)	.747
Self-Perceived Physical Health	.99 (.97, 1.01)	.330
Self-Perceived Mental Health	1.01 (.99, 1.03)	.188
Depression Symptoms	.96 (.92, 1.01)	.092
Dysthymia Symptoms	.92 (.83, 1.02)	.108
Used Heroin or Cocaine in Past Year	.93 (.86, 1.02)	.107
Social Support	1.00 (.99, 1.00)	.205
Discriminatory Healthcare Experiences	.95 (.87, 1.03)	.205
Healthcare Provider Distrust	.58 (.47, .72)	<.001

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