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Abstract

The major focus for the present study was to examine the effects of provider stigmatization on the medical care of HIV+ patients, by using an experimental paradigm and examining a conceptual framework to clarify the relationship between provider stigmatization and negative treatment outcomes. Initial qualitative findings from focus groups ($n = 18$) indicated that several key elements of stigmatizing treatment experiences included judgmental and condescending language, patient avoidance, increased physical distance between patient and provider during conversations and procedures, and use of extra, unnecessary precautions (e.g. use of extra gloves, masks). These provider behaviors were experimentally manipulated and incorporated into computerized vignettes containing audio and visual stimuli depicting “typical” medical appointments. In the experimental phase, participants ($n = 90$) were randomly assigned to view either a highly stigmatizing or a non-stigmatizing treatment vignette and then subsequently rate their willingness to engage in HIV care. Findings indicated that patients assigned to the highly stigmatizing condition were the most unwilling to engage in HIV care as demonstrated in lower intentions to remain in care, disclose sexual and substance use risk behaviors, and discuss medication adherence difficulties. As hypothesized, the effect of the experimental stigma condition on patients’ willingness to engage in care was mediated by patients’ feelings of comfort and their perceptions of stigma within the patient-provider interaction. Findings from the present study may help to inform the development of interventions to assist healthcare providers in creating more positive treatment experiences for their HIV+ patients to improve implementation of self care and reduction of risk behaviors.

HIV-Related Stigmatization in Treatment Settings: Effects on Patient Comfort, Risk
Disclosure, and Treatment Decisions

by

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Dissertation

Submitted in partial fulfillment of the requirements for the
degree of Doctor of Philosophy in Clinical Psychology
in the Graduate School of Syracuse University

August 2012

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HIV-Related Stigmatization in Treatment Settings: Effects on Patient Comfort and Treatment Decisions

Over one million people in the United States are currently infected with HIV and global estimates indicate that 33 million are now living with HIV/AIDS worldwide (UNAIDS, 2007). With the advent of highly active antiretroviral therapy (HAART), many who are living with HIV can anticipate sustained viral suppression and much improved life expectancy relative to patients living with HIV earlier in the epidemic. Despite biomedical advances, HIV-infected individuals still face many challenges, prominent among which is the widespread social stigma associated with HIV disease. Stigmatization broadly refers to viewing a person, or a group of persons, as devalued, spoiled or flawed in the eyes of society, resulting in stereotyping, prejudice, status and power loss, social isolation, and discrimination (Crocker, Major, & Steele, 1998). Although negative attitudes toward HIV+ individuals have decreased somewhat in recent years, HIV-related stigmatization remains prevalent both in the United States and globally (Mahajan et al., 2008). Studies suggest that the persistence of HIV-related stigmatization is the result of a complex relationship of several interacting factors, including misconceptions about HIV being transmitted through casual contact, the symbolic association of HIV to homosexuality and drug use, and the belief that HIV+ persons are to blame for becoming infected (Pryor, Reeder, & Landau, 1999; Pryor, Reeder, Yeadon, & Hesson-McInnis, 2004).

HIV+ individuals are cognizant of this stigmatization. In a recent clinic-based study of 221 HIV+ men and women, 42% indicated that others behaved negatively towards them because of their HIV status and 29% reported that people avoid being

around them because they are HIV+ (Vanable, Carey, Blair & Littlewood, 2006). Indeed, the effects of HIV-related stigma on persons living with HIV are significant and wide ranging. A significant proportion of HIV+ persons report experiencing physical violence, decreased social support, and job-related difficulties as a result of disclosing their HIV status (Berger, Ferrans, & Lashley, 2001; Rothenberg, Paskey, Reuland, Zimmerman, & North, 1995; Vara-Diaz, Serrano-Garcia, & Toro-Alfonso, 2005; Zierler et al., 2000). Stigma-related experiences also contribute to stress and adjustment difficulties in HIV+ individuals (Clark, Lindner, Armistead, & Austin, 2003; Lee, Kochman, & Sikkema, 2002). In addition, research indicates that stigma interferes with disease management, inhibits disclosure of HIV status to sexual partners, and undermines HIV prevention efforts among at-risk populations (Chesney & Smith, 1999; Lindau et al., 2006; Vanable et al., 2006).

Provider Stigmatization: A Focus on Patient Self Care and Transmission Risk Reduction

The experience of stigmatization in health care settings may be particularly detrimental to the health and well being of persons living with HIV. Treatment advances and the advent of HAART have allowed many HIV+ individuals to live longer and healthier lives (Wood et al., 2003), but successful management of HIV requires strict adherence to demanding medication regimens, careful attention to diet and health behaviors, and vigilant efforts to control infections that can harm the immune system (Agne, Thompson, & Cusella, 2000; Bodenlos et al., 2007). Healthcare providers, including physicians, nurses, and medical students, play a critically important role in overseeing care for persons living with HIV. In so far as instances of negativity and

discomfort among providers likely contribute to poor patient-provider communication, provider stigma may reduce patients' willingness to attend appointments, reduce serostatus disclosure to healthcare providers, and interfere with patient comprehension of important medical instructions (Bodenlos et al., 2007; Catz, Kelly, Bogart, Benotsch, & Mcauliffe, 2000; Heckman, Catz, Heckman, Miller, & Kalichman, 2004). Indeed, provider stigmatization may greatly impact the care received by HIV+ individuals, though few studies have examined this assertion. As such, the present study aims to fill this gap by examining the impact of provider stigmatization on several aspects of HIV medical care related to communication, patients' psychological comfort, and the disclosure of behaviors that may compromise HIV+ patients' health.

Provider Stigmatization in the Context of Patient-Provider Interactions

Existing research suggests that the development and maintenance of positive patient-provider relationship plays an especially important role in predicting which patients will remain in care and openly discuss their risk behaviors and medication adherence difficulties (Mallinson, Rajabiun, & Coleman, 2007). For persons living with HIV, initial interactions with medical providers serve as a critical opportunity to develop positive patient-provider relationships. Instances of provider stigmatization, expressed through specific behaviors and overall demeanor, can presumably create barriers to the process of gaining the trust necessary for a strong working relationship between HIV+ individuals and their treatment providers. Qualitative reports from HIV+ individuals indicate that stigmatizing experiences at the time of disclosure can lead to decreased trust in current providers and also deter serostatus disclosures with future healthcare providers (Agne, Thompson, & Cusella, 2000). Indeed, unsatisfactory treatment experiences (in

general) have been found to negatively influence patients' perceptions and expectations of their providers, with reduced trust in one's provider predicting decreased adherence to HIV clinic appointments (Whetten, et al., 2006).

The CDC reports that 75% of HIV+ persons are aware of their diagnosis, and of those, approximately one third are not receiving HIV care (Glynn & Rhodes, 2005). Although attributable to a variety of causes, this statistic demonstrates that despite being aware of one's HIV status, barriers exist which deter some HIV+ individuals from enrolling or remaining in HIV care. Demonstration of stigmatizing behaviors from a healthcare provider may be one of these barriers, with HIV+ persons' decisions to enroll in treatment potentially being deterred by previous experiences with stigmatizing demeanor or actions of providers. The failure to enroll in HIV care not only poses a substantial health risk to HIV+ persons, but has also been found to contribute to increased HIV transmission, as HIV+ persons who forgo treatment often have been found to have higher viral loads and therefore pose a greater risk for infection to their sexual partners (Kalichman, Rompa, Luke, & Austin, 2002). Studies are needed which examine possible deterrents to enrollment in HIV care.

Open communication within a patient-provider relationship has perhaps become an even more important issue in recent years, as CDC guidelines now recommend that HIV care providers deliver HIV-prevention services to identify and reduce patients' transmission related risk behaviors at routine medical visits (Grodensky, Golin, Boland, Patel, Quinlivan, & Price, 2008). Effective interventions necessitate the honest and accurate disclosure of one's transmission related risk behaviors, which in turn requires a certain level of trust within the patient-provider relationship. These prevention efforts not

only serve to protect the health of HIV+ individuals' sexual partners and the larger population, but also have the potential to protect HIV+ patients themselves in terms of becoming infected with other sexually transmitted diseases which may compromise their health further.

Positive patient-provider relationships are also a critical element in interventions with substance using HIV+ patients. HIV+ patients who perceive stronger relationships with their provider are more likely to discuss their substance use at medical visits (Metsch, et al., 2008). Subsequently, engaging in discussions of substance use with HIV+ care providers is associated with increased likelihood of entering into substance abuse treatment (Korthuis, et al., 2008). In this context, stigmatizing experiences may decrease HIV+ patients' willingness to disclose risky substance use behaviors, thereby precluding any chances to effectively intervene with the patient.

Similar concerns pertain to sexual risk behaviors and medication adherence, such that providers demonstrating stigmatizing behaviors may decrease the chance of their patients being forthright about sexual risk-taking and adherence difficulties. Indeed, research points to an association between poor patient-provider relationships and reduced adherence to highly active antiretroviral therapies (HAART) regimens (Johnson, et al., 2006; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004). Without a strong sense of trust in their providers, patients may be less able to effectively manage the side-effects of HAART, the complexity of dosing schedules, and the special dietary instructions that make it difficult to maintain the level of adherence required to ensure complete viral suppression (Bangsberg, et al., 2001; Chesney, 2003; Trotta, et al., 2002). Thus, stigmatization among providers may serve as a significant barrier to high quality patient

care by way of its effects to the patient-provider relationship in general, and more specifically its effects to the areas of communication regarding disclosure of risk behavior and subsequent patient receptivity to risk reduction messages from providers. With provider-based intervention initiatives garnering more attention and support in HIV research, it is critical to undertake studies that increase our understanding of the mechanisms through which provider stigmatization may interfere with provider based efforts to promote sexual risk reduction, medication adherence, and related health behavior changes.

As medical providers continue to play a critical role in promoting the health and well-being of HIV+ individuals, it is important to understand if certain behaviors within the treatment settings may be perceived as stigmatizing by patients and hence detract from this process. Thus, the major focus for the present study was to examine the effects of provider stigmatization on several important aspects of HIV treatment. More specifically, the study uses both qualitative focus groups and an experimental paradigm to (1) identify key characteristics of stigmatizing treatment experiences and (2) characterize the association of HIV-related stigmatization to patients' decisions to enroll in care, disclose risky sexual and substance use behaviors, discuss medication adherence difficulties, and their willingness to engage in conversations related to risk reduction and promotion of self care. The present study tests the hypothesis that the presence of stigmatization in patient provider interactions will decrease the willingness of HIV+ patients to engage in the above mentioned elements of HIV treatment related to intentions to enroll in care, intentions to openly communicate with their providers, and decisions to disclose sensitive health information related to sexual risk, substance use, and medication

adherence difficulties. By utilizing an experimental paradigm that assesses HIV+ patients' reactions to hypothetical vignettes of stigmatizing and non-stigmatizing patient-provider interactions and then their subsequent decisions to engage in various aspects of HIV care, the present study extends the limited field of research evaluating the impact of provider stigmatization.

HIV-related Stigmatization within Treatment Settings

An important basis for conducting the present study lies in the fact that stigmatization within healthcare settings remains prevalent even today. Nearly 30 years into the epidemic, available data provides evidence to suggest that a significant subset of healthcare providers still harbor stigmatizing beliefs about HIV+ individuals and demonstrate behaviors detrimental to their medical care including patient avoidance, inadequate care, differential treatment, and to a lesser extent, refusal of treatment (Anderson, Vojir, & Johnson, 1997; Buseh & Stevens, 2006; Carter, Lantos, & Hughes, 1996; Ladany, Stern, & Inman, 1998; McCann, 1999; McDaniel & Carlson, 1995). However, although recent literature has provided much description about the experience of HIV-related stigmatization in treatment settings, few studies have examined the impact that provider stigmatization may have on the medical care of HIV+ patients. To inform the present research examining the impact of provider stigmatization on HIV patients' willingness to engage in care and communicate openly with their providers, it is important to first review the general literature surrounding provider specific, HIV-related stigmatization. Reviewed qualitative and quantitative findings describe the widespread nature of provider stigmatization as experienced by HIV+ patients, examining frequencies of specific provider behaviors and providing detailed accounts of

stigmatizing treatment experiences and the ways in which HIV+ patients' perceive provider behaviors and demeanor. Studies examining the effects of provider stigma receive a more detailed examination. The review reports on studies occurring since 1995, as a thorough review of earlier studies was completed by Eldridge and St. Lawrence (1995). Broadly, earlier findings indicated a high occurrence of stigmatizing attitudes and behaviors from providers including blaming HIV+ individuals for their infection, unfounded fear of contagion, and frequent treatment refusals. For the current review, an emphasis was placed on identifying gaps and limitations in existing research, hence providing a basis for the importance of conducting the present study.

Provider behaviors indicative of stigmatization were categorized as those pertaining to (1) subtle indicators related to provider demeanor and (2) more overt indicators tied to specific aspects of provider care. Behaviors demonstrating a negative demeanor are those which are often perceived by a patient as stigmatizing, but the intent behind such behaviors is largely unknown (Rintamaki et al., 2007). They include nonverbal and verbal communication of negative affect, such as irritations or anger, nervousness, or fear at having to work with HIV+ individuals. In contrast, stigmatizing behaviors in the form of care provision are more overt and may directly compromise treatment (Rintamaki et al., 2007). As shown in Table 1, a total of 14 studies provide qualitative or quantitative data on stigmatizing behaviors of healthcare providers as reported by HIV+ patients. The table specifies each study's sample size, participant characteristics, design, objectives, and major findings, while also summarizing the study's limitations and method in which provider stigma was operationalized and

assessed. Table 2 provides a summary of the stigmatizing behaviors examined by each study.

Stigmatizing Behavior Related to Demeanor

As the experimental paradigm of the present study utilizes vignettes incorporating both visual and audio elements to depict patient-provider interactions, the success of the study design relies heavily on the accurate depiction of both stigmatizing and non-stigmatizing provider behaviors and treatment experiences. As such, it is important to understand precisely which behaviors HIV+ patients note as indicative of a stigmatizing treatment experience in terms of both subtle cues of a provider's demeanor and attitude, as well as more overt behaviors. This first section of the review examines findings from studies that report data on negative demeanor among providers, as reported by HIV+ patients. Behaviors demonstrating a negative demeanor are those that are often perceived by a patient as stigmatizing, but the intent behind such behaviors is largely unknown including judgmental language, nonverbal behaviors, expression of discomfort, and negative affect. Though these demeanor-related actions may not have as obvious a detrimental impact as a refusal of treatment, they remain some of the most reported negative experiences of HIV+ patients, especially in more recent years.

Judgmental or deficient communication. Seven qualitative studies reported data on negative experiences within the realm of provider communication (see Table 2). Some of the most frequently reported negative experiences of HIV+ patients involved providers' use of judgmental language. Language of this nature often pertains to making attributions about a patient's acquisition of HIV, blaming the patient for their infection, and judging patients negatively based on their HIV+ status. Another complaint noted in

this literature pertained to the general lack of communication between the patient and provider as related to the HIV+ individuals' health, medication, prevention, or other treatment details. In two studies focusing on the experiences of HIV+ mothers (Lindau et al., 2006; Marcenko & Samost, 1999), a subset of participants reported experiences in which nurses and physicians spoke to them in ways that indicated moral disapproval of their decision to become pregnant while HIV+. In Blake et al. (2008), a qualitative study focusing on HIV testing and care experiences, many of the HIV+ women in the sample ($n=64$) noted deficits in providers' willingness to communicate with them about prevention strategies and treatment elements.

In three other qualitative studies (Buseh & Stevens, 2006; Rintamaki et al., 2007; Surlis & Hyde, 2001), patients described experiences in which providers made negative attributions about the route in which they became infected. For example, in a study conducted by Buseh and Stevens (2006), an African American woman reported that her physician assumed she became infected through intravenous drug use because of her ethnicity. More overt accounts of victim blaming were noted in Rintamaki et al.'s (2007) study of HIV+ veterans, with one participant reporting pain during a blood draw, upon which the nurse replied, "If you hadn't done this to yourself, we wouldn't have to be going through this!" (pp. 963). Similar accounts of blaming were noted by intravenous drug users in Surlis and Hyde's (2001) qualitative study of HIV+ individuals receiving nursing care in a hospital setting. Thus, findings regarding judgmental communication appear to demonstrate a high frequency of patient blaming and negative judgment of HIV+ individuals.

Nonverbal behaviors related to proximity, eye contact, and extra precautions. Three studies reported provider stigmatization as experienced through inadequate eye contact, increased distance between the patient and provider, or the use of seemingly unnecessary precautions during health visits (Blake et al., 2008; Lindau et al., 2006; Rintamaki et al., 2007). All of these studies were qualitative in nature, with patients providing firsthand accounts of their treatment experiences. HIV+ patients reported “being stared at and watched” by providers (Blake et al., 2008), as well as receiving “the sort of looks” that denoted negative judgment (Lindau et al., 2006). HIV+ veterans (Rintamaki et al., 2007) reported perceiving stigma when providers demonstrated less than adequate amounts of eye contact and distanced themselves during treatment visits. Among veteran participants ($N=50$), some recounted experiences in which physicians placed themselves across the room, behind another patient’s bed, and even out in the hallway to discuss treatment or other AIDS-related issues (Rintamaki et al., 2007). Such behaviors not only risk injuring the patient emotionally, but also threaten their rights to confidentiality. In both Blake et al.’s (2008) qualitative study of HIV+ women and Rintamaki et al.’s (2007) qualitative study of HIV+ veterans, patients reported the use of extra gloves in situations in which one pair of gloves was likely adequate. An additional account noted surgeons wearing protective suits and face shields during a discussion taking place well in advance of a patient’s surgery (Rintamaki et al., 2007). Patients reported a heightened sensitivity to the precautions taken by providers, as they had witnessed incidents in which the precautions taken with them were noticeably different than those taken with other patients. Although limited to only three qualitative studies,

these studies nonetheless provide narrative accounts of the way in which nonverbal behaviors of providers can be perceived as stigmatizing among HIV+ patients.

Expression of discomfort or negative affect. Four studies (1 qualitative and 3 quantitative) reported stigmatizing experiences related to provider discomfort or expression of negative affect (see Table 2). HIV+ veteran patients in Rintamaki et al. (2007) reported many instances in which their providers were overtly nervous or fearful during treatment, as well as experiences where providers demonstrated hostility, irritation, and anger through their facial expressions, vocal tones, or other non-verbal mannerisms. Most apparent examples of such behavior occur when providers shifted their demeanor immediately after discovering the patient's HIV+ status. For example, Kinsler et al. (2007) reported that 20% of the HIV+ participants they surveyed ($N=223$) reported that a healthcare provider had been uncomfortable with them since learning of their HIV diagnosis. Similarly in the quantitative study by Schuster et al. (2005), 20% of surveyed participants from a nationally representative sample of HIV+ individuals ($N= 2466$) reported the experience of being seen by a physician who appeared to be uncomfortable around them after learning that they were HIV+. Discomfort and negative affect were also assessed in a final quantitative study (Thrasher et al., 2008) that examined the relationship between discriminatory healthcare experiences and adherence to HAART. Though statistics for individual items were not listed, 41% of the HIV+ participants ($N=1886$) reported experiencing at least one of the six discriminatory healthcare experiences, two of which were associated with provider affect and discomfort. Thus findings across the four studies assessing provider discomfort suggest that a small but significant proportion of HIV+ patients perceive their providers to be uncomfortable

around them and note affective displays of negativity in the form of irritability, nervousness, or anger.

Stigmatizing Behavior Related to Provision of Care

In contrast to above findings related to provider demeanor, stigmatizing behaviors in the form of care provision can be considered more overt stigma encounters which compromise the medical treatment of HIV+ individuals including patient avoidance, delayed treatment, lack of touch, differential or inadequate care, and treatment refusal. Though stigmatization of this nature occurs at a lessened frequency than compared to the start of the epidemic, HIV+ patients nonetheless continue to report experiencing these provider behaviors. As such, they are relevant to the present study and will inform the content of both the qualitative focus groups and the treatment vignettes of the experimental phase of the study. Stigmatization findings related to the provision of care are reviewed below.

Patient avoidance or delayed treatment. Eight studies (5 qualitative and 3 quantitative) provided reports of experiences in which treatment was delayed or patients were avoided by their providers presumably because of their HIV status (see Table 2). In four qualitative studies, patients reported incidents in which their appointments were delayed for extended periods (Blake et al., 2008; Marcenko & Samost, 1999), staff would not bring them their food (Buseh & Stevens, 2006), and physicians would not acknowledge their presence in the room (Rintamaki et al., 2007). Indeed, quantitative survey data from Schuster et al. (2005) and Kinsler et al. (2007) indicated that between 18% and 19% of HIV+ participants reported perceiving that some healthcare provider preferred to avoid them. As both Schuster et al. (2005) and Kinsler et al. (2007) utilized

the same item, “Since you have had HIV, has any health care provider preferred to avoid you?”, it is unclear what specific act of avoidance the participants might be reporting on (e.g. canceling appointments, avoiding touch, etc.). In the qualitative study by Surlis and Hyde (2001), hospital patients who had become infected with HIV through intravenous (IV) drug use were more likely to report that nurses ignored them as compared to those infected through homosexual activity. They believed they were avoided even more so because of the combination of their HIV status and their IV drug use. In sum, both qualitative and quantitative studies suggest that a significant minority of HIV+ patients report experiences in which they were avoided or felt ignored by their providers.

Lack of touch during treatment. A majority of health visits require providers to physically touch their patients to perform assessments (blood pressure, physicals) and procedures (dressing wounds, surgeries). As such, when providers decrease their level of touch, or refuse to do so altogether, treatment quality may decline. In two of the reviewed qualitative studies (Blake et al., 2008; Lindau et al., 2006), patients reported incidents in which their providers refused to touch them and perform physical examinations. In both studies focusing on HIV+ women, participants reported feeling subsequent shame (Blake et al., 2008) and threats to their safety, with one woman reporting that she had even been transported to another hospital by taxi because no one wanted to touch her (Lindau et al., 2006). Though literature is limited, available qualitative reports denote that providers’ unwillingness or aversion to touching HIV+ individuals remains an important issue and concern for some patients.

Inadequate or differential treatment. Six studies (3 qualitative and 3 quantitative) reported data concerning the question of whether HIV+ patients perceived

that they received differential or inadequate treatment based on their serostatus (see Table 2). For example, veteran patients in Rintamaki et al.'s (2007) qualitative study reported that health providers sometimes spent inadequate time on their needs, leaving them to experience unnecessary pain during procedures. Irish hospital patients from another qualitative study (Surlis & Hyde, 2001) indicated that providers treated them differentially based on their mode of infection, with patients infected through IV drug use believing they received the poorest care.

Two quantitative studies also reported findings related to inadequate or differential treatment due to HIV status. In a survey study by Elford et al. (2008), 14% of HIV+ patients recruited from HIV outpatient clinics in London ($N=1385$) reported that they had been treated differently or unfairly by a healthcare provider because of their HIV status. Differential or unfair treatment was reported to occur most often from dentists (25%), followed by general practitioners (17%), with 5% noting unsatisfactory treatment by healthcare providers at HIV specialty clinics. In contrast, participants in Bodenlos et al.'s (2007) study of patients' attitudes towards their healthcare providers in an HIV clinic setting reported high levels of satisfaction in terms of their providers' treatment efforts and overall quality of care. Thus, findings regarding the quality of care HIV+ patients perceive they are receiving appear to be mixed, with two studies noting a high frequency of poor or differential care (Elford et al., 2008; Rintamaki et al., 2007) and another reporting high ratings of healthcare quality (Bodenlos et al., 2007).

Treatment refusal. Treatment refusal based on a person's HIV status is the most overt form of stigmatization. Such experiences were noted in six of the reviewed studies of patient reports of provider stigmatization (see Table 2). Approximately 4% of African

American females sampled ($N=366$) in Wingwood et al.'s (2007) qualitative study reported being denied medical care as a result of being HIV+. Higher incidence of treatment refusals were noted in quantitative, survey-based studies by Schuster et al. (2005) and Kinsler et al. (2007), with 8% and 19% of patients reporting this experience respectively. In addition to an outright denial of care, treatment refusals can take the form of refusal to perform certain procedures or being referred to other providers. For example, in qualitative studies focusing on the treatment experiences of HIV+ veterans (Rintamaki et al., 2007) and HIV+ mothers (Lindau et al., 2006), participants provided accounts of nurses refusing to draw blood, dentists refusing to pull teeth, and incidents in which they presented with emergency needs and were transferred to other hospitals after providers learned of their serostatus. In sum, recent findings denote that a subset of HIV+ individuals still encounter refusals for medical treatment, though at a decreased frequency relative to studies carried out earlier in the epidemic (Weinberger, Conover, Samsa, & Greenberg, 1992).

Summary

The reviewed studies of provider stigmatization provide information on the extent to which HIV+ patients continue to have stigmatizing experiences within medical care settings and validate the need for conducting the present study. Indeed, as provider stigma remains a concern for a subset of HIV+ patients, studies examining its impact are needed. Although differences in study methodologies and sampling strategies preclude definitive prevalence estimates, both qualitative and quantitative data from the review suggest that a significant minority of HIV+ patients continue to experience stigmatization in healthcare settings. Findings suggest that some HIV+ patients experience negativity

from health care providers, including judgmental communication, increased distance during treatment, lessened eye contact, the use of unnecessary precautions, and the expression of discomfort or negative affect. While stigmatization related to the direct markers of HIV care provisions (e.g., inadequate care, refusal of treatment) was noted to occur less frequently, such behaviors were nonetheless experienced by a subset of HIV+ patients sampled across studies. Indeed, patients reported multiple instances where providers (1) avoided, delayed, or refused treatment, (2) were uncomfortable with or avoided direct physical contact with patients, and (3) instances where treatment was inadequate or differential because of a patient's HIV status. The reviewed literature describing experiences of provider stigmatization in the form of both negative demeanor and altered provision of care informs the design of the present study in terms of the content of the qualitative focus group interview guide as well as the development of the hypothetical treatment vignettes used in the experimental phase of the study. Although existing studies provide a foundation for understanding which provider behaviors are perceived to be stigmatizing by HIV+ patients, qualitative focus groups will be helpful in informing on more recent experiences of provider stigmatization, as well as provider behaviors that have occurred most often specifically among the present study's sample population.

Impact of Provider Stigmatization on HIV Care

The studies reviewed thus far focus on providing descriptive data to characterize stigmatization as perceived by HIV+ patients. Several quantitative studies focus more broadly on the question of whether provider stigmatization is associated with markers of treatment access and self care, including appointment attendance, HAART adherence,

access to care, and perceived quality of care. A review of this literature provides a foundation for the present study, as the included studies are the few examples of correlational research examining the impact of provider stigmatization on HIV care. Although the present study focuses specifically on the impact of provider stigmatization on HIV+ patients' decisions to engage in care and willingness to discuss sensitive topics like sexual and substance use risk behaviors and medication adherence, reviewed findings nonetheless offer initial data on the impact of stigmatization on aspects of HIV self care and patients' perceptions of the care they receive.

Appointment attendance. Regular appointment attendance is integral to the successful management of HIV. During routine clinic visits, providers monitor disease status and immune functioning, make treatment adjustments, provide support for medication adherence, and strive to control infections that can harm immune systems. In Bodenlos et al. (2007), findings indicated that HIV clinic patients ($N=109$) who perceived less provider stigmatization reported better appointment attendance. Indeed, low stigmatization and a positive provider relationship, combined with having a large social support network and being on a HAART medication regimen accounted for 27% of the model's variance in predicting appointment attendance. This finding is particularly relevant to the present study, as one of the outcomes of interest pertains to HIV+ patients' intentions to remain in care following a stigmatizing treatment experience. Findings from Bodenlos et al. (2007), suggest that the experience of provider stigmatization does indeed play a role in predicting which patients are more likely to actively engage in care, as defined by consistent appointment attendance.

Quality and access to care. Two studies examined the association between provider stigmatization and access to care, defined in terms of affordability, availability, convenience, and specialist accessibility. First, in Kinsler et al. (2007), 26% of a sample of HIV+ men and women recruited from medical centers, outreach programs, case management services, and HIV clinics in the Los Angeles area ($N=223$) endorsed at least one item indicating experiences of provider stigmatization (See Table 1). Fifty-eight percent of the sample also endorsed at least one of six items related to low access of care, with bivariate and multivariate analyses indicating that higher perceptions of provider stigmatization at baseline assessment were associated with lower access to care at the six month follow-up assessment (Kinsler et al., 2007). Second, Schuster et al. (2005) confirmed their hypothesis that higher perceptions of provider stigmatization would be related to lower access to care among their nationally representative sample of 2466 HIV+ individuals, using the same measures utilized by Kinsler et al. (2007). The authors (Schuster et al., 2005) also found that patients reporting higher levels of stigmatization were more likely to report receiving a lower quality of medical and hospital care. Taken together, findings from these two studies denote that patients perceiving higher levels of stigmatization from their providers are more likely to report lower access to care and lower quality of care received. As two of the stigma items utilized in Kinsler et al. (2007) and Schuster et al. (2005) related to patient avoidance and treatment refusal, these findings suggest provider stigmatization may affect an HIV+ individual's access to care by limiting the amount of available treatment centers they are able receive care at. In addition, after experiencing negative interactions with providers, patients may be

reluctant to return follow up appointments or seek out other treatment even when in great need (Kinsler et al., 2007).

HAART adherence. A study conducted by Thrasher et al., (2008) examined the association of healthcare discrimination and provider distrust to HAART adherence, with an emphasis on explaining potential disparities in adherence based on racial/ethnic differences. Discriminatory experiences directed towards HIV+ patients did not emerge as a predictor of adherence difficulties. Further, a hypothesized mediating path between ethnicity, provider stigmatization, and adherence was not supported. However, findings did indicate that discriminatory experiences were associated with provider distrust and weakened belief in the effectiveness of HAART, variables which subsequently predicted adherence difficulties. Thrasher et al.'s (2008) findings speak to importance of considering indirect pathways in understanding the effect of stigmatization on health and treatment outcomes by way of stigma's effects to the patients' perceptions of their providers. Drawing from this research, the present study has also considered patients' perceptions of the provider and feelings within the treatment interaction as relevant factors to explaining the effect of stigmatization on HIV+ patients' decisions to engage in care.

Summary

Three studies provide data on the relationship of provider stigmatization to treatment outcomes of HIV+ patients. Taken together, they provide initial data on the impact of perceived stigmatization from healthcare providers on HIV care, both in terms of the treatments provided by healthcare workers and also in patients' efforts regarding self care. These reviewed correlational studies provide initial evidence for a link between

provider stigmatization and detrimental effects to treatment in terms of lower perceived quality of care, lower access to care, decreased appointment attendance, and to a lesser extent, lower HAART adherence. Although additional research is needed to address methodological limitations, reviewed findings provide preliminary evidence to suggest that provider stigmatization negatively impacts the medical care of HIV+ individuals. Findings provide a strong basis for conducting the present study, which will contribute to the small literature that has examined the impact of provider stigmatization on aspects of HIV treatment and self care. The present study will also extend the literature by providing the first experimental examination of this area of study.

Limitations of Existing Studies

The reviewed literature documents the existence of HIV-related stigmatization among healthcare providers and its potential effects to the medical treatment and self care of HIV+ patients. However, several inconsistencies and gaps in our understanding of provider stigmatization exist due to methodological limitations within the literature. Limitations of the present literature include a general lack of studies examining the impact of provider stigma, a lack of quality and consistency in the measures used to assess provider stigma, and a lack of studies utilizing experimental designs to examine the experience of provider stigmatization and its impact on various aspects of HIV care and HIV+ patients' perceptions of their treatment experiences. Such limitations are discussed, with attention paid to how the present study addresses them through both its focus and design.

Lack of Studies Examining the Impact of Provider Stigma

Broadly, there is a need for studies that specifically aim to examine the effects of provider stigmatization on the medical care of HIV+ individuals. Although several qualitative studies provide anecdotal evidence for the link between provider stigmatization and poor treatment outcomes, there are relatively few empirically-based studies that examine such questions. Those that do exist are correlational in nature. A growing number of well-designed, theoretically informed studies have begun examining the impact of societal stigma on HIV+ individuals' emotional and physical health. Indeed, experiencing HIV-related stigmatization (not provider-specific) negatively impacts mental health (Berger et al., 2001; Clark et al., 2003), as well as contributes to delays in entering into care, lapses in medication adherence, and fewer status disclosures to physicians (Chesney & Smith, 1999; Venable et al., 2006). Research on provider-specific stigmatization would benefit from a greater focus on empirically-based studies that seek to document the impact of stigma on the medical treatment of HIV+ individuals including engagement in care, patient-provider communication, and issues related to risk behavior and medication adherence. The present study helps to fill this gap in the literature, clarifying how provider stigmatization can affect the above mentioned HIV treatment and self care variables.

Lack of Quality in the Conceptualization and Measurement of Provider-specific HIV Stigmatization

In stigmatization research, the operationalization and assessment of HIV-related stigmatization varies widely across studies. This lack of consistency in stigma measurement creates difficulties when trying to generalize and compare findings across

studies and over time (Eldridge & St. Lawrence, 1995; Mahajan et al., 2008; Nyblade, 2006). For empirically-oriented studies involving patient self-report, measures are often restricted to small item sets and narrowly focused on extreme behavioral markers of stigmatization such as treatment refusal. Recent qualitative studies provide a richer understanding of the stigma experiences of HIV+ individuals within treatment settings, and future research would benefit from incorporating this information into the development of better tools to assess perceptions of provider stigma. The present study addresses this limitation, as its operationalization of provider stigma is multifaceted in nature. The study incorporates findings from previous literature and information gathered from qualitative focus groups to create detailed representations of provider stigma in vignettes depicting a range of provider behaviors related to both demeanor and the provision of care.

Reviewed studies also lacked time-sensitive language in their measures, often assessing instances of stigma since the time of diagnosis. This approach not only lacks the specificity required to capture current trends related to stigmatization in treatment settings, but is also prone to error associated with memory recall difficulties. Needed are studies that capture more in-the-moment measures of patient perceptions of provider treatment behaviors. The present study's design addresses this limitation as well, requiring HIV+ patients to rate their level of psychological comfort (e.g. level of worry, nervousness, etc.) and beliefs about the patient-provider relationship immediately following the presentation of (potentially) stigmatizing behaviors in a hypothetical care visit via a computer program. This design indeed allows for time-sensitive assessments of

reactions to provider stigma and lessens the possibility of recall errors often found in traditional survey based studies.

Lack of Experimental Study Designs

In the few existing studies that examine the impact of HIV+ patients' perceptions of provider stigma, none have utilized an experimental design to examine stigma's association with negative treatment outcomes. Indeed, past research has relied solely on self report measures of perceptions of provider stigma within the treatment setting and has been correlational in nature. A major limitation of these studies pertains to the potential risk of attributional biases. Indeed, all of the patient-based studies operationalized provider stigma as behaviors *perceived* by HIV+ patients to be stigmatizing, with no outside validation of the providers' actual behaviors. Given the historically negative treatment of HIV+ individuals within our culture, HIV+ patients may be especially prone to perceiving threat or injustice in situations that may actually be benign (Chapman, 2002; Frable, Blackstone, & Scherbaum, 1990). As such, HIV+ persons may be more alert to potential threats, hyperaware of people's treatment toward them, and potentially more likely to label neutral behavior as stigmatizing.

The use of an experimental paradigm, as utilized in the present study, has the potential to address these limitations and advance stigmatization research in several ways. First, relative to correlational studies, experimental designs allow for an examination of the *causal effects* of stigmatizing provider behaviors to HIV+ patients' perceptions of treatment experiences and their decisions to engage in HIV care in terms of treatment enrollment, disclosure, and receptivity to risk reduction messages. Secondly, an experimental design allows for the level of stigmatizing behaviors demonstrated by

providers to be controlled and manipulated across HIV+ patient subjects, thereby limiting the effects of attributional biases in the examination of stigma's impact on HIV care. The vignette design of the present study allows for an examination of the potentially differential effects of having a highly stigmatizing treatment experience as compared to a treatment experience characterized by more neutral or positive provider behaviors while controlling for the exact stimuli being perceived by the patients (via the creation of the standardized vignettes). In this design, the patients' perceptions of the provider behaviors are directly assessed through their self report, while the exact provider behaviors that are being experienced by the HIV+ patients are controlled in the standardized vignettes. Indeed, it is yet unknown which of the two, the behaviors or the perceptions of the behaviors, is more closely linked (if either) with treatment outcomes of HIV+ patients.

In sum, the existing literature pertaining to HIV-related, provider stigmatization informs the focus, content, and design of the present study. Limitations of previous research leave a gap in our understanding of the impact of provider stigmatization on the lives of HIV+ individuals. The present study begins to address these limitations and advances the current state of provider stigmatization research.

Theoretical Considerations of the Present Study

The theoretical framework of the present study integrates findings from the provider stigmatization literature with the broader literature on patient-provider relationships to help explain the ways in which negative provider interactions may influence patients' decisions to engage in medical care. The Interaction model of Client Health Behavior (IMCHB; Cox, 1982), described below, informs the mediational model utilized in the present study. The mediational model of the present study is described in

detail, drawing reference from the IMCHB model while also elaborating on its own unique focus on the effects of provider stigmatization on HIV+ patients' feelings of psychological comfort (e.g. level of worry, nervousness, etc.), intentions to enroll in care, intentions to openly communicate with the provider, and their disclosure of sensitive health information related to sexual risk behaviors, substance use, and lapses in medication adherence.

The Interaction Model of Client Health Behavior

Although not specific to HIV care literature, the Interaction Model of Client Health Behavior (Cox, 1982) provides a useful framework for considering the role of patient-provider interactions in determining health outcomes. Indeed, this model captures the dynamic relationship between patient background characteristics, cognition, affect, and patient-provider interactions in predicting patient health outcomes, and has been used in its entirety or in parts as the guiding framework in studies predicting a range of health outcomes, including the use of prenatal care (Cox & Roghmann, 1984), engagement in self breast exams (Cox, Montgomery, Rai, McLaughlin, Steen, & Hudson, 2008), weight control behaviors (Troumbley & Lenz, 1992), children's physical activity and diet (Robinson & Thomas, 2004), and satisfaction with medical care (Benkert, Hollie, Nordstrom, Wickson, & Bins-Emerick, 2009). The Interaction Model of Client Health Behavior (IMCHB) is multidimensional and dynamic, as illustrated in Figure 1. Of relevance to the present study, the IMCHB describes (1) individual patient characteristics (client singularity) and (2) patient-provider interactions as the elements of care most predictive of health outcomes.

Individual patient characteristics. Individual patient characteristics include demographic background, availability of social supports, environmental constraints, previous experiences in healthcare, as well as their level of motivation to engage in healthcare. In addition, the IMCHB model also posits that each patient will differ from other patients in their cognitive appraisal of and affective response to their medical condition and treatment process. The model dictates that these aspects of client singularity have important effects on the subsequent patient behavior and treatment outcomes, such that the characteristics, cognitions, and emotions of an individual will first affect how they behave in patient-provider interaction, which will then affect health outcomes. Findings from Cox et al. (2008) and Troumbley and Lenz (1992) provide support for the importance of considering patient characteristics when predicting patient behavior and treatment outcomes. In both studies, participant background characteristics were found to be predictive of health behaviors, with findings from Troumbley and Lenz also demonstrating that patients with psychological distress are more likely to engage in risky health behaviors and have poorer health outcomes (e.g. risky driving, high blood pressure, experience illness, etc.).

Patient-provider relationship. According to Cox's (1982) model, positive patient-provider interactions are defined in large part by the provider's ability to demonstrate their competency, provide affective support, give the patient control in decisions, and provide health information in the proper amounts as based on the highly individualized needs of the patient. Failure of providers to correctly assess and subsequently meet the patient's needs within the patient-provider interaction may negatively affect the patient health care decisions, behaviors, and treatment outcomes by

lowering the patient's level of motivation and self confidence and skewing their appraisal of their health status, treatment needs, and quality of care received (Cox, 1982). For example, in Benkert et al.'s (2009) examination of the IMCHB model, findings demonstrated that the complex relationship between patients' racial identity and their perceptions of the client-professional relationship had significant effects on patients' satisfaction with primary care. The patient-provider interaction element included in the present study is more narrowly focused than that originally described in the IMCHB (Cox, 1982), using standardized vignettes to portray specific aspects of patient-provider relationships related to provider stigmatization.

Model of the Present study

The present study adapts several aspects of the IMCHB model to examine the impact of provider stigmatization on HIV+ patients' engagement in treatment. Both patient characteristics and treatment interactions were incorporated into the present study's conceptualization of how provider stigmatization effects patients' decisions to engage in treatment. Patient characteristics are operationalized as participant demographics and previous experiences with stigmatization in healthcare settings. Characteristics related to cognitive appraisal and affective response are operationalized in the present study as perceptions of stigmatization and their psychological comfort (level of worry, nervousness, etc.) within the patient-provider interaction respectively. For the present study, *engagement in treatment* is operationalized in terms of patients' intentions to enroll in care, intentions to openly communicate with their provider, and the disclosure of sensitive health information related to sexual risk behaviors, substance use, and lapses in medication adherence. Specifically, the model posits that HIV+ patients' perceptions

of stigmatization for a hypothetical patient-provider interaction and their feelings of psychological comfort with the provider will mediate the relationship between the experimental manipulation of provider stigmatization and HIV+ patients' decisions to engage in treatment (See Figure 2). It is proposed that when providers engage in stigmatizing behaviors, HIV+ patients' (1) perceive the devaluing nature of these behaviors, (2) their perceptions of the patient-provider relationship are harmed, and (3) their level of psychological comfort (e.g. level of worry, nervousness, etc.) within the treatment setting will decrease. A patient's lowered sense of comfort, perceptions of stigmatization, and negative perceptions of the patient-provider relationship would then negatively influence their decisions to remain in care, disclose sensitive health information, and engage in discussions related to sexual risk behaviors, substance use, and medication adherence difficulties.

The role of motivational biases. In focusing specifically on outcome variables related to the disclosure of sensitive health information, the present study also considers the potential role of motivational biases in our conceptualization of the effects of provider stigmatization of patients' disclosure of socially sensitive health behaviors. In particular, it is believed that patients who experience stigmatization and negativity during a medical visit may be motivated to under-report socially sensitive behaviors because of concern about the possibility of experiencing further stigmatization from the provider.

The literature on self-report accuracy for socially sensitive behaviors suggests that impression management and social desirability biases can lead to underreporting of behaviors that are seen as socially unacceptable (see e.g., Schroder, Carey, and Venable, 2003). Thus, research suggests that patients disclose higher rates of sexual risk behavior

when they are assured of anonymity relative to when they are asked about their past behaviors in a face to face interview (e.g., Des Jarlais, 1999; Metzger et al., 2000). Likewise, individuals are more likely to under-report substance use behaviors as the level of privacy afforded in the mode of assessment decreases (Moskowitz, 2004; Wright, Aquilino, Supple, 1998). Patients also vary in their degree of concern about impression management, and such differences help to explain under-reporting of substance use behaviors (e.g., Davis, Thake, and Vilhena, 2010).

Within the present study's framework, motivational biases to under-report sensitive health behaviors are considered to be of potential relevance to the proposed mediational model. Put simply, when a HIV+ patient perceives that their provider is behaving in disrespectful or uncaring manner because of their HIV status, they may experience discomfort with the idea of communicating openly with the provider. In turn, patients may be reluctant to disclose socially sensitive behaviors because of fear that such disclosures will elicit increased negativity and judgment from the provider. That is, patients will likely underreport risky behaviors related to sexual behavior, substance use, and medication lapses in an effort to avoid further feelings of shame and to present oneself in a more positive light (e.g. "the good patient"). As such, the model posits that participants' who engaged in the stigmatizing treatment interaction (vs. the non-stigmatizing vignette) would be less likely to disclose accurate (and potentially embarrassing) information regarding their risk behaviors, as a function of their decreased feelings of comfort with the provider and their perceptions of being devalued by the provider because of their HIV status.

Summary of the Mediational Model

The present study tests the hypothesis that provider stigmatization within a medical visit will negatively impact HIV+ patients' decisions to engage in treatment and openly communicate with the provider. It was predicted that patients' perceptions of this stigmatization and discomfort with the hypothetical provider would mediate the relationship between the experimental manipulation of provider stigmatization and HIV+ patients' decisions to engage in treatment. The mediational model of the present study draws upon several elements of the IMCHB (Cox, 1982) by incorporating both client characteristics (e.g. participant demographics, past stigma experiences, psychological comfort, and perceptions of stigma) and treatment interactions in its conceptualization of how provider stigmatization effects patients' decision to openly communicate with providers and disclose sensitive information. The model also draws upon the literature on self-report biases to support the hypothesized effects of stigmatization on disclosure of sensitive self-report data. Indeed, the basic tenets of the IMCHB (i.e. client singularity and patient-provider interactions) are relevant in examining the effects of provider stigmatization on the health and treatment outcomes of HIV patients, in so much as negative provider attitudes and behaviors may be detrimental to the formation of the patient-provider relationship, impair a provider's ability to provide needed emotional support, detract from the provision of health and treatment messages, decrease patients' feelings of psychological comfort, and negatively affect patients' perceptions of the care they receive. Within the framework of the present study, provider stigmatization was hypothesized to negatively impact health outcomes via its impact on patient-provider interactions and subsequent negative changes to patients' level of motivation to engage in

care, their need to present themselves in a socially desirable fashion, and their trust in their provider. The present study examines this model, hypothesizing that the relationship between provider stigmatization and HIV+ patients' decisions to engage in treatment (i.e. intentions to enroll in care, intentions to openly communicate with provider, disclosure of sensitive health information) would be mediated by HIV+ patients' perceptions of stigmatization within the hypothetical patient-provider interaction and their comfort with the provider.

Overview of the Present Study

The major focus for the present study was to examine the effects of provider stigmatization on several important aspects of HIV treatment related to patients' decisions to engage in care, including intentions to enroll in HIV care, intentions to engage in discussions related to risk behaviors, adherence challenges, and risk-reduction strategies, and the actual disclosure of sexual risk behavior, substance use, and lapses in medication adherence. Although many recent studies have documented the existence of stigmatization in medical treatment settings, few have examined the impact of provider stigmatization on HIV+ patients' decisions to engage in various aspects of HIV care, and none have utilized experimental designs to address limitations inherent in survey based studies. The small existing literature supports an association between provider stigmatization and lower appointment attendance, lower access to care, and to a lesser extent, reduced HAART adherence, among HIV+ patients. However, conclusions are limited by the correlational nature of the findings. The present study addresses these limitations by not only exploring the extent to which HIV+ patients perceive stigmatization within the treatment setting, but also examining the effects these

perceptions of stigma have on their decisions to engage in important aspects of HIV care including issues related to disclosure, patients' psychological comfort, and willingness to participate in risk reduction conversations.

In using an experimental design, the present study utilizes a standardized and behaviorally oriented approach to assessing patient's reactions to stigmatization in health care settings. In so doing, the present study advances a conceptual framework to clarify the relationship between provider stigmatization, patients' feelings of psychological comfort and perceptions of stigma in the patient-provider interaction, and aspects of HIV care pertaining to HIV+ patients' willingness to disclose risk behaviors, engage in risk reduction discussions, and enroll in care. Outcome variables as a whole are referred to as "engagement in care." Specifically the model of the present study posits that the relationship between provider stigmatization and HIV+ patients' engagement in care will be mediated by HIV+ patients' perceptions of stigmatization within the hypothetical patient-provider interaction and their sense of psychological comfort (with regard to the provider in general and specifically in relation to engaging in conversations related to sexual risk behavior, substance use, and medication adherence).

The present study also examines demographic characteristics and previous experiences of provider stigmatization as possible covariates or moderators for the proposed model. For example, the study explores whether differences in a participant's degree of previous experiences with provider stigmatization alter the strength of the hypothesized causal relationship between the experimental stigmatization manipulation and participant's subsequent decisions to engage in care. In the study's experimental paradigm, HIV+ patients were randomized to provide ratings of either a highly

stigmatizing or a non-stigmatizing hypothetical treatment encounter with a physician described as very competent in treating HIV+ patients. Patients provided several ratings of general feelings of psychological comfort (e.g. level of worry, nervousness, etc.) with the provider while viewing the hypothetical treatment vignette and provided ratings regarding their comfort discussing risk behaviors with the provider, perceptions of stigmatization within the hypothetical patient-provider interaction, and their subsequent decisions to engage in various aspects of HIV care (e.g. intentions to enroll in care, disclose of sexual and substance use risk behaviors, and intentions to participate in medication adherence and risk reduction conversations) after the presentation of the vignette.

By using an experimental paradigm and characterizing the mechanisms through which provider stigmatization affects HIV+ patients' decisions to engage in care, the present research fills an important gap in the literature. An understanding of the mechanisms underlying the patients' decisions to engage in care and openly communicate with their providers will help to highlight areas where changes to provider demeanor, language, or behaviors may be especially helpful. As such, the current research may inform the development of interventions to assist healthcare providers in creating more positive treatment experiences for their HIV+ patients to improve implementation of self care and reduction of risk behaviors. Qualitative focus groups informed the development of the hypothetical treatment vignettes of the experimental phase of the present study. Hypotheses for this between-subjects study were tested using an experimental paradigm assessing HIV+ patients' reactions to medical treatment

scenarios that vary in their degree of provider stigmatization, as depicted using visual representations and audio recordings of the hypothetical patient/provider interactions.

Aims and Hypotheses of the Present Study

Utilizing both qualitative focus groups and an experimental paradigm, the present study aims to: (1) identify key characteristics of stigmatizing treatment experiences among men and women receiving HIV treatment, (2) validate vignettes depicting stigmatizing and non-stigmatizing treatment interactions, and (3) characterize the association of HIV-related stigmatization to patients' decisions to enroll in care, disclose risky sexual and substance use behaviors, discuss medication adherence difficulties, and their willingness to engage in conversations related to risk reduction and promotion of self care. The present study utilizes a between-subjects experimental design, randomizing participants into "stigma" and "non-stigma" vignette conditions. Vignette conditions depicting hypothetical patient-provider interactions varied based on the visual stimuli and audio recordings presented to the HIV+ participants using a computer program developed with MediaLab software (Jarvis, 2006). HIV+ participants were asked to imagine that they were the patient depicted in the hypothetical treatment vignette and then rated their feelings of psychological comfort, perceptions stigmatization within the patient-provider relationship, and decisions to engage in various aspects of HIV care.

The randomized stigma vignette condition serves as the study's independent variable of interest. The mediational variables of the present study include HIV+ patients' perceptions of stigmatization within the hypothetical patient-provider interaction and ratings of the patients' psychological comfort with the provider (generally and in relation to discussing sensitive sexual, substance use, and adherence-related information) assessed

after individual, potentially stigmatizing provider behaviors are displayed. The dependent variables include several treatment outcomes pertaining to HIV+ patients' decisions to engage in care. Specifically, the present study focuses on patient's intentions to remain in care, intentions to discuss risk behaviors and risk reduction strategies, and actual disclosure of sexual risk behaviors, substance use, and lapses in medication adherence to the provider described in the hypothetical vignettes. What follows is a summary of the aims and the major study hypotheses.

Aim 1: To conduct qualitative research that will help to identify key characteristics of stigmatizing treatment experiences. The first aim of the present study was achieved through the use of three qualitative focus groups, totaling 18 HIV+ men and women, with the aim of determining what elements of patient-provider interactions were perceived to be most stigmatizing. These responses informed the development of vignettes to be used during the validation and experimental phases of the present study.

Aim 2: Validate vignettes depicting stigmatizing and non-stigmatizing treatment interactions. The second aim of the present study was achieved by conducting a small pilot study to examine the validity of the vignettes as depictions of stigmatizing and non-stigmatizing treatment interactions. HIV+ patients ($n = 20$) viewed both of the computerized vignettes, rated their level of psychological comfort (e.g. level of worry, nervousness, etc.) with the featured providers, rated their perceptions of the stigmatizing nature of the vignettes, and also provided verbal feedback to the research assistant about suggestions for improving the vignettes. Revisions to the vignettes would have been based on a lack of statistical differences in psychological comfort and

stigmatization ratings provided for the two vignette conditions, though such revisions were not necessary.

Aim 3: To characterize the association of HIV-related stigmatization to patients' decisions to engage in medical care. A major goal of the present study was to determine whether stigmatization within medical treatment settings affects HIV+ patients' decisions to enroll in HIV care, intentions to communicate openly with their providers about risk and self-care behaviors, and the self-reported disclosure of risky sexual behavior, substance use, and lapses in medication adherence. This aim was achieved by assessing HIV+ patients' reactions to medical treatment vignettes depicting either high levels of provider stigmatization or no stigmatization and their subsequent decisions to engage in various aspects of HIV care. Reactions to the vignette were operationalized as participants' perceptions of stigmatization within the hypothetical patient-provider interaction and their ratings of psychological comfort with the hypothetical provider (generally and in relation to disclosure of sensitive sexual, substance use, and adherence-related information) following the presentation of the patient-provider interaction. Following the presentation of the vignette, participants rated their intentions to enroll in care, and their intentions to engage in conversations related to risk behaviors and self care. Participants were also asked to disclose personal risk behaviors related to sexuality, substance use, and lapses in medication adherence. The vignette and all study measures were administered via a computer program designed using MediaLab software (Jarvis, 2006).

Hypothesis 1: Impact of provider stigmatization on patient comfort and perceptions of stigmatization within the patient-provider interaction. It was

hypothesized that the presence of provider stigma would lead to lower ratings of patient psychological comfort and higher perceptions of stigmatization within the patient-provider interaction. Specifically, it was hypothesized that patients assigned to the “stigma” treatment vignette would report lower levels of comfort with the provider and increased perceptions of stigmatization within the patient-provider interaction following exposure to stimuli demonstrating various provider behaviors (e.g. eye contact, level of touch, etc.) as compared to those in “non-stigma” condition.

Hypothesis 2: Effects of provider stigmatization on patient engagement in care. It was hypothesized that the presence of provider stigma would lead to lower engagement in HIV medical care. Specifically, it was hypothesized that patients assigned to the “stigma” treatment vignette would report lower intentions to engage in care as compared to those in “non-stigma” conditions. This would be demonstrated by lower intentions to enroll in care and lower intentions to engage in conversations related to risky sexual behaviors, substance use, and medication adherence difficulties. In addition, it was predicted that participants in the “stigma” group would report lower rates of disclosure of actual sexual risk behavior, substance use, and lapses in medication adherence.

Hypothesis 3: Mediating effects of patient comfort and perceptions of stigmatization on engagement in care. It was hypothesized that lower ratings of psychological comfort and higher perceptions of stigma within the patient-provider interaction would lead to lower engagement in HIV medical care. In particular, it was hypothesized that patients reporting lower levels of comfort and higher perceptions of stigma within the patient-provider interaction featured in the vignette would also report

lower willingness to enroll in care, engage in conversations related to risky sexual and substance-related behaviors, discuss medication adherence difficulties, and disclose personal risk behaviors to the provider from their vignettes. Further, it was hypothesized that participants' feelings of comfort and perceptions of stigmatization within the patient-provider interaction would mediate the effect of stigmatization (as operationalized as "stigma" and "non-stigma" randomized conditions) on patients' decisions to engage in care.

Exploratory Aim 1: Examine the impact of previous experiences of provider stigmatization on participants' feelings of psychological comfort, their perceptions of stigmatization within the treatment vignettes, and their decisions to engage in care. An exploratory aim of the study was to test whether participants' previous experiences with provider stigmatization influenced the strength of the relationship between provider stigmatization and participants' subsequent decisions to engage in care. In particular, the present study seeks to clarify whether past negative experiences impact patients' psychological comfort in a treatment setting (as tested using the vignette methodology), their perceptions of patient-provider interactions, and their future decisions to engage in care.

Orientation to Methods, Results, and Discussion Sections

The presentation of the methodology, results, and discussion sections of the present study are organized according to the three phases of the protocol: qualitative focus groups, validation sub-study, and the experimental phase. Hence, descriptions of the major aims, participants, measures, procedures, analytic strategy, results, and discussion are first presented for Phase 1, followed by separate methodology and

results/discussion sections for Phase 2, and finally those for Phase 3. Detailed recruiting procedures are noted in the description of Phase 1.

Phase 1: Qualitative Focus Groups

The major aim of Phase 1 was to conduct qualitative research that would help to identify key characteristics of stigmatizing treatment experiences. Participant responses would inform the development of vignettes to be used during the validation and experimental phases of the present study.

Methods

Participants. Eighteen HIV+ male and female adults were recruited during outpatient medical visits at the University Hospital Outpatient Infectious Disease (ID) Clinic, a teaching hospital affiliated with State University of New York (SUNY) Upstate Medical University. University Hospital is a Designated AIDS Care center providing outpatient and inpatient medical care for HIV infected people from the 15 county Central New York area, with an active outpatient population of approximately 785 HIV+ patients. Women and individuals from minority groups were included in this study. One third of the sample ($n=6$) was comprised of women, 61% were African American, 22% were Caucasian, and among men, 66% identified as men who have sex with men (MSM). Three focus groups (6 participants each) were conducted.

Measures.

Background characteristics and health history. Demographic and medical history data were collected to characterize the sample (See Appendix A). Demographic questions were assessed using standard questions developed in previous research with the population. Because health-related factors may relate to participants' willingness to

engage in HIV care, patients also reported on several health indicator variables including viral load and CD4+ counts at last clinic visit, presence of AIDS diagnosis, time since HIV infection, and current medications.

Qualitative interview. A qualitative interview guide was utilized to facilitate discussion for three focus groups. Each focus group lasted approximately two hours. Focus group content pertained to participants' experiences of HIV-related stigmatization within healthcare settings, positive experiences with providers, and suggestions for improving HIV-related healthcare experiences. Further details of the interview process are included in the procedures section.

Procedures.

Recruitment. For all phases of the study, the principal investigator (PI) worked in collaboration with staff at the Infectious Disease Clinic to recruit HIV+ patients during routine visits. A designated health care provider (e.g., triage nurse) informed patients about the opportunity to participate in the study and obtained verbal assent from patients regarding their willingness to be introduced to the PI. Patients who provided oral assent (to meet with the research staff) were then introduced to the PI or research assistant who provided a description of the study. The study description stated that the purpose of the research was to identify what medical provider behaviors are perceived as stigmatizing by HIV+ patients and to gain a better understanding of how providers' behaviors can affect the care of HIV+ patients. Eligibility for the all phases of the study was limited to those who were HIV+, at least 18 years of age, English-speaking, and physically and psychologically capable of providing informed consent as determined by treatment providers.

Study protocol. After the initial meeting with the PI, qualitative focus group participants were informed of the time, date, and location of the focus groups and scheduled accordingly. Upon arriving for the focus group, participants were again given a thorough description of the requirements, risks, benefits, and confidentiality protections of the study, as outlined in the qualitative interview protocol (See Appendix C). Participants were then asked to sign consent forms (See Appendix D), complete a brief demographics sheet (See Appendix A), and participate in a two-hour discussion group. After the completion of the group, participants were compensated \$20 for their time, and signed a receipt (Appendix E) before leaving the lab.

Data collection. At the time of the focus group, the facilitator first provided an overview of the focus group procedures and provided an overview of the consent form. After participants provided informed consent, they completed a brief demographics survey. Then, the focus group began with initial introductions of group members and the facilitators (PI and additional graduate student assistant).

Next, the facilitator initiated the focus group by asking a series of questions designed to prompt a discussion about both stigmatizing experiences in medical treatment settings, as well as and positive experiences interactions with medical providers (See Appendix B). Participants were first asked about any negative experiences they have had in medical care, with respect to the providers' behaviors, the participant's subsequent feelings, and their perceptions about why they were treated poorly. After this introduction to negative treatment experiences, participants were asked more specifically about experiences of provider stigmatization. They were questioned about what they perceive stigmatization to be and also given a definition consistent with how it has been previously

defined in research to help direct discussions. Initial questions were open-ended, asking participants to report on treatment experiences (early and more recent) they found to be stigmatizing. Facilitators asked follow-up questions to clarify (1) what aspects of the provider interaction were stigmatizing and (2) how the participant came to attribute the negative behaviors to HIV-related stigmatization (vs. racial stigma, poor social skills, poor medical skills, etc.). Following the open discussion of stigmatizing and positive provider interactions, facilitators inquired about provider behaviors reported by HIV+ individuals in previous studies but not yet mentioned by the present study's participants (e.g. eye contact, distance, etc.). Subsequent questions prompted discussions surrounding HIV+ participants' perceptions of the emotional, social, and treatment-related effects of experiencing stigmatization from a healthcare provider. Closing discussions explored participants' ideas for improved interactions with medical providers and obtain feedback about their participation in the focus group.

Qualitative data synthesis. Each focus group was audio-taped and reviewed several times by the principal investigator, with extensive notes taken upon each review. The process of data synthesis entailed the PI completing an open-coding of the detailed notes to capture maximum detail and complexity in the data. The focus group interview guide topics served as the initial framework upon which the coding classification scheme was derived, with additional topics pertinent to stigmatizing treatment experiences that emerged during the focus groups being added to the classification scheme. Coding was structured to differentiate stigmatizing treatment experiences related to provider's overt behaviors, treatment practices, demeanor, and language, as well as document the commonality of patient experiences and the relative frequency of which they occurred.

Results and Discussion

Focus group participants reported a variety of stigmatizing experiences, including those related to provider demeanor, as well as more serious instances of stigmatization related to provision of care. As shown in Table 3, the most frequently reported experiences of provider stigmatization were related to judgmental language and avoidance and distancing within the exam room, with 56% and 44% of focus group participants ($n = 18$) reporting such instances respectively. In one instance, a female participant who had sought treatment for chest pain reported that upon disclosure of her HIV status to a hospital nurse, “Her demeanor changed. She was less friendly and ignored me. I was left hooked up to an EKG machine for three hours. My boyfriend had to search the hospital to get someone to help me.” Participants frequently reported being blamed for their HIV infection, with providers also making assumptions about the way they became infected and speaking to them in condescending manners. One female participant noted that when she disclosed her status, a nurse responded, “Well, you shouldn’t be out on the street messing around.” Many participants also reported instances in which their providers stood far away from them in the exam room and also tried to touch them as little as possible during examination procedures like taking blood pressure, using a stethoscope, and taking their temperature. Approximately one-third of participants (28%) also reported that their providers demonstrated awkward, uncomfortable, or nervous body language while treating them or upon finding out that they were HIV+. For example, one participant noted that upon disclosing his status, his provider appeared “more cold and standoffish,” adding that “he couldn’t maintain eye contact with me.”

Though noted less frequently, participants also reported instances in which providers took unnecessary precautions while treating them (22%), provided a lower standard of care because of the participants' HIV status (22%), ignored the patients' symptoms because they were HIV+ (22%), and demonstrated a lack of knowledge in HIV-related treatment issues (22%). For example, several participants reported providers wearing masks in the exam room during routine check-ups, with one participant reporting that his physician put on two pairs of gloves to examine him when he presented with leg pain. Two participants reported instances of being denied care entirely.

Based on these qualitative data, salient and commonly occurring stigmatizing behaviors of providers were identified to inform the development of the treatment vignette content utilized in the validity and experimental phases of the protocol. Audio and visual stimuli were created based on these identified experiences with consideration for the frequency of such occurrences and the capabilities of reproducing such experiences via the audio and visual design of the study's experimental manipulation.

Phase 2: Validation Sub-study

The major goal of this small validity sub-study was to validate the present study's treatment vignettes depicting stigmatizing and non-stigmatizing patient provider interactions. This goal was accomplished by first creating the vignettes and then completing a small pilot study to confirm whether they were believable and adequately depicted stigmatizing and non-stigmatizing treatment experiences.

A second goal of the validity sub-study was to examine the feasibility and utility of using a "short-form" vs. a "long-form" version of the computerized questionnaire. In the "short-form" version, the four segments (audio and associated pictures) of the

treatment vignettes were presented together, with each segment being presented immediately following the preceding segment. Measures of patient comfort and perceptions of stigma were presented once following the presentation of the final vignette segment. In the “long-form” version, the four segments of the treatment segments were presented individually (one at a time), with measures of patient comfort and perceptions of stigma being presented after each vignette segment for a total of four presentations of such items. Statistical analyses were conducted to determine whether there were significant differences in comfort and stigma ratings between short and long form versions. If no differences emerged, this would provide justification for using the time-efficient “short-form” presentation.

Methods

Participants. Twenty HIV+ male and female adults were recruited during outpatient medical visits at the University Hospital Outpatient Infectious Disease (ID) Clinic for the validity sub-study phase of the present research. Seventy percent of the sample was male, 55% identified as Caucasian, 35% identified as African American, 70% were unemployed, 30% had an AIDS diagnosis, and 85% were on a HAART medication regimen.

Measures.

Background characteristics and health history. Demographic and medical history data were collected in order to characterize our sample (See Appendix A). Demographic questions were assessed using standard questions developed in previous research with the population. Because health-related factors may relate to participants’ willingness to engage in HIV care, patients also reported on several health indicator

variables including viral load and CD4+ counts at last clinic visit, presence of AIDS diagnosis, time since HIV infection, and current medications.

Patient comfort. HIV+ patients' level of psychological comfort within the hypothetical treatment interaction was assessed by a brief measure of psychological patient comfort developed by Spake et al. (2003). This eight item measure has good internal consistency and has previously been used to predict patients' intentions to remain in care with their physicians (Spake & Bishop, 2009). Alpha in the current sample was approximately .95 across the experimental "stigma" and "non-stigma" vignettes and short and long form versions of the validity study questionnaire program. Participants were asked to rate their feelings within the patient-provider relationship depicted in the vignette along eight related dimensions, including discomfort-comfort, uneasiness-at ease, tense-relaxed, worried-worry free. Although the original measure was rated on a 10-point dimensional scale, the present study utilized a 7-point dimensional scale to be consistent with other study measures (See Appendix F). In addition, a more specific assessment of comfort related to engaging in conversations about sexual risk behaviors, substance use, and adherence difficulties was completed at the close of the vignette presentation (See Appendix F). Participants were asked (via ACASI) to imagine themselves as the patient depicted in the vignette and respond to the psychological comfort items. For example: "Please imagine that you are the patient portrayed in this vignette. Now rate how you feel interacting with this provider in terms of feeling comfortable. Now rate how you feel interacting with this provider in terms of feeling worried."

Responses were rated using a 7-point Likert scale ranging from 1 (extremely uncomfortable, extremely worried) to 7 (extremely comfortable, extremely worry free). These items were presented to participants completing the “long-form” version four times, immediately following the presentation of each of the four segments of the hypothetical medical visit. Participants completing the “short-form” version completed this measure once following the presentation of the final vignette segment. Each segment of the treatment vignette featured one or two provider behaviors being manipulated across the two stigma conditions (e.g. eye contact, lack of touch, judgmental language). After the vignette presentation, participants completing both the short and long form version responded to three additional comfort items pertaining specifically to comfort in engaging in conversations with the vignette provider about (1) sexual risk behaviors, (2) substance use, and (3) medication adherence-related issues. For the purposes of the present validation study, summed psychological comfort ratings (Spake et al., 2003) and ratings on individual conversation-related comfort items were treated as separate dependent variables.

Perceptions of provider devaluation. HIV+ patients’ perceptions of the stigmatizing and devaluing nature of the hypothetical treatment interaction were assessed following their ratings of psychological comfort (See Appendix F). These items were presented to the participants completing the “long-form” version four times, immediately following the presentation of each of the four segments of the hypothetical medical visit. Participants completing the “short-form” version completed this measure once following the presentation of the final vignette segment. Nine items were created by the PI to reflect reactions to and perceptions of the treatment interaction as related to the experience of

being devalued (a defining characteristic of stigmatization). As defined by Crocker, Major, and Steele (1998), a stigmatized person is one whose social identity calls into question their humanity, such that the person is devalued, spoiled or flawed in the eyes of society. In essence, people who are stigmatized are no longer viewed as individuals, but as mere representatives of a particular socially identified and devalued group, and, consequently, are assumed to possess many or all of the characteristics associated with that group. Items created by the PI reflect these concepts.

Participants were asked to imagine that they were the patient in the vignette and respond via ACASI to such items as: “I felt devalued by this provider,” “I believe this provider made negative judgments about me,” and “I believe this provider was comfortable treating me.” Scale ratings reflect a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). For the purposes of the validation study, the sum score of devaluation ratings were treated as the dependent variables of interest. The psychometric properties of this measure were examined in terms of its internal consistency, with the measure having an alpha of approximately .75 across the experimental “stigma” and “non-stigma” vignettes and short and long form versions of the validity study questionnaire program.

Procedures.

Recruitment. Recruitment procedures are described in Phase 1 methodology.

Experimental manipulation of provider stigmatization: Patient-provider interaction vignettes. A description of the present study’s vignettes depicting stigmatizing and non-stigmatizing patient-provider interaction is outlined in the following subsections, detailing the technology utilized to present the vignettes, the content of the

vignettes, and the format of the vignettes in terms of how they were presented to the participants.

Technology utilized. MediaLab software (Jarvis, 2006) was used to create a computer program that (1) presented the visual and audio elements of the patient-provider interaction vignettes, as well as (2) provided a computerized assessment of the study's independent and outcome measures of interest. MediaLab offers a flexible programming framework for integrating assessments and experimental content from a variety of media formats (e.g., video, audio, PowerPoint, questionnaires). The PI is experienced in MediaLab software (Jarvis, 2006) programming, having completed prior research utilizing a computerized, hypothetical vignette design (Heath & Venable, 2009).

Vignette content. Creation of the treatment vignettes for the validation and experimental phase of the study was informed by the qualitative focus groups that were tasked with identifying key elements of provider behaviors that have been experienced by HIV+ patients and were considered to be stigmatizing. Based on these findings, and a thorough review of prior qualitative and quantitative provider stigmatization research, medical visit vignettes incorporated varying levels of the provider's use of judgmental language, spatial proximity, eye contact, negative affect and discomfort, lack of touch, respect for confidentiality, and avoidance. The PI also consulted with providers (mostly nurse practitioners) at the Infectious Disease Clinic for additional input regarding the structure and content of typical, first-time medical appointments (e.g. questions asked, procedures completed, length of interactions, etc.).

Prior to the presentation of the vignettes, participants were instructed (via audio recordings presented on the computer) to imagine that they were the patient depicted in

the interaction on the screen. They were asked to take in their surroundings, imagine themselves sitting on the exam table, and focus on the thoughts and feelings that they might be having. They were informed of the premise of the medical appointment, which was described as involving a first time appointment following a move to a new city. They were told that although the doctor has the patient's previous treatment records, he or she plans to discuss some of the information for verification and clarification of certain details. They were informed that the doctor was very competent in treating HIV+ patients and had been practicing at the clinic for several years. After this preliminary information was presented to the participants, the presentation of the vignette began.

The basic elements of the medical appointment scenario proceeded as follows: (1) provider enters room and greets patient, (2) provider chooses a location in the room to sit, (3) provider asks about general health and well-being, (4) provider refers to patient's chart and asks about information related to means of transmission (e.g. male-to-male sexual contact, male-to-female sexual contact, IV drug use, etc.), recent illnesses and procedures, and HIV status indicators (CD4 count, viral load), (5) patient and provider discuss medication options, (6) provider does brief physical exam on patient (checks heart beat and breathing, examines ears and throat, etc.), (7) provider discusses recent headache symptoms with patient, (8) provider summarizes findings to patient and outlines treatment plan, (9) provider exits room and returns with headache medications, (10) provider returns and alerts patient that they will be asked several questions related to sexual risk behaviors and substance use.

Throughout the hypothetical treatment visit, specific elements related to provider demeanor and behaviors were manipulated, so as to be presented in either stigmatizing or

non-stigmatizing ways. This was accomplished through modifying the provider's use of judgmental language, spatial proximity, eye contact, negative affect and discomfort, lack of touch, respect for confidentiality, and avoidance. In order to maintain a high level of experimental control, the vignettes were standardized so that (1) the credentials of the provider described in the vignette were the same (i.e. highly competent), (2) the same actors were portrayed in all visual depictions, (3) the same actor's voice was used to portray the provider across conditions, and (4) the flow and content of the treatment visits (e.g. greeting, conversations, procedures) was consistent across conditions. The presentation of the vignette took approximately ten minutes.

Vignette format. Vignettes incorporated photographs of a hypothetical medical provider and audio voice recordings to demonstrate varying levels of stigmatization within the treatment visit. Photographs and audio recordings for stigmatizing and non-stigmatizing treatment vignettes differed in terms of the provider's use of judgmental language, spatial proximity, eye contact, negative affect and discomfort, lack of touch, respect for confidentiality, and avoidance. Audio recordings were also used to narrate the hypothetical patient-provider interactions, providing step-by-step descriptions of the providers' behaviors throughout the medical visit. Additional audio recordings were used to simulate patient-provider discussions, with actors portraying the voices of the patient and the provider. Voices for the narrator were provided by the PI, with voices for the patient and provider provided by several student actors chosen based on their appropriateness for the roles. Both male and female patient versions were created to increase participants' ability to identify with hypothetical patient. Photographs of the manipulated provider behaviors were taken by the PI using a high quality digital camera.

Photos of an older student actor (age 30 or older) were used for the vignettes. Photos depicted a hypothetical provider engaging in various aspects of the outlined vignette scenario in an actual medical examination room to increase believability of the interactions. Photographs were presented simultaneously with the corresponding audio description of the treatment visit to provide visual representations of the potentially stigmatizing provider actions.

The treatment vignettes of the patient-provider interactions within the medical care visit were presented in four segments, with each segment presenting one or two provider behaviors such as eye contact (or lack thereof), judgmental language regarding HIV status (or more non-judgmental statements), and placing oneself across the room from the patient (as compared to choosing the seat nearest them). Figures 3, 4, 5, and 6 provide illustrative examples of how the “stigma” and “non-stigma” vignette segments were arranged in the long and short form versions of the program. Though these figures are not meant to be exact representations of the visual or audio content of the actual study vignettes, they provide an example of the intended general layout and nature of the treatment vignettes. The “stigma” condition featured stigmatizing behaviors in all four segments and the “non-stigma” condition featured no stigmatizing behaviors in all of the segments.

Study protocol. After the initial meeting with the PI, validity phase participants either followed the investigator to the assigned lab space and immediately completed the study protocol (after clinic visit) or were informed of available times and dates and scheduled accordingly. Upon arriving for the validity phase of the study, participants were greeted by the PI who followed protocol procedures (See Appendix G) and

provided a thorough description of the study via the informed consent procedures (See Appendix H). The validity phase stimuli and questionnaire battery were administered using audio computer-assisted self-interviewing (ACASI) on a desktop computer. Before beginning, the PI introduced the computerized study protocol and described how the computer program works. The PI answered questions the participant had and confirmed the participant's ability to successfully interact with the computer program. For participants with limited computer exposure, the PI provided additional instruction on the use of the mouse and keyboard as necessary. Participants were also instructed that if they had any difficulties with the computer program to ring a bell on the desk and the PI would assist them.

After completing consent procedures and filling out a brief demographics questionnaire (see Appendix A), participants viewed both the "stigma" and "non-stigma" vignettes on a computer. The ordering of the vignettes was randomized. Participants in the "long form" version of the survey rated their level of comfort (e.g. level of worry, nervousness, etc.) with the provider and how stigmatizing they perceived the vignette interaction to be after each of the four segments of a vignette, via a questionnaire presented on the computer (See Appendix F). Participants completing the "short-form" version provided ratings for comfort and perceptions of stigmatization once, immediately following the presentation of the fourth vignette segment. Following the presentation of both vignettes, participants engaged in a brief discussion with the PI regarding their reactions to the vignettes. The discussion assessed whether the "stigma" vignette segments were perceived to be adequately stigmatizing by the participant and if they were distinguishable enough from the "non-stigma" vignette segments. Suggestions for

improving the vignettes were elicited from the participants. After completing this protocol, participants were compensated \$10.

Analytic strategy. Analyses for the validity sub-study consisted of both between-subjects and within-subjects t-tests to evaluate differences between ratings for the “stigma” and “non-stigma” vignettes. Between-subjects t-tests evaluated potential differences in psychological comfort and stigmatization ratings between persons viewing the “stigma” vignette first and persons viewing the “non-stigma” vignette first. Within-subjects t-tests evaluated participants’ ratings of comfort and perceptions of stigmatization on the “stigma” vignette as compared to their ratings on the “non-stigma” vignette. The potential effect of presentation order of the vignettes was also examined. All analyses were performed on averaged comfort and stigmatization ratings, with “long-form” responses averaged across vignette segments to compare with “short-form” responses. There was an expectation of significant differences in psychological comfort and stigmatization ratings between the stigmatizing and non-stigmatizing manipulations. It was also expected that there would not be any statistical differences between comfort and stigma scores between short and long form versions.

Results and Discussion

Significant differences in perceptions of stigmatization and comfort ratings were found when comparing participant responses to the “stigma” and “non-stigma” vignettes when using both the short and long form survey formats (see Table 3). Results from t-tests also indicated no significant order effects of the presentation of the vignettes, nor any significant differences between stigma and comfort ratings when comparing long and short form versions of the survey (see Table 3). These latter results provide support for

the use of the more time-efficient and participant-favored (via verbal feedback) “short form” survey protocol in the experimental phase of this study. Overall, findings support the use of the vignettes as a valid experimental manipulation of HIV-related stigmatization within a medical treatment setting, as the provider in the “stigma” vignette was rated as more stigmatizing/devaluing of his patients and found to induce lower feelings of comfort within the treatment setting. As such, no changes were made to the content of the vignettes for the experimental phase of the study.

Phase 3: Experimental Study

The major goal of the experimental phase of the present study was to determine whether stigmatization within medical treatment settings affects HIV+ patients’ decisions to engage in HIV care and communicate openly with their providers about risk and self-care behaviors such as unprotected sex, drug use, and medication adherence. This goal was achieved by assessing HIV+ patients’ reactions to medical treatment vignettes depicting either high levels of provider stigmatization or no stigmatization and their subsequent decisions to engage in various aspects of HIV care.

Methods

Participants. Ninety HIV+ male and female adults were recruited during outpatient medical visits at the University Hospital Outpatient Infectious Disease (ID) Clinic for the experimental phase of the present research. Cell sizes between conditions were equal, with 45 participants randomized to the “stigma” condition (29 males, 16 females) and 45 participants randomized to the “non-stigma” condition (29 males, 16 females). Of the experimental phase participants, 34.4% were female, 69% of males identified as MSM, 52% were African American, 71% were unemployed, 22.2% held an

AIDS diagnosis, and 83.3% were on a HAART medication regimen. The complete demographic characteristics of the experimental sample can be found in Table 5.

Measures.

Background characteristics and health history. Demographic questions were assessed using standard questions developed in previous research with the population (See Appendix A). Because health-related factors may relate to participants' willingness to engage in HIV care, patients also reported on several health indicator variables, including viral load and CD4+ counts at last clinic visit, presence of AIDS diagnosis, time since HIV infection, and current medications.

Previous HIV-related stigmatization experiences. Past research suggests that HIV+ persons may be more alert to potential threats, hyperaware of people's treatment toward them, and potentially more likely to label neutral behavior as stigmatizing (Chapman, 2002; Frable, Blackstone, & Scherbaum, 1990). It stands to reason that the risk of these appraisals may be heightened if an HIV+ individual has experienced previous instances of stigmatization in a healthcare setting. As such, an original measure assessing previous experiences with provider HIV-related stigmatization was included in the present study to include as a possible covariate or moderator in the model (See Appendix I). Fifteen items assessed the number of times the participant had experienced various types of stigmatizing experiences while in a healthcare treatment setting. The measure contains items related to more demeanor-based aspects of HIV-related stigmatization (e.g. lessened eye contact, judgmental language, discomfort), as well as stigmatizing behaviors related to the provision of care (e.g. avoidance, differential care, refusal of treatment). This measure was presented at the end of the study, and participants

reported how many times they have experienced each stigma item as based on a five point rating scale ranging from 0 (never) to 4 (more than 10 times). The measure was created following a review of the relevant qualitative and quantitative provider stigmatization literature and was evaluated in terms of internal consistency (Chronbach's alpha), individual item performance, and factor structure (via exploratory factor analyses) following data collection. Factor analyses indicated that the scale performed well as a single factor measure, with the model accounting for 57% of the variance explained. This measure also demonstrated strong internal consistency with an alpha of .91.

Patient comfort. HIV+ patients' level of psychological comfort was assessed following the presentation of the vignette by a measure of psychological patient comfort developed by Spake et al. (2003). Further detail about this eight item measure is provided in the validity phase methodology. Participants were asked (via ACASI) to imagine themselves as the patient depicted in the vignette and respond to the comfort items. These items were presented to the participants once, immediately following the presentation of the final segment of the hypothetical medical visit. Factor analyses indicated that the scale performed well as a single factor measure, with the model accounting for 89% of the variance explained. This measure also demonstrated strong internal consistency with an alpha of .95. In addition, a more specific assessment of comfort related to engaging in conversations about sexual risk behaviors, substance use, and adherence difficulties was also completed at the close of the vignette presentation. For the purposes of the experimental study, both a composite score of comfort ratings (Spake et al., 2003) and individual conversation-related (sexual behavior, substance use, adherence difficulties) comfort items were examined as mediator variables of interest.

Perceptions of stigmatization within the patient-provider interaction.

Perceptions of stigmatization within the hypothetical treatment interaction were assessed in two ways (See Appendix K). First, the measure of devaluation that was developed for the validity phase of the present study was used (see validity phase methodology for detailed description). As described earlier, this subscale consists of nine items (rated on 7-point Likert scale) created to reflect reactions to and perceptions of the treatment interaction as related to the specific experience of being devalued (a defining characteristic of stigmatization). Participants were asked to imagine that they are the patient in the vignette and respond to the items via ACASI.

The second way that perceptions of stigmatization was assessed was through an adaptation of the 13-item Engagement with Health Care Providers scale (Bakken, et al., 2000), with modifications to accommodate the experimental nature of the present study. Items from this subscale focus on participants' perceptions of the patient-provider relationship. The original scale has strong internal consistency and has been successfully used with HIV+ patient populations (Bakken, et al., 2000; Metsch, et al., 2008). Items were modified to assess participants' beliefs about the future actions of the hypothetical providers and nature of the patient-provider relationship presented in the vignettes (e.g. "I believe this provider would involve me in treatment decisions."), rather than assess the current nature of their patient-provider interactions (e.g. "My provider involves me in treatment decisions.") as indicated in the original scale. Examples of additional items include: "I believe this provider would respect me," "I believe this provider would care about me," and "I believe this provider would see me when I ask." Scale ratings reflect a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree).

The psychometric properties of the entire perceptions of stigmatization measure were examined in terms of its internal consistency (e.g. Chronbach's alpha) and factor structure via exploratory factor analyses. The factor structure of the entire perceptions of stigmatization measure was examined to determine whether the measure in its entirety or its potential subscales should be treated as mediator variables in the planned analyses. Contrary to original expectations, factor analyses indicated that the scale performed well as a single factor measure, with the model accounting for 77% of the variance explained. This measure also demonstrated strong internal consistency with an alpha of .96.

Engagement in care. HIV+ patients' engagement in care was assessed using several brief measures created specifically for this study (See Appendix L). Engagement in care measures served as the primary dependent variables of interest and were assessed using two types of items: (1) those that assessed a participant's *intentions* to engage in various aspects of care, and items that assessed (2) participants' *disclosure* of actual risk behaviors. Participants' intentions to engage in care were operationalized as participants' intentions to (1) remain in care with the provider portrayed in the vignette, (2) discuss sexual risk behaviors with the provider, (3) discuss substance use with the provider, and (4) discuss medication adherence difficulties with the provider. These items were worded to assess the likelihood of participants engaging in these various treatment activities and will be rated on a 7-point Likert scale ranging from 1 (extremely unlikely) to 7 (extremely likely). Assessment of actual patient disclosure included nine items pertaining to (1) sexual risk behavior, (2) substance use, and (3) lapses in medication adherence. Items required participants to report the frequency in which they have actually engaged in various risk behaviors.

An assessment approach based on patients' *intentions* to engage in care and openly communicate with their providers about risky behaviors was utilized to allow for a larger pool of responses from the sample. As some participants may not engage in the various risk behaviors assessed in the present study, items were worded in terms of their intentions to disclose in the hypothetical event that these behaviors had occurred (e.g. "In the event that you happened to engage in X, how likely is it that you would disclose this to the provider?"). Although the more direct assessment of disclosure (e.g. having the participant choose whether to actually disclose their own risky behavior to the hypothetical provider) has greater external validity, such an approach could potentially be limited by the number of participants in the sample who had actually engaged in the behavior of interest. As such, it was deemed important to include both an intentions-based measure of disclosure and a more direct assessment of patient disclosure following a potentially stigmatizing treatment experience. The psychometric properties of all engagement in care measures were examined to assure their internal consistency (e.g. Chronbach's alpha).

Intentions to remain in care. Participants' intentions to remain in care with the provider shown in the vignette was assessed with the single item, "How likely is it that you would remain in care with this provider?" and measured on a 7-point Likert scale.

Intentions to discuss sexual risk behaviors. Intentions to discuss sexual risk behaviors included items related to disclosing unprotected anal/vaginal sex with a steady partner of HIV- or unknown serostatus (historically vs. occurrences within the past three months), disclosing unprotected anal/vaginal sex with a casual partner of HIV- or unknown serostatus (historically vs. occurrences within the past three months), and also

initiating a conversation about difficulties achieving and maintaining safer sex practices. The decision to use the three month point as the cut off for “recent” sexual experiences is based on several findings supporting the reliability of self reports of sexual risk behaviors measured at this time frame (Carey et al., 2001; Jaccard et al., 2002; Kauth, St. Lawrence, & Kelly, 1991). As actual sexual risk behaviors were assessed later in the study, items assessing intentions to disclose sexual behaviors were also based on the three month time frame for the purpose of item consistency. Items were worded in terms of their willingness to disclose as based on the hypothetical event that these behaviors had occurred (e.g. “In the event that you happened to have unprotected anal sex, how likely is it that you would disclose this to the provider?). These items were rated on a 7-point Likert scale ranging from 1 (extremely unlikely) to 7 (extremely likely). This measure demonstrated strong internal consistency with an alpha of .95.

Intentions to discuss substance use risk behaviors. Intentions to discuss substance use risk behaviors included items related to disclosing substance abuse and dependence (historical vs. recent, alcohol vs. other drugs), disclosing needle sharing, and initiating conversations about seeking substance use treatment. Similar to the sexual risk items, intentions to disclose substance use were based on a three month time frame to distinguish intentions to disclose “recent” vs. “historical” occurrences of risk behavior. As some participants may not have engaged in these substance use risk behaviors, items were worded in terms of their intentions to disclose based on the hypothetical event that these behaviors had occurred (e.g. “In the event that you happened to have shared needles during drug use, how likely is it that you would disclose this to the provider?). These items will be rated on a 7-point Likert scale ranging from 1 (extremely unlikely) to 7

(extremely likely). This measure demonstrated strong internal consistency with an alpha of .97.

Intentions to discuss medication adherence difficulties. Intentions to discuss medication adherence difficulties included items related to disclosure of unintentional non-adherence to HAART (e.g. forgetting, misplacing medications, sleeping through doses), disclosure of intentional non-adherence to HAART (e.g. purposely skipping doses, medication vacations, taking meds not as prescribed), and initiating conversations related to difficulties with medication adherence. Similar to the other risk items, intentions to disclose adherence difficulties were based on a three month time frame to distinguish willingness to disclose “recent” vs. “historical” lapses in medication adherence. Items were worded in terms of their intentions to disclose, presuming that these behaviors had occurred (e.g. “In the event that you happened to skip taking your medications, how likely is it that you would disclose this to the provider?). These items will be rated on a 7-point Likert scale ranging from 1 (extremely unlikely) to 7 (extremely likely). This measure demonstrated strong internal consistency with an alpha of .96.

Disclosure of health risk behaviors. In contrast to the aforementioned outcome variables, items assessing disclosure of health risk behavior assessed the participants’ willingness to disclose their actual sexual and substance use related risk behaviors, as well as lapses in medication adherence. This measurement domain included nine items that assessed the participants’ history of risk behaviors and was designed to closely represent the types of risk assessment questions that a provider typically asks during a routine medical treatment visit in terms of content, specificity, and quantity (See

Appendix L). Items were read to the participants in the voice of the provider (neutral tone) in order to mimic as closely as possible what it would be like to disclose sensitive information to the provider they viewed in the treatment vignette.

Three items assessed history of *sexual risk behavior*, including number of lifetime sexual partners, number of partners in past three months, and percentage of time in which condoms were used in the past three months.

Four items assessed history of *substance use*, including two alcohol use items assessing quantity and frequency of use in past three months (Quantity Frequency method), one item providing a basic assessment of lifetime drug use, and one item assessing frequency of drug use in the past three months.

Two items were used to assess *lapses in HIV medication adherence*, with one item assessing how long ago a dose of medication was purposely skipped, and another item assessing the total percentage of HAART doses taken in the previous week.

Other than items related to sexual partner history, disclosure items provided participants with categorical, ordered response choices to identify frequency of condom use, alcoholic consumption, and missed medication doses, typically on a five point scale. The rationale for using a categorical response format was to control for participant error in item interpretation, subsequent errors when entering responses, and to eliminate the need to handle extreme outlier responses in data analyses. As some items assessed for typical behaviors across a time period, categorical responses allow participants to report *ranges* of behaviors, that may be more accurate representations of their activities (vs. having to choose one number). Although participants will not see the assigned score of their response (e.g. 3-4 alcoholic drinks in one week = 2, more than 6 drinks in one week

= 4), these scores were used to describe a basic, relative level of risk present in their behaviors. Sexual behavior items related to lifetime and recent number of sexual partners were presented in open-response format to allow for the large range of sexual partner experiences expected in the clinical participant population, rather than estimate and determine meaningful cutoffs for categorical responses.

Responses to personal disclosure items were examined individually rather than via composite variables after discovering the poor internal consistency of the potential subscales. Higher scores on all items were conceptualized to represent increased willingness to disclose risk behaviors, rather than actual differences in risk behaviors between the stigma and non-stigma experimental groups. This conceptualization was based on the assumption that randomization would control for behavioral differences between the experimental groups, thus allowing any significant differences in the quantity or frequency of reported risk behaviors between groups to be attributed to the effects of stigmatization on participants' willingness to disclose sensitive information. All measures assessing HIV+ patients' decisions to engage in care were presented via ACASI, following the complete presentation of the treatment vignettes and the measures of patient psychological comfort and perceptions of the patient-provider relationship.

Procedures.

Recruitment. Recruitment procedures are described in Phase 1 methodology.

Experimental manipulation of provider stigmatization. Provider stigmatization was operationalized as varying levels of stigmatizing demeanor and treatment behaviors presented to HIV+ participants through the use of hypothetical vignettes. Vignettes of hypothetical HIV medical care visits incorporated visual and audio stimuli and were

presented to participants via a computer screen (for further description of vignettes, refer to validity sub-study methodology). Patient-provider interactions in the vignettes were manipulated to portray two experimental conditions: “stigma” and “no stigma.” As noted previously, the vignettes used in the experimental phase of the present study were reviewed by HIV+ patients in the validity sub-study and found to accurately depict stigmatizing and non-stigmatizing patient-provider interactions. Scripts for these vignettes can be found in Appendix M. As a between-subjects study, participants in the experimental phase were randomized to a condition and viewed only one treatment vignette. To maintain a high level of experimental control, the vignettes (stigma and no stigma conditions) were standardized so that (1) the credentials of the provider described in the vignette were the same (i.e. highly competent), (2) the same actor was portrayed in all visual depictions, (3) the same actor’s voice was used to portray the provider across conditions, and (4) the flow and content of the treatment visits (e.g. greeting, conversations, procedures) was consistent across conditions. The “stigma” condition featured stigmatizing behaviors in all four segments and the “non-stigma” condition featured zero stigmatizing behaviors in all of the segments. For further illustration of the presentation of the vignette segments, see Figures 3, 4, 5 and 6.

Study protocol. After the initial meeting with the PI, experimental phase participants either followed the investigator to the assigned lab space and immediately complete the study protocol (after clinic visit) or were informed of available times and dates and scheduled accordingly. Upon arrival, participants were greeted by the PI who followed protocol procedures (See Appendix N) and provided a thorough description of the study via the informed consent procedures (See Appendix O). The experimental

stimuli and questionnaire battery were administered using audio computer-assisted self-interviewing (ACASI) on a desktop computer. Because ACASI affords greater privacy over traditional paper and pencil questionnaires and interviewer administered surveys, ACASI may have enhanced participants' willingness to disclose sensitive information (Schroder, Carey, & Venable, 2003). Similar to the validity sub-study, the PI first introduced the computerized study protocol, described how the computer program works, answered any questions the participant had, and ensured the participant's ability to successfully interact with the computer program. For participants with limited computer exposure, the PI provided additional instruction on the use of the mouse and keyboard as necessary. Participants were also instructed that if they had any difficulties with the computer program to ring a bell on the desk and the PI would assist them. Participants then completed the small battery of self-report assessments (e.g. demographics, health-related variables) and responded to one treatment vignette as depicted on the computer through visual and audio components. The ordering of the protocol was as follows: (1) reporting of background and health information, (2) presentation of the treatment vignette with, (3) ratings of psychological comfort, (4) ratings of perceptions of stigmatization within the hypothetical patient-provider interaction, (5) ratings on measures assessing decisions to engage in care, and (6) ratings on the Experiences of HIV-related Stigmatization in Healthcare Settings measure. After completing this protocol, participants were compensated \$20 for approximately 45 minutes to one hour of their time and signed a receipt.

Experimental phase analyses.

Descriptive and preliminary analyses. The full sample was described using summary statistics (frequency, mean, standard deviation) obtained from self-reported demographic information, health status variables (i.e., AIDS diagnosis, HIV-related hospitalizations), medical history variables (initiation of HAART, time elapsed since diagnosis), and past experiences of HIV-related stigmatization in healthcare settings. Summary statistics were also generated for the proposed mediating and outcome variables of interest (i.e., perceptions of patient-provider relationship, psychological comfort, intentions to enroll in care, intentions to disclose sexual and substance use risk behaviors, intentions to discuss medication adherence difficulties, and actual disclosure of personal risk behaviors). Finally, analyses pertaining to measure reliability and factor structure were performed to ensure strong internal consistency of the proposed mediators and dependent variables, with particular attention paid to the newly created measures.

Equivalency between study conditions. To assess for equivalence between the “stigma” and “non-stigma” vignette conditions, separate ANOVA and Chi-square analyses were performed on demographic variables, health status variables, and the measure of past stigmatizing experiences reported during the experimental phase protocol. Non-significant findings would indicate that the randomization procedure was successful. Any significant differences in demographic, health status, or past stigma characteristics between the conditions would be considered as additional covariates in analyses examining primary study hypotheses.

Analyses for aim 3: To characterize the association of HIV-related stigmatization to patients’ decisions to engage in medical care. First, bivariate analyses

were conducted to identify the association between mediators (perceptions of patient-provider relationship and level of comfort), dependent variables (treatment engagement measures), and relevant demographic, health status, past stigma experiences, and medical history variables to identify potential covariates and moderators for the mediational model. To examine study hypotheses, regression equations were conducted using an SPSS macro designed to examine multiple mediator models (Preacher & Hayes, 2008) using the product-of-coefficients mediation approach and bootstrapping statistical methods. This macro also allows for the statistical control of covariates and comparisons between indirect effects in mediation analyses. Separate regression analyses were performed for the intentions and disclosure outcome variables representing engagement in care: (1) intentions to remain in care, (2) intentions to discuss sexual risk behaviors, (3) intentions to discuss substance use, (4) intentions to discuss medication adherence difficulties, and (5) disclosure of personal risk behaviors (nine items examined in separate regression equations). Stigma condition (stigma vs. no stigma) served as the models' independent variable of interest, with patients' perceptions of stigmatization within the hypothetical patient-provider interaction and levels of psychological comfort within the treatment setting serving as the models' proposed mediators.

Support for study hypotheses would be provided by significant unstandardized regression coefficients for the direct effect of stigma level on engagement in care outcome variables reaching significance at the conventional .05 level. This was similarly expected for the regression paths between stigma level and the mediating variables regarding perceptions of stigmatization within the patient-provider interaction and psychological comfort. Finally, in examining the mediation hypothesis, it was expected

that Sobel's test of the models' total indirect effects would be significant, demonstrating that the effects of stigma on engagement of care are either partially or fully mediated by the effects of patient perceptions of stigmatization within the patient-provider interaction and patients' psychological comfort.

Results

Equivalency between study conditions. T-test and Chi-square analyses revealed few differences between participants randomized to the “stigma” and “non-stigma” conditions on demographic variables, health status variables, and the measure of past stigmatizing experiences reported during the experimental phase protocol. As noted in Table 5, the only significant difference noted was for paid work hours, with participants in the “stigma” condition reporting significantly more work hours than those in the “non-stigma” condition, $t(23) = -2.07, p = .05$. However, as only 24 participants were included in this analyses (due to high rates of unemployment among participants) and work hours was not significantly related to study outcome measures, it was not selected as a covariate in subsequent analyses. These largely non-significant findings indicate that the randomization procedure was successful.

Descriptive findings. In performing initial descriptive analyses, all mediating and “intentions-based” outcome variables were found to have normal distributions, with no signs of significant skew or kurtosis. In contrast, seven of the nine disclosure-based outcome variables presented with non-normal distributions as a function of significant skew, and in some cases, the presence of extreme outliers (lifetime and recent sexual behavior items). Such outcome variables were transformed using log transformations to correct for skew, with extreme outliers also truncated to three standard deviations away

from the mean. All analyses were performed using both original and transformed versions of variables, with no significant differences in outcome noted. Statistics presented within the text and associated tables and figures report findings from analyses performed with the transformed variables.

As shown in Table 6.1, significant correlations were noted between the mediating variables of the present study (perceptions of stigma, general comfort, and specific disclosure comfort measures), between the intention-based outcome variables, and finally between the mediators and the intentional outcome variables. Correlations were in the expected direction, with perceptions of stigma being significantly (negatively) correlated with comfort measures (other mediating variables) and intention-based outcome measures assessing intentions to a) remain in care, b) disclose sexual risk behavior, c) disclose substance-related risk behavior, and d) disclosure medication adherence difficulties. In contrast, comfort-based mediating variables were positively correlated with intention-based outcome variables, such that higher levels of comfort were associated with greater likelihood to remain in care and disclose risk activities.

Only two significant associations were noted for mediators and disclosure-based outcome variables. As noted in Table 6.2, the only significant correlations were found between general patient comfort and report of number of sexual partners in the past three months ($r = -.22, p < .05$) and also between comfort related to discussion of sexual risk and report of lifetime number of sexual partners ($r = -.23, p < .05$). Contrary to study hypotheses, both of these significant negative correlations suggest that increased patient comfort was associated with decreased reporting of sexual risk. Perceptions of stigma and

patient comfort were not related to participants' reports of any of the other sexual, substance-related, and medication adherence risk behaviors.

Bivariate examination of effects of stigma condition on engagement in care.

Summary statistics in Table 7 present mean values for mediating and outcome variables for both experimental conditions, with significant differences reported via t-test statistics. As noted, participants in the “non-stigma” condition reported significantly lower perceptions of stigma, higher levels of comfort (general and disclosure related), and greater intentions to remain in care and to disclose risk behaviors than those in the “stigma” condition (see Table 7).

Two trends ($p < .10$) were noted among disclosure-based outcome variables (see Table 7). First, participants in the “non-stigma” condition reported missing doses of their HAART medications more recently than did participants in the “stigma” condition. Second, participants in the “non-stigma” condition reported using condoms less frequently than participants in the “stigma” condition. No differences between the groups were found for number of lifetime and recent sexual partners, alcohol consumption, or lifetime and recent drug use variables. Such outcomes may suggest greater disclosure of risk behaviors from participants in the “non-stigma” condition.

Exploratory Aim: Impact of previous experiences of provider stigmatization.

Correlational analyses were used to examine the relevance of previous experiences of provider stigmatization as a covariate or moderator of the proposed mediational model. As no significant associations were noted between previous experiences of stigmatization and the mediating and outcome measures of the present study (see Tables 6.1 and 6.2), it

was not selected as a covariate in subsequent analyses regarding primary study hypotheses.

Primary study hypotheses: Mediation model of the association of HIV-related stigmatization to patients' decisions to engage in medical care. Regression equations predicting intention-based and disclosure-based outcomes were conducted using an SPSS macro designed to test multiple mediator models (Preacher & Hayes, 2008). The macro relies upon the product-of-coefficients mediation approach and bootstrapping statistical methods. Results are first described in terms of the overall fit of the mediational models (see Table 8), indicating the extent to which provider stigmatization accounted for a significant percentage of the variance in the engagement in care outcome measures. Results are secondarily described using illustrative figures of separate *a* (IV to mediator), *b* (mediator to DV), *c* (full direct effect of IV on DV), and *c'* (remaining direct effect of IV on DV after accounting for indirect effects via mediators) paths. Although Sobel's test and bootstrapping procedures do not rely on examining the statistical significance of separate *a* and *b* paths (e.g. Baron and Kenny's causal steps mediation approach), these figures provide useful information about the relationships between the individual variables in the model. Lastly, results are described in terms of the significance of their unstandardized coefficients from Sobel's test of the indirect effects of provider stigmatization (experimental IV) on engagement in care via the mediating pathways (*ab* paths) of the model. Confidence intervals (CI) pertaining to the coefficients were created via bootstrapping resampling procedures and are also provided in Tables 9.1-9.4 and Tables 10.1-10.9.

Intention-based mediation models. In focusing on the intention-based mediation models, it was hypothesized that participants' feelings of comfort and perceptions of stigmatization within the patient-provider interaction would mediate the effect of stigmatization (as operationalized as "stigma" and "non-stigma" randomized conditions) on participants' decisions to engage in care and openly engage in conversations about risk behaviors regarding sexuality, substance use, and medication non-adherence. Results described below outline the performance of the proposed mediator models, noting overall model fit, as well as providing information about the specific individual associations (model paths) between all of the included variables in the models (e.g. IVs, mediators, DVs).

Mediational model fit. Findings related to overall model fit provided support for the present study's primary mediational hypotheses, such that the negative effects of provider stigmatization (experimental manipulation) on engagement in care were significant and these effects were mediated through the IV's negative effects to participants' perceptions of stigmatization and feelings of comfort. As shown in Tables 9.1 to 9.4, the total direct and indirect effects of provider stigmatization accounted for a significant proportion of the variance in participants' intentions to remain in care, $F(3, 86) = 122.90, p < .001, R^2 = .80$, disclose risky sexual behavior, $F(4, 85) = 26.69, p < .001, R^2 = .54$, disclose substance-related behaviors, $F(4, 85) = 23.69, p < .001, R^2 = .51$, and disclose medication adherence difficulties, $F(4, 85) = 10.90, p < .001, R^2 = .31$.

Individual a and b pathways. Pathways from the IV to the mediating variables ($a1-a3$) were all significant with unstandardized path coefficients ranging from -3.67 to 3.23 (all $ps < .001$), demonstrating the negative effects of provider stigmatization

(experimental manipulation) on participants' perceptions of stigmatization and feelings of comfort. Differences were noted among intention-based outcome models with regards to the significance of *b* paths from mediating variables to DVs, such that perceptions of stigma, general patient comfort, and specific comfort measures related to disclosure did not yield significant regression paths to every intentions outcome measure. These findings suggest that participants' perceptions of stigmatization and feelings of comfort did not consistently predict participants' intentions to remain in care and open engage in conversations related to risk behaviors, such that the performance of each mediator was unique to the outcome variable examined. As noted in Figures 7.1-7.4, perceptions of stigma yielded a significant *b* path in models predicting intentions to remain in care ($B = -.57, p < .001$), intentions to disclose sexual risk behaviors ($B = -.44, p < .01$), and intentions to disclose medication adherence difficulties ($B = -.41, p < .05$), with a trend noted for intentions to disclose substance-related risk behavior ($B = -.30, p < .1$). The path coefficients for general patient comfort were only significant for models predicting intentions to remain in care ($B = .55, p < .001$) and intentions to disclose sexual risk behavior ($B = .47, p < .05$), with specific disclosure-related comfort measures being significantly associated only with intentions to disclose substance-related risk behavior ($B = .37, p < .1$).

Direct c and c' pathways. As noted in Figures 7.1-7.4, direct effects, as indicated in *c* pathways from the IV to the DV, were all significant with unstandardized path coefficients ranging from -1.61 to -3.40 (all $ps < .001$), indicating that the experimental stigma condition was predictive of participants' intentions to remain in care, disclose sexual risk behavior, disclosure substance-related risk behaviors, and disclosure

medication adherence difficulties. When indirect effects of the IV via the mediating variables were accounted for, remaining direct effects (c' path coefficients) of the experimental stigma condition (IV) on intentions-based outcome variables were found to be non-significant, indicating the presence of mediation (see Figures 7.1-7.4). The latter finding supports the hypothesis that the negative effects of provider stigmatization on patients' intentions to engage in care are mediated by HIV+ patients' ability to perceive the stigmatization within the patient-provider relationship and also their experience of lower levels of comfort.

Sobel's test of indirect effects and bootstrapping resampling analyses. Results from Sobel's test of indirect effects and additional bootstrapping analytical procedures of the macro (Preacher & Hayes, 2008) provide a final source of support for the present study's primary mediational hypotheses regarding the effects of provider stigmatization (experimental manipulation) on engagement in care being mediated through the IV's effects to participants' perceptions of stigmatization and feelings of comfort. Indeed, findings from Sobel's tests and bootstrapping procedures supported all intentions-based mediation models, such that the total indirect effects of the experimental stigma condition (IV) on the intent-based DVs (remain in care, disclose risk behaviors) via participants' perceptions of stigma and reports of comfort were significant at the $p < .001$ level for each model (see Tables 9.1-9.4). Similarly, percentile based and bias corrected and accelerated 95% CI ranges did not include a value of zero for any of the models, providing further support for the significance of the models' total indirect effects, as obtained through bootstrapping resampling procedures. As shown in Tables 9.1-9.4, there were differences among the "intentions-based" models with regard to the significance of

individual mediating *ab* paths, such that all mediating pathways (e.g. perceptions of stigma, general comfort, disclosure specific comfort) were not significant in every model. These findings suggest that although all individual mediating paths (e.g. stigma → comfort → intent to disclose substance-related risk behaviors) did not significantly predict every outcome variable, the *composite* of all the mediational paths of the model (i.e. stigma → perceptions of stigma, comfort, disclosure comfort → intentions outcome) were successful in predicting HIV+ participants intentions to remain in care and disclose risk behavior related to sexual activity, substance use, and medication non-adherence.

Significant mediating pathways for the “intent to remain in care” model included perceptions of stigma ($B = -1.86, p < .001$) and general patient comfort ($B = -1.71, p < .001$). The “intentions to disclose sexual risk behavior” model included the same mediating pathways, with the perceptions of stigma ($B = -1.86, p < .001$) and general patient comfort ($B = -1.71, p < .001$) paths both having significant path coefficients, while the path for the sexual disclosure comfort measure did not reach significance. The comfort measure concerning substance-related disclosure was the only significant mediating pathway ($B = -1.11, p = .007$) for the “intent to disclose substance-related risk behavior” model, with a trend noted for the perceptions of stigma path ($B = -.98, p = .08$). Finally, for the “intent to disclose HAART non-adherence” model, Sobel’s test of indirect effects indicated that perceptions of stigma was a significant mediating pathway ($B = -1.31, p = .04$). However, confidence interval ranges obtained through bootstrapping resampling procedures contained a value of zero for both percentile and bias corrected and accelerated CIs, suggesting that mediating pathway coefficient may not statistically differ from zero.

Disclosure-based mediation models. In focusing on the disclosure-based mediation models, it was hypothesized that participants' feelings of comfort and perceptions of stigmatization within the patient-provider interaction would mediate the effect of stigmatization (as operationalized as "stigma" and "non-stigma" randomized conditions) on participants' decisions to disclose sensitive information about their actual sexual behavior, substance use, and medication adherence practices. Results described below outline the performance of the proposed mediator models, noting overall model fit, as well as providing information about the specific individual associations (model paths) between all of the included variables in the models (e.g. IVs, mediators, DVs).

Mediational model fit. Findings related to overall model fit failed to provide support for the present study's primary mediational hypotheses, such that the effects of provider stigmatization (experimental manipulation) on disclosure were non-significant and these effects were not mediated through participants' perceptions of stigmatization and feelings of comfort. As shown in Table 8, the total direct and indirect effects of provider stigmatization did not account for a significant proportion of the variance in any of the disclosure-based outcome models. This is largely expected given that no significant differences between the groups were found during bivariate analysis (t-tests) on any of the disclosure-based outcome variables, leaving very little between group variance to be explained. The few significant findings from mediational analyses are reported with the understanding that groups did not significantly differ from each other. A trend was noted for the "disclosure of lifetime sexual partners" model, with the manipulation of provider stigmatization accounting for 7% of the variance in the number of lifetime sexual partners reported by participants, $F(4, 72) = 2.46, p < .10, R^2 = .07$. The

direction of this effect was unexpected, as the presence of stigma was associated with disclosure of greater number of lifetime sexual partners. Further discussion of results for the disclosure-based outcomes is completed with consideration of the poor fit of the mediational models.

Individual a and b pathways. As with “intentions-based” outcomes, pathways from the IV to the mediating variables ($a1-a3$) were all significant with unstandardized path coefficients ranging from -3.67 to 3.23 (all $ps < .001$), demonstrating the negative effects of provider stigmatization (experimental manipulation) on participants’ perceptions of stigmatization and feelings of comfort. Few significant findings were noted among disclosure-based outcome models with regards to the significance of b paths from mediating variables to DVs, such that perceptions of stigma, general patient comfort, and specific comfort measures related to disclosure did not yield significant regression paths for many of the disclosure outcome measures. Such findings suggest that participants’ perceptions of stigmatization and feelings of comfort were largely not associated with participants’ decisions to disclose risky behaviors. As noted in Figures 8.1-8.9, perceptions of stigma did not yield any significant b path in the disclosure-based models. The b path coefficients for general patient comfort were only significant for models predicting disclosure of lifetime drug use ($B = -.32, p < .05$), frequency of drug use in past three months ($B = -.06, p < .05$), with specific disclosure-related comfort measures being significantly associated with disclosure of lifetime sexual partners ($B = -.23, p < .01$).

Direct c and c' pathways. In examining the direct relationship between stigmatization and patients’ disclosure of risk behavior, findings largely failed to provide

support for the present study's primary hypotheses. As noted in Figures 8.1-8.9, direct effects, as indicated in *c* pathways from the IV to the DV, were non-significant for seven of the nine disclosure-based models, indicating that the experimental stigma condition was largely not predictive of participants' actual disclosure of sexual risk behavior, substance use, and HAART non-adherence. Trends were noted for the direct path for recent condom use and recency of missed HAART doses (see Figures 8.3 & 8.8), such that the presence of provider stigmatization (experimental manipulation) was associated with lower disclosure of failure to use condoms and missing recent doses of HAART. When indirect effects of the IV via the mediating variables were accounted for, remaining direct effects (*c'* path coefficients) of the experimental stigma condition (IV) on condom use remained at a trend level, while effects to recency of missed HAART doses were found to be non-significant, providing initial support for the presence of mediation in this model.

Sobel's test of indirect effects and bootstrapping resampling analyses. Results from Sobel's test of indirect effects and additional bootstrapping analytical procedures of the macro (Preacher & Hayes, 2008) failed to provide strong support for any of the proposed disclosure-based mediation models. Indeed, the total indirect effects of the experimental stigma condition (IV) on the disclosure based DVs (disclosure of risk behaviors) via participants' perceptions of stigma and reports of comfort were non-significant for all the disclosure-based models (see Tables 10.1-10.9). Similarly, percentile based and bias corrected and accelerated 95% CI ranges included values of zero for all of the models, providing further support for the non-significance of the models' total indirect effects, as obtained through bootstrapping resampling procedures.

Additionally, as shown in Tables 10.1-10.9, very few models possessed any individually significant mediating pathways (e.g. perceptions of stigma, general comfort, disclosure specific comfort).

Perceptions of stigma did not account for significant mediating pathways in any of the disclosure-based models. Sobel's test of indirect effects indicated that generalized patient comfort provided a significant mediating pathway for disclosure of recent drug use ($B = .20, p < .05$) and disclosure of lifetime drug use ($B = 1.00, p < .05$). However, confidence interval ranges pertaining to disclosure of lifetime drug use contained a value of zero for bias corrected and accelerated CIs, suggesting that mediating pathway coefficient may not statistically differ from zero. The mediating pathway through disclosure specific comfort measures was found to be significant for only the "disclosure of lifetime sexual partners model" ($B = .70, p < .01$). Based on these findings, alternative single mediator models were examined. These post hoc analyses revealed that stigma condition accounted for a significant amount of variance in the disclosure of lifetime sexual partners when disclosure-specific comfort was entered as the sole mediating pathway (see Tables 11.1 & 11.2). No significant improvements were noted in overall model fits for lifetime and recent drug use models (see Tables 11.1, 11.3, 11.4).

Discussion

Summary of major findings. HIV remains a highly stigmatized illness and is associated with a number of adverse consequences among HIV+ individuals (Lee, Kochman, & Sikkema, 2002; Vanable et al., 2006). The experience of stigmatization in health care settings may be particularly detrimental to the health and well being of persons living with HIV. Although many recent studies have documented the existence of stigmatization in medical treatment settings, few have examined the impact of provider stigmatization on HIV+ patients' decisions to engage in various aspects of HIV care. The present study used an experimental design and a behaviorally oriented approach to assess patients' reactions to medical treatment scenarios in order to examine the impact of stigmatization on health care engagement. It was hypothesized that participants' perceptions of stigmatization and feelings of comfort within the patient-provider relationship would mediate the effects of provider stigmatization (experimentally manipulated) on participants' intentions to remain in care and openly engage in risk reduction conversations, as well as their decisions to disclose actual risk behaviors. Hypotheses were tested using an experimental design that randomized participants into "stigma" and "non-stigma" vignette conditions in which HIV+ participants were presented with visual stimuli and audio recordings depicting hypothetical patient-provider interactions. Stigmatizing and non-stigmatizing vignettes differed in terms of distancing, avoidance, use of extra precautions, negative demeanor, and judgmental language. Primary study analyses were conducted within the framework of multiple mediator models based on the product-of-coefficients approach and bootstrapping analytical techniques.

Two important findings emerged from the study. The first major finding pertains to the negative impact provider stigmatization can have on HIV+ patients' sense of comfort, their perceptions of the patient provider relationship, and ultimately their decisions related to care and sharing sensitive, health-related information with their healthcare providers. Findings from bivariate and mediational analyses confirmed that when the provider behaved in stigmatizing ways, HIV+ participants reported higher perceptions of stigmatization, more discomfort, and lower intentions to engage in care. Thus, participants were impacted in terms of their cognitive appraisal of the interaction, their emotional responses, and subsequent intentions to engage openly with the provider. Indeed, exposure to the "stigmatizing" provider lead to greater feelings of being devalued, more negative perceptions of the patient-provider relationship, and greater discomfort. Additionally, participants randomized to the "stigma" condition also reported having significantly lower intentions to remain in care and disclose sensitive health information regarding sexual risk activity, substance use, and medication non-adherence to the provider viewed in the vignette.

In contrast to the "intentions-based" findings, no significant differences were noted for outcomes that focused on actual disclosure of risky sexual, substance, and non-adherence related behaviors, with the presence of provider stigmatization having little effect on participants' willingness to disclose sensitive information on the computerized survey. Indeed, participants randomized to the "stigma" and "non-stigma" conditions reported similar numbers of sexual partners, alcohol and drug use habits and histories, and medication adherence behaviors. Trend-level differences were noted for reports of condom use and disclosure of the recency of missed HAART doses, with participants

exposed to the “non-stigmatizing” provider being more likely to report instances of unprotected sex and lapses in medication adherence. These trend-level differences suggest that provider stigmatization may influence HIV+ patients’ decisions to be forthcoming about potentially risky sexual behaviors and less-than-perfect medication adherence. Additional research is warranted to explore these intriguing, yet inconclusive, trends in the data.

The second major finding of this study pertains to the mediating pathways through which provider stigmatization negatively impacted patients’ intentions to openly communicate with their providers and effectively engage in their care. As hypothesized, findings from mediational analyses demonstrated that the effects of provider stigmatization (e.g. the experimental manipulation) on intention-based outcome measures were mediated by patients’ perceptions of stigmatization within the patient provider interaction and their feelings of comfort. Indeed, models containing stigma condition (IV), patient perceptions of stigmatization (mediator), general patient comfort (mediator), and measures of disclosure-specific comfort (mediator) performed very well in predicting participants’ intentions to remain in care and disclose risky sexual, substance use, and medication non-adherence behaviors with models explaining 30-80% of the variance in these intention-based outcome measures. For all of these models, the direct effect of stigma condition became non-significant after accounting for the total indirect effects of the mediating pathways, an indication of the presence of mediation. To elaborate on these findings, when the provider engaged in stigmatizing behaviors, HIV+ patients’ (1) perceived the devaluing nature of these behaviors, (2) their perceptions of the patient-provider relationship were harmed, and (3) their level of psychological comfort within

the treatment interaction decreased. Subsequently, these negative cognitive appraisals and affective responses to the stigmatizing interaction influenced their decisions to decline future treatment with the provider and lessened their willingness to disclose sensitive information about their health behaviors and engage in discussions related to sexual risk behaviors, substance use, and medication adherence difficulties.

As noted, provider stigmatization (as experimentally manipulated) was not associated with significant differences in actual disclosure of risk behaviors among study participants in the “stigma” and “non-stigma” groups. Largely due to this lack of significant group differences and associated lack of between group variance, mediational models aimed at explaining the effect of stigma on patient disclosure performed poorly. Additionally, seven of the nine disclosure-based outcome variables required transformations due to non-normal distributions (e.g. extreme outliers regarding sexual partner numbers, skew due to low frequency use of drugs and alcohol) with several of the variables still not adhering to what could be considered preferred standards of skew and kurtosis even after the transformations were performed (though they were greatly improved). Indeed, variance explained through these mediational models ranged from .3% to 7% (a trend level effect for prediction of lifetime sexual partners). Examination of mediating paths suggests that even though participants exposed to stigmatizing provider behaviors reported perceiving more stigmatization and feeling less comfortable with the provider (IV to mediator paths), these perceptions and feelings did not influence the degree to which patients disclosed sensitive personal information on the computerized survey (mediator to DV paths).

Study strengths, limitations, and future directions. This present study is the first to utilize an experimental design to examine the detrimental effects of provider stigmatization on HIV+ patients' treatment decisions and intentions to disclose sensitive health information. The strength of this design is that it provides evidence of a causal relationship between provider stigmatization and patient response.

A second strength of the present study concerns the use of a multidimensional operationalization of HIV-related provider stigmatization. Stigma measures from previous empirical studies involving patient self-report are often restricted to small item sets that focus on extreme behavioral markers of stigmatization such as treatment refusal. The present study addressed this limitation by carefully constructing detailed representations of provider stigma in vignettes depicting a range of provider behaviors related to both demeanor and the provision of care. In addition, the present study allowed for time-sensitive assessments of immediate reactions to provider stigma, thereby lessening the possibility of recall errors. Finally, use of a computerized design likely increased patients' perceptions of confidentiality, thus decreasing the chances of socially desirable responding often found in traditional survey based studies.

One limitation of the present study concerns the use of a dichotomized experimental manipulation of stigma, with one condition being highly stigmatizing and the other containing no elements of a stigmatizing interaction. In focusing on the highly stigmatizing interaction, the vignette was created to contain numerous examples of stigmatizing behaviors to characterize what a "stigmatizing provider" might look like. In reality, it may be unlikely that a provider would demonstrate this entire spectrum of stigmatizing behaviors, and if they did, such behaviors would probably not take place in

the span of a single treatment visit. Given that this study was the first of its kind to experimentally examine the impact of provider stigma on medical care decisions, it was deemed important to first get a clear picture of the effects of HIV-stigmatization in a very apparent form. Future experimental research should examine the effects of stigmatization as operationalized on a continuum, either in the level of extremity, the quantity, or the types (e.g. verbal, non-verbal) of stigmatizing behaviors patients are exposed to.

A second limitation of the present study concerns the use of hypothetical vignettes. Vignettes were developed to provide a realistic depiction of stigmatizing and non-stigmatizing medical appointments. Further, participants were encouraged to imagine themselves in the situation that was depicted in the vignette, “as if they were the patient.” By participant report, these efforts were largely successful. HIV+ patients in the validity study indicated that the behavior of the provider in the stigmatizing vignette was indeed stigmatizing and realistic, offering validity to the *content* of the vignettes. However, even the most carefully constructed vignettes are only modest approximations of what patients experience during an *actual* provider visit. The lack of significant findings for disclosure of actual sexual behavior, substance use, and adherence difficulties may be due to inherent design limitations associated with using vignettes as a mode of delivery for an experimental manipulation of an interaction. Though these items were read to the participants in the voice of the provider to mimic as closely as possible what it would be like to disclose sensitive information to the provider, this approximation may not have been a powerful enough mode of delivery to influence participants’ comfort with disclosing health behavior lapses. In sum, although the content of the vignettes may have been powerful in eliciting reactions from participants, the mode of delivery may have

been too weak of an approximation to affect participants' actual disclosure of risk behaviors.

A final limitation of the present study is the presence of high overlap between variables as indicated by the high correlations among the study's mediating variables. Although the multiple mediator statistical design of the present study allowed for correlations between the included mediator variables, future studies would benefit from conceptualizing and/or operationalizing patients' reports of comfort and perceptions of stigma in ways that better allow for more distinct comparisons of the effects of these variables. In addition, to further extend the findings from the present study, future experimental designs should include participant randomization to realistic stigmatizing and non-stigmatizing healthcare care experiences taking place within real medical facilities and portrayed by live "actors." In so doing, research could provide additional insight into the impact of provider stigmatization on patient behavior. Ultimately, studies that utilize experimental manipulations of stigmatization will help to provide a more comprehensive understanding of the ways in which provider stigma effects HIV+ patients' decisions to communicate openly with their provider and effectively engage in their care. This is important within the context of healthcare not just within the United States, but globally as well. In looking to future research, the present study provides a step-by-step research framework (qualitative interviews, vignette development and testing, experimental procedures) for identifying the content of stigmatizing behavior within treatment settings and understanding its impact on HIV+ patients. The portability of this protocol allows for the examination of provider stigmatization across many cultures and treatment settings. With future research and intervention efforts, it is the

hope that provider stigmatization will eventually be examined, understood, and decreased on a global scale.

Implications for the IMCHB model and practical applications. Findings from the present study provide support to Cox's (1982) IMCHB model, emphasizing the impact of patient-provider relationships on treatment decisions and patient behaviors. As discussed, findings demonstrated that the effects of provider stigmatization were mediated by patients' feelings of comfort within the treatment interaction, patients' abilities to perceive the presence of devaluing nature of the stigmatizing behaviors, and their negative views of the quality of the patient-provider relationship (with the latter two comprising the study's perceptions of stigma measure). As dictated in Cox's (1982) IMCHB model, positive patient-provider interactions are defined in large part by the provider's ability to demonstrate their competency, provide affective support, give the patient control in treatment decisions, and provide health information in the proper amounts as based on the highly individualized needs of the patient. Provider stigmatization likely inhibits the development of positive patient-provider relationship, as patients are left feeling devalued, disrespected, emotionally unsupported, uncomfortable, and vulnerable due to the behaviors of the persons responsible for their medical care. As a function of stigmatization, providers may fail to form positive working relationships with their HIV+ patients. In failing to achieve a sense of comfort and trust with their providers, patients' may be less willing to disclose important information about their health and health behaviors in fear of further negative judgment and emotional pain. Without such patient honesty, physicians are not able to obtain a complete picture of their

patients' lives and health conditions and, consequently, are limited in their ability to provide high quality health care.

In focusing on practical implications, findings from the present study suggest that instances of provider stigmatization, expressed through specific behaviors and overall demeanor, play an important role in predicting which patients will likely remain in care and openly discuss their risk behaviors and medication adherence difficulties. As demonstrated in the present study, the process of evaluating the quality of the patient-provider relationship and making decisions about disclosure can begin as early as the first appointment with the provider. Thus, it is important for medical care providers to understand how certain protocols (e.g. use of gloves, frequent assessments of sexual behavior, etc.), language, and behaviors within the treatment settings may be perceived as stigmatizing by patients and hence detract from this process.

Routine training programs for health care providers would benefit from focusing on practical steps to prevent HIV-related stigmatization within treatment settings. Such trainings should aim to help professionals in the health care field gain an awareness of how even the subtlest of their behaviors may be interpreted by the HIV+ patients they treat. A first step in developing such trainings would be to undertake future research to pinpoint the "hot-button" provider behaviors noticed most frequently by HIV+ patients and found to cause the most damage to the patient-provider relationship. Identifying a few key areas for behavioral intervention would allow for the fairly quick training of a large number of providers, with a chance for maximum recall and dissemination of learned skills. It is also suggested that providers be exposed to HIV care settings and to HIV+ patients multiple times throughout their medical training to increase their skill,

confidence, and comfort in developing working relationships with this patient population. By teaching providers to focus on and potentially reshape certain aspects of their demeanors, language, and nonverbal behaviors, it is the hope that positive patient-provider relationships can be formed and the overall quality of patient experiences within HIV care could be increased.

Conclusions

In summary, the present study provided initial evidence regarding the negative effects of provider stigma on HIV+ patients' willingness to openly communicate about risk behaviors and make decisions about the future of their care. Compared to patients who were not exposed to provider stigmatization, patients exposed to stigmatizing language and behaviors from the healthcare provider were less willing to remain in care and less willing to disclose sexual and substance use related risk behaviors and medication adherence difficulties. These effects were mediated by patients' perceptions of the degree of stigmatization present within the patient provider relationship and their feelings of comfort throughout the medical appointment. Future explorations of the impact of provider stigmatization on HIV+ patient's healthcare decisions and health outcomes are needed in order to inform the development of stigma reduction interventions and ultimately improve the medical treatment of HIV+ individuals.

Table 1. Patient Reports of Provider Stigmatization

| <i>First Author</i> | <i>Study Design</i> | <i>Study Objectives</i> | <i>Sample</i> | <i>Stigma Variable/Measure</i> | <i>Findings</i> | <i>Limitations</i> |
|---------------------|---|--|---|--|---|--|
| Agne (2000) | qualitative (pilot): interviews quantitative (primary): self-report survey | 1. describe predictors of serostatus disclosures to healthcare providers | Pilot: HIV+ (N=7) - gender: 5 men -age range: 25-35 -health status: many experienced multiple health problems Primary: HIV+ (N=107) -gender: 89% male -sex. or: 75% homosexual -race: not provided -M age: not provided | Pilot: interviews regarding healthcare experiences and disclosure Primary: Perceived Stigma - one Likert item - general perceptions of HIV as stigmatizing disease - items from Medical Interview Satisfaction Scale - ratings of provider communication and care quality | Pilot: -all reported that they disclosed to their providers -many noted that they would not disclose in the future because of negative experiences with stigma at time of disclosure -stigma experiences: avoidance and delay of treatment, disrespectful treatment, inadequate care Primary: -despite feeling stigmatized, most patients still disclosed -provider relational factors important to disclosure decision | Pilot: -very small sample size Primary: -poor stigma measure: not “provider specific” and only 1 item -patient reports perceived stigma only, with no observable measures of provider stigma |

| | | | | | | |
|-----------------|-------------------------------------|--|---|--|---|--|
| Blake (2008) | qualitative: focus groups | 1. describe experiences of women receiving HIV testing and care | HIV+ women (N=23) and HIV- at risk women (N=41) -gender: 100% female -sex. or: not provided -race: 59% Black -M age: 32 | Interviews about HIV testing and health care experiences | -HIV stigma as a barrier to testing for at-risk HIV- women -HIV+ women noted that having a caring provider was critical to a positive provider relationship and their decision to stay in care | -patient reports of perceived stigma only, with no observable measures of provider stigma -study more tightly focused on provider-relationships rather than provider based stigma |
| Bodenlos (2007) | quantitative: self-report survey | 1. assess how attitudes towards healthcare providers impact appointment attendance among HIV+ patients | HIV+ (N=109) -gender: 59% male -sex. or: not provided -race: 85% Black -M age: 38 | Attitudes Toward HIV Health Care Providers Scale: - 19 Likert items - newly created - Professionalism and Emotional Support subscales | - positive relationship with healthcare provider team predictor of better appt. attendance | -stigma not overtly measured in scale which focuses more on provider relationships -appt attendance measured retroactively so cause and effect relationship not able to be stated |

| | | | | | | |
|---------------|---|--|---|---|--|---|
| Buseh (2006) | qualitative: longitudinal individual interviews | 1. examine HIV+ African American women's life experiences and responses to stigma | HIV+ women (N=29) -gender: 100% women -sex. or.: not provided -race: 100% black -M age: 40 | -interviews about life experiences and HIV, including stigma experiences | -stigma (general) caused multiple constraints: damaged self esteem, loss of hope, rejection, social restrictions -stigma from providers caused women to perceive the providers as lacking in beneficence and competence | -patient reports of perceived stigma only, with no observable measures of provider stigma -small sample |
| Elford (2008) | quantitative: self-report survey | 1. assess the extent to which HIV+ persons experience discrimination because of their serostatus | HIV+ (N=1385) -black, hetero. women (n=448) -black, hetero. men (n=210) -gay or bisexual men: (n=727) (85% white) -M age: mid to late 30s | Discrimination due to HIV status: - one item (have you been treated unfairly because of status) - followed by list of persons to check for presence of perceived discrimination | -30% reported discrimination -of the 414 people reporting discrimination: 50% discriminated by healthcare workers - discrimination (in general) associated with depression, suicidal thoughts, time since diagnosis and body signs of AIDS | -stigma effects not provider-specific -limited stigma assessment -patient reports of perceived stigma only, with no observable measures of provider stigma -maybe unable to separate out racial or sexual orientation stigma from HIV stigma |

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|-----------------------|---|---|---|--|---|--|
| <p>Gardezi (2008)</p> | <p>qualitative: individual interviews</p> | <p>1. better understand HIV-related stigma and its potential effects to prevention practices, access to treatment, and disease response</p> | <p>HIV+ (N=30) HIV- (N=74) -gender: 50% female -sex or.: not provided -race: East African and Caribbean indiv. in Canada - age range: 17-54</p> | <p>-interviews with HIV+: impact of diagnosis, disclosure, experiences accessing health and support services -focus groups with HIV-: HIV in community, stigma, and associated issues</p> | <p>- HIV+ positive participants spoke highly of healthcare they receive, but they also encountered discriminatory attitudes from some healthcare and service providers -general distrust of medical system and official institutions and tendencies to avoid seeking medical care and social services.</p> | <p>-provider stigma not distinctly separated from general community stigma in discussion -HIV-related stigma not separated from racial stigma creating possible confounds - patient reports of perceived stigma only, with no observable measures of provider stigma</p> |
| <p>Kinsler (2007)</p> | <p>quantitative: survey at baseline and 6 month follow-up</p> | <p>1. evaluate the relationship between perceived stigma from a healthcare provider and access</p> | <p>HIV+ (N=223) -gender: 80% male -sex or.: 54% infected through homo. contact -race: 46% black -M age: not provided</p> | <p>Perceived Stigma: -HCSUS measure - 4 items - health care provider specific (discomfort, treated as</p> | <p>-provider stigma reported by ¼ (baseline) and 1/5 (follow up) of participants -more than half reported low access to healthcare</p> | <p>-small number of stigma items (may lack sensitivity) - patient reports of perceived stigma only, with no observable measures of</p> |

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|---------------|--|--|--|---|---|--|
| | | to care among HIV+ patients | | inferior, preferred to avoid, refusal of care) | -those with more perceived stigma had more than twice the odds of reporting low access to care | provider stigma |
| Lindau (2005) | qualitative: semi-structured individual interviews | 1. better understand the healthcare experiences of HIV+ pregnant women | HIV+ mothers (N=15) -gender: 100% female -race: mostly black -M age: 28 -income: most below poverty line | -interview items regarding experiences with healthcare, pregnancy, contraception, and perinatal prevention of HIV | -10 women received no or extremely intermittent prenatal care, with 4 receiving limited and late-onset care -reported poor attendance due to previously negative and dehumanizing interactions with health and child welfare systems -reported disrespect (judgmentalism, reluctance to provide care for), lack of regard for privacy and confidentiality, refusal of touch, refusal of treatment | -small sample size -stigma experienced by HIV+ women in study may be higher than normal because had added stigma of being HIV+ and pregnant - patient reports of perceived stigma only, with no observable measures of provider stigma |

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|-------------------------|---|---|---|--|---|--|
| <p>Marcenko (1999)</p> | <p>qualitative: six focus groups</p> | <p>1. better understand the healthcare experiences of HIV+ pregnant women</p> | <p>HIV+ mothers (N=40) -gender: 100% female -race: 70% black -time since dx: 50% between 4 and 5 years -M age: 34</p> | <p>-interviews about experiences with healthcare, family planning, parenting</p> | <p>-many described experiences in which providers were disrespectful, insensitive, and unhelpful</p> <p>-reported abrupt visits, being ignored for long periods of time, and instances in which they were judged and confronted about their lifestyles</p> <p>-many women reported that their providers did not make efforts to educate them about medication regimens and side effects, leading to decreased adherence</p> | <p>-small, nonrandom sample of women</p> <p>- patient reports of perceived stigma only, with no observable measures of provider stigma</p> |
| <p>Rintamaki (2007)</p> | <p>qualitative: individual and group interviews</p> | <p>1. examine the healthcare experiences of HIV+ men in the</p> | <p>HIV+ veterans (N=50) -gender: 100% male -sex or.: 68% hetero.</p> | <p>Perceived Stigma -3 provider specific interview items as part of</p> | <p>-subtle (nonverbal communication, nervousness) and extreme (abuse, denial of services) examples of stigma noted by</p> | <p>- patient reports of perceived stigma only, with no observable measures of provider stigma</p> |

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|-----------------|-----------------------------------|--|--|---|---|--|
| | | military and their perceptions of stigma in healthcare contexts | -race: 46% black -M age: 50 | overall stigma discussion -open ended interview questions about forms and effects of HIV stigmatization | most participants -sensing dislike associated with loss of trust and willingness to return to treatment - certain provider behaviors can be perceived as stigmatizing even if they are not intended as such | -small sample may not be generalizable (male, vets, older, had HIV long time) |
| Schuster (2005) | quantitative: self-report surveys | 1. to determine whether HIV-infected people perceived that physicians and other health care providers have discriminated against them. | HIV+ (N=2466) -gender: 77% male -sex or.: 56% msm activity -race: 49% white -M age: not provided | Perceived Stigma -HCSUS measure - 4 items - health care provider specific (discomfort, treated as inferior, preferred to avoid, refusal of care) | -26% reported at least 1 type of stigma in clinical settings -provider stigma linked to lower access to care, lower quality of care, and lower trust in doctors | -limited assessment of stigma -only included persons who had disclosed their status to their providers -may be difficult for some patients to separate experiences of other stigma from their HIV stigma |

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|---------------|------------------------------------|--|--|--|---|---|
| Surlis (2001) | qualitative: individual interviews | 1. explore HIV+ patients' experiences during hospitalization and perceptions of stigma from nursing staff in Ireland | HIV+ (N=10) -gender: 70% men -sex or.: not provided -race: not provided -M age: not provided, with range between 29-50 | Interview (open style) with focus on patient's positive and negative experiences of nursing care | -patients reported both positive and negative interactions with nurses -stigma displayed by nurses in their speech by blaming the patients and/or treating them differently -effects of stigma included: patient shame and discomfort, delays in receiving treatment, lesser quality of treatment compared to other patients, unwanted disclosure of status | -extremely small sample limits generalizability - patient reports of perceived stigma only, with no observable measures of provider stigma |
|---------------|------------------------------------|--|--|--|---|---|

| | | | | | | |
|-----------------|--|---|--|---|--|--|
| Thrasher (2008) | quantitative: interview at baseline, 6 month, and 12 month follow-up | 1. assess relationship between discriminatory healthcare experience, provider distrust, race, and adherence | HIV+ (N=1911) -minority: over 50% -gender: 33% female -sex or.: 28% homosexual. -age: 35% < 35 -yrs since dx: 3 -non-minority: < 50% -gender: 12% female -sex or.: 69% homosexual. -age: 30% < 35 -yrs since dx: 3 | Interview (structured) -discriminatory healthcare experiences - HCSUS measure: -6 dich. items (3 at baseline, 3 at follow-up) -hostility and disrespect, lessened attention, refused service, discomfort, treated as inferior, preferred to avoid | -41% reported at least 1 of 6 discriminatory experiences -minorities less likely to report discriminatory experiences -no direct relationship between provider discrimination and HAART adherence -indirect relationship found with effects of provider discrimination to adherence found through decreased trust in providers and weakened beliefs in worth of HAART | -newer study using older sample (1996) may not reflect more current discriminatory experiences -discrimination reported “since had HIV” may bias results as some participants could have reported on incidents early on in epidemic - patient reports of perceived stigma only, with no observable measures of provider stigma |
|-----------------|--|---|--|---|--|--|

| | | | | | | |
|-----------------|---|---|--|--|---|---|
| Wingwood (2007) | quantitative: survey read by interviewers | 1. examine the relationship between discriminatory experiences and health outcomes among HIV+ women | HIV+ women (N=366) -gender: 100% female -sex or.: not provided -race: 84% black -M age: 35 | Discrimination -3 items (yes/no) -denied medical care, lost job, had to move because of status | -16% reported experiencing discrimination -4.4% denied medical care -HIV discrimination linked with poorer health outcomes in black women including: greater stress, lower self-esteem, more depression, more unprotected sex, less likely to seek care | -medical discrimination not singled out from other stigma items in analyses -limited assessment of stigma (3 items) -unable to separate racial discrimination from HIV discrimination - patient reports of perceived stigma only, with no observable measures of provider stigma |
|-----------------|---|---|--|--|---|---|

Table 2. Summary of Patient Reported Provider Stigmatization Studies

| <i>First Author (Year)</i> | <i>Stigmatizing Behavior related to Demeanor</i> | | | | <i>Stigmatizing Behavior related to Provision of Care</i> | | | |
|----------------------------|--|---|--------------------------------|--|---|----------------------|-----------------------------------|--------------------------|
| | <i>Judgmental Speech or other Communication Issues</i> | <i>Nonverbal Behaviors (Proximity, Eye Contact)</i> | <i>Extra Precautions Taken</i> | <i>Discomfort or Negative Affect (Irritation, Fear, Nervousness)</i> | <i>Avoidance/ Ignoring/ Delayed Treatment</i> | <i>Lack of Touch</i> | <i>Inadequate or Differential</i> | <i>Refused Treatment</i> |
| Agne (2000) | | | | | | | X | |
| Blake (2008) | X | X | X | | X | X | | |
| Bodenlos (2007) | | | | | | | X | |
| Buseh (2006) | X | | | | X | | | |
| Elford (2008) | | | | | | | X | |
| Gardezi (2008) | X | | | | | | | |
| Kinsler (2007) | | | | X | X | | | X |
| Lindau (2006) | X | X | | | | X | | X |
| Marcenko (1999) | X | | | | X | | | |
| Rintamaki (2007) | X | X | X | X | X | | X | X |

| | <i>Stigmatizing Behavior related to Demeanor</i> | | | | <i>Stigmatizing Behavior related to Provision of Care</i> | | | |
|----------------------------|--|---|--------------------------------|--|---|----------------------|-----------------------------------|--------------------------|
| <i>First Author (Year)</i> | <i>Judgmental Speech or other Communication Issues</i> | <i>Nonverbal Behaviors (Proximity, Eye Contact)</i> | <i>Extra Precautions Taken</i> | <i>Discomfort or Negative Affect (Irritation, Fear, Nervousness)</i> | <i>Avoidance/ Ignoring/ Delayed Treatment</i> | <i>Lack of Touch</i> | <i>Inadequate or Differential</i> | <i>Refused Treatment</i> |
| Schuster (2005) | | | | X | X | | | X |
| Surlis (2001) | X | | | | X | | X | |
| Thrasher (2008) | | | | X | X | | X | X |
| Wingwood (2007) | | | | | | | | X |
| Total | 7 | 3 | 2 | 4 | 8 | 2 | 6 | 6 |

Table 3. Frequency of Provider Stigmatization Instances-Qualitative Focus Groups

| Stigmatizing Behavior | % of Participants (<i>n</i> =18) |
|--|-----------------------------------|
| Judgmental Language (blame, assumptions about transmission, condescension) | 56% |
| Avoidance or Distancing | 44% |
| Body Language (discomfort) | 28% |
| Demeanor Shifts | 22% |
| Extra Precautions (gloves, masks, etc.) | 22% |
| Non-competence in Treating HIV | 22% |
| Provided Differential Care because HIV+ | 22% |
| Problems ignored because HIV+ | 22% |
| Confidentiality Issues | 17% |
| Rushing Appointments or not Listening to Patient | 17% |
| Lack of Physical Contact | 11% |
| Refusal of Care | 11% |

Table 4. Validity Sub-study: Vignette Comparisons

| | T |
|---|----------|
| <i>Perceptions of Stigma</i> | |
| Stigma vs. No Stigma (long form) | 3.26** |
| Stigma vs. No Stigma (short form) | 7.16*** |
| Long Form vs. Short Form (stigma vignette) | -1.70 |
| Long Form vs. Short Form (no stigma vignette) | .18 |
| <i>Comfort Ratings</i> | |
| Stigma vs. No Stigma (long form) | -3.78** |
| Stigma vs. No Stigma (short form) | -7.19*** |
| Long Form vs. Short Form (stigma vignette) | 2.09 |
| Long Form vs. Short Form (no stigma vignette) | -2.50 |

Note: [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Table 5. Demographic Characteristics of Experimental Phase Sample

| | Full Sample (N=90) | | Stigma Condition (N=45) | | No-Stigma Condition (N=45) | |
|-------------------------------------|-----------------------|-----|----------------------------|-----|-------------------------------|-----|
| | M (SD) | % | M (SD) | % | M (SD) | % |
| Age | 45.2 (11.1) | | 45.7 (11.5) | | 44.6 (10.9) | |
| Gender | | | | | | |
| Male | | 64% | | 64% | | 64% |
| Female | | 34% | | 33% | | 36% |
| Transgendered | | 1% | | 2% | | 2% |
| Hispanic/Latino | | 9% | | 7% | | 11% |
| Race | | | | | | |
| African American | | 52% | | 53% | | 51% |
| Caucasian | | 40% | | 40% | | 40% |
| Employed | | 29% | | 38% | | 20% |
| Paid Hours of Work/Week | 33 (14.6) | | 37.2 (13.7)* | | 25.4 (13.8)* | |
| Have Primary Relationship Partner | | 63% | | 67% | | 60% |
| High School Education or Less | | 31% | | 60% | | 53% |
| Years since HIV Diagnosis | 11.5 (7.6) | | 11 (7.5) | | 12 (7.2) | |
| AIDS Diagnosis | | 22% | | 22% | | 22% |
| HIV-related Hospitalizations | | 29% | | 24% | | 33% |
| Taking HAART Medications | | 83% | | 80% | | 87% |
| Previous Experience with HIV Stigma | 3.61 (6.56) | | 4.29 (8.43) | | 2.93 (4.26) | |

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table 6.1. Correlation Table: Association of Mediators and Intention Outcome Variables

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|----|---------|--------|--------|--------|--------|-------|--------|--------|--------|----|
| 1 | 1 | | | | | | | | | |
| 2 | -.88*** | 1 | | | | | | | | |
| 3 | -.84*** | .93*** | 1 | | | | | | | |
| 4 | -.82*** | .86*** | .89*** | 1 | | | | | | |
| 5 | -.89*** | .92*** | .91*** | .88*** | 1 | | | | | |
| 6 | .10 | -.17 | -.20 | -.17 | -.18 | 1 | | | | |
| 7 | -.71*** | .72*** | .67*** | .70*** | .66*** | -.172 | 1 | | | |
| 8 | -.68*** | .67*** | .63*** | .70*** | .63*** | -.128 | .85*** | 1 | | |
| 9 | -.57*** | .55*** | .48*** | .57*** | .52*** | -.103 | .74*** | .80 | 1 | |
| 10 | -.87*** | .87*** | .81*** | .75*** | .85*** | -.096 | .65*** | .63*** | .52*** | 1 |

Legend:

- 1 (Perceptions of Stigma)
- 2 (Comfort-general)
- 3 (Comfort-sexual behavior)
- 4 (Comfort-substance use)
- 5 (Comfort-med adherence)
- 6 (Previous Experiences of Stigma)
- 7 (Intention to Disclose Sexual Risk Behaviors)
- 8 (Intention to Disclose Substance Use Risk Behaviors)
- 9 (Intentions to Disclose Medication Adherence Difficulties)
- 10 (Intention to Remain in Care)

Note: † trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Table 6.2. Correlation Table: Association of Mediators and Disclosure Outcome Variables

| | Lifetime Sexual Partners (log) | Recent Sexual Partners (log) | Recent Condom Use Neglect | Recent Drinking Frequency (log) | Recent Drinking Quantity (log) | Extent of Lifetime Drug Use | Recent Illegal Drug Use Frequency (log) | Recency of Last Skipped Medication Dose (log) | Overall HAART Non-adherence (log) |
|--------------------------------|--------------------------------|------------------------------|---------------------------|---------------------------------|--------------------------------|-----------------------------|---|---|-----------------------------------|
| Perceptions of Stigma | .061 | .138 | -.082 | -.025 | .010 | .046 | -.048 | -.160 | .016 |
| Comfort-general | -.127 | -.211* | .111 | .034 | -.007 | -.162 | -.071 | .134 | .039 |
| Comfort-sexual behavior | -.228* | -.203 | .128 | .098 | .016 | -.149 | .031 | .132 | .041 |
| Comfort-substance use | -.122 | -.149 | .108 | -.022 | -.085 | -.109 | .000 | .137 | .042 |
| Comfort-med adherence | -.067 | -.163 | .105 | .044 | .026 | -.096 | -.024 | .160 | -.030 |
| Previous Experiences of Stigma | .134 | .173 | .095 | .081 | .024 | -.067 | -.029 | -.111 | .060 |

Note: [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Table 7. Summary Statistics for Mediator and Dependent Variables

| | No-Stigma Condition (N=45) | Stigma Condition (N=45) | T |
|--|----------------------------------|-------------------------------|-------------------|
| | M (SD) | M (SD) | |
| <i>Mediators</i> | | | |
| Perceptions of Stigma | 2.00 (.82) | 5.23 (1.52) | -12.54*** |
| Comfort-general | 5.55 (1.11) | 2.44 (1.69) | 10.33*** |
| Comfort-sexual behavior | 5.42 (1.11) | 2.11 (1.77) | 9.64*** |
| Comfort-substance use | 5.64 (1.43) | 2.69 (1.82) | 8.56*** |
| Comfort-adherence | 6.00 (1.33) | 2.33 (1.72) | 11.31*** |
| <i>Intentions Outcome Variables</i> | | | |
| Intention to Remain in Care | 5.96 (1.45) | 2.44 (1.69) | 9.29*** |
| Intention to Disclose Sexual Risk Behaviors | 4.89 (1.45) | 2.90 (1.88) | 5.70*** |
| Intention to Disclose Substance Use Risk Behaviors | 5.05 (1.50) | 2.97 (1.88) | 5.82*** |
| Intentions to Disclose Medication Adherence Difficulties | 5.33 (1.43) | 3.72 (1.87) | 4.50*** |
| <i>Disclosure Outcome Variables</i> | | | |
| Number of Lifetime Sexual Partners ^a | 76.18 (296.82) | 101.89 (244.99) | .28 |
| Number of Recent Sexual Partners ^a | 1.49 (2.90) | 1.73 (2.90) | .55 |
| Recent Condom Use Neglect | 3.333 (1.78) | 2.67 (1.65) | 1.84 [†] |
| Recent Alcohol Use Frequency ^a | 1.53 (.79) | 1.49 (.94) | .62 |
| Recent Alcohol Use Quantity ^a | 1.53 (.97) | 1.51 (.843) | -.09 |
| Extent of Lifetime Drug Use | 2.36 (1.23) | 2.40 (1.20) | -.17 |
| Frequency of Recent Drug Use ^a | 1.69 (1.13) | 1.53(1.06) | .76 |
| Recency of Missed HAART Doses ^a | 1.76 (1.50) | 1.29 (.90) | 1.90 [†] |
| Overall HAART Non-Adherence ^a | 2.78 (3.40) | 2.93 (3.72) | .05 |

Note. ^a Means and standard deviations presented are based on non-transformed variables for ease of viewing potential differences between groups. However, T-tests were performed on Log transformed versions of these variables. [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Table 8. Summary Table of Mediational Model Fits

| Dependent Variables | Model Summary | | |
|--|-------------------------|---------|-------------------|
| | Adjusted R ² | df | F |
| <i>Intention DVs</i> | | | |
| Intention to Remain in Care | .804 | (3, 86) | 122.90*** |
| Intention to Disclose Sexual Risk Behaviors | .536 | (4, 85) | 26.69*** |
| Intention to Disclose Substance Use Risk Behaviors | .505 | (4, 85) | 23.69*** |
| Intentions to Disclose Medication Adherence Difficulties | .308 | (4,85) | 10.90*** |
| <i>Disclosure DVs</i> | | | |
| Disclosure of Lifetime Sexual Partners ^a | .071 | (4, 72) | 2.46 [†] |
| Disclosure of Recent Sexual Partners ^a | .012 | (4, 84) | 1.26 |
| Disclosure of Recent Condom Use | .014 | (4, 85) | 1.31 |
| Disclosure of Alcohol Use Frequency ^a | .029 | (4, 85) | .37 |
| Disclosure of Alcohol Use Quantity ^a | .020 | (4, 85) | .56 |
| Disclosure of Lifetime Drug Use | .027 | (4, 85) | 1.62 |
| Disclosure of Recent Drug Use ^a | .030 | (4, 85) | 1.69 |
| Disclosure of Recency of Missed HAART Doses ^a | .003 | (4, 85) | .93 |
| Disclosure of Overall HAART Adherence ^a | .013 | (4, 85) | .71 |

Note: ^a Analyses performed on Log transformations of these outcome measures. [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Table 9.1. Mediation Model: The Effect of HIV Stigma on Intentions to Remain in Care through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship.

| Path | Point Estimate | Product of Coefficients | | | Bootstrapping | | | |
|------------------------|----------------|-------------------------|---------|-------|-------------------|-------|----------------------------|-------|
| | | SE | Z | p | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
| | | | | | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | .16 | .38 | .42 (t) | .674 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Stigma Perceptions | -1.86 | .45 | -4.16 | <.001 | -2.81 | -1.00 | -2.80 | -1.09 |
| Patient Comfort: Gen. | -1.71 | .38 | -4.45 | <.001 | -2.62 | -.89 | -2.61 | -.90 |
| Total Indirect Effects | -3.56 | .42 | -8.54 | <.001 | -4.38 | -2.84 | -4.23 | -2.78 |

Table 9.2. Mediation Model: The Effect of HIV Stigma on Intentions to Disclose Sexual Risk Behavior through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship.

| Path | Point Estimate | Product of Coefficients | | | <u>Bootstrapping</u> | | | |
|------------------------|----------------|-------------------------|----------|----------|----------------------|-------|----------------------------|-------|
| | | SE | Z | <i>p</i> | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
| | | | | | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | .69 | .47 | 1.48 (t) | .143 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Stigma Perceptions | -1.41 | .53 | -2.66 | .008 | -2.59 | -.10 | -2.41 | -.09 |
| Patient Comfort: Gen. | -1.46 | .62 | -2.36 | .018 | -2.86 | -.16 | -2.82 | -.23 |
| Patient Comfort: Sex | .18 | .52 | .34 | .734 | -1.06 | 1.41 | -1.00 | 1.50 |
| Total Indirect Effects | -2.69 | .43 | -6.28 | <.001 | -3.91 | -1.79 | -3.78 | -1.64 |

Table 9.3. Mediation Model: The Effect of HIV Stigma on Intentions to Disclose Substance Use Related Risk Behavior through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship.

| Path | Point Estimate | Product of Coefficients | | | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
|------------------------|----------------|-------------------------|---------|----------|-------------------|-------|----------------------------|-------|
| | | SE | Z | <i>p</i> | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | .28 | .50 | .56 (t) | .575 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Stigma Perceptions | -.98 | .56 | -1.74 | .083 | -2.24 | .53 | -2.35 | .50 |
| Patient Comfort: Gen. | -.27 | .53 | -.52 | .61 | -1.82 | .99 | -1.73 | 1.19 |
| Patient Comfort: Subs. | -1.11 | .52 | -2.68 | .007 | -2.01 | -.30 | -1.93 | -.23 |
| Total Indirect Effects | -2.36 | .44 | -5.34 | <.001 | -3.92 | -1.09 | -3.71 | -1.00 |

Table 9.4. Mediation Model: The Effect of HIV Stigma on Intentions to Disclose HAART Non-adherence through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship.

| Path | Point Estimate | Product of Coefficients | | | <u>Bootstrapping</u> | | | |
|------------------------|----------------|-------------------------|-------|----------|----------------------|-------|----------------------------|-------|
| | | SE | Z | <i>p</i> | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
| | | | | | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | .19 | .55 | .34 | .74 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Stigma Perceptions | -1.31 | .64 | -2.03 | .042 | -2.72 | .26 | -2.82 | .04 |
| Patient Comfort: Gen. | -.92 | .64 | -1.45 | .148 | -2.52 | .37 | -2.49 | .47 |
| Patient Comfort: Med | .43 | .70 | .62 | .54 | -1.52 | 1.83 | -1.34 | 2.00 |
| Total Indirect Effects | -1.80 | .46 | -3.90 | <.001 | -3.28 | -.79 | -2.97 | -.72 |

Table 10.1. Mediation Model: The Effect of HIV Stigma on Disclosure of Lifetime Sexual Partners through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship. (LOG)

| Path | Point Estimate | Product of Coefficients | | | <u>Bootstrapping</u> | | | |
|------------------------|----------------|-------------------------|----------|----------|----------------------|-------|----------------------------|-------|
| | | SE | Z | <i>p</i> | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
| | | | | | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | -.11 | .24 | -.47 (t) | .64 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Stigma Perceptions | -.28 | .26 | -1.05 | .292 | -.83 | .30 | -.88 | .26 |
| Patient Comfort: Gen. | -.28 | .29 | -.97 | .33 | -.95 | .33 | -1.00 | .32 |
| Patient Comfort: Sex | .70 | .26 | 2.66 | .008 | .26 | 1.32 | .26 | 1.38 |
| Total Indirect Effects | .15 | .19 | .76 | .45 | -.23 | .52 | -.20 | .58 |

Table 10.2. Mediation Model: The Effect of HIV Stigma on Disclosure of Sexual Partners in Past Three Months through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship. (LOG)

| Path | Point Estimate | Product of Coefficients | | | <u>Bootstrapping</u> | | | |
|------------------------|----------------|-------------------------|----------|----------|----------------------|-------|----------------------------|-------|
| | | SE | Z | <i>p</i> | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
| | | | | | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | -.03 | .10 | -.33 (t) | .74 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Stigma Perceptions | -.08 | .11 | -.72 | .469 | -.34 | .26 | -.35 | .31 |
| Patient Comfort: Gen. | .12 | .12 | 1.00 | .319 | -.16 | .42 | -.15 | .47 |
| Patient Comfort: Sex | .04 | .10 | .40 | .692 | -.20 | .26 | -.24 | .24 |
| Total Indirect Effects | .09 | .08 | 1.15 | .248 | -.04 | .25 | -.04 | .27 |

Table 10.3. Mediation Model: The Effect of HIV Stigma on Disclosure of Recent Condom Use Neglect through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship.

| Path | Point Estimate | Product of Coefficients | | | <u>Bootstrapping</u> | | | |
|------------------------|----------------|-------------------------|-----------|------|----------------------|-------|----------------------------|-------|
| | | SE | Z | p | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
| | | | | | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | -.67 | .36 | -1.84 (t) | .069 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Stigma Perceptions | .86 | .68 | 1.25 | .210 | -.53 | 2.37 | -.58 | 2.16 |
| Patient Comfort: Gen. | .06 | .79 | .08 | .940 | -1.58 | 1.67 | -1.77 | 1.79 |
| Patient Comfort: Sex | -.42 | .69 | -.61 | .540 | -1.88 | 1.08 | -1.88 | .98 |
| Total Indirect Effects | .50 | .49 | 1.01 | .309 | -.60 | 1.79 | -.65 | 1.67 |

Table 10.4. Mediation Model: The Effect of HIV Stigma Disclosure of Frequency of Alcohol Use through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship. (LOG)

| Path | Point Estimate | Product of Coefficients | | | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
|------------------------|----------------|-------------------------|----------|----------|-------------------|-------|----------------------------|-------|
| | | SE | Z | <i>p</i> | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | -.05 | .07 | -.68 (t) | .500 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Stigma Perceptions | .01 | .08 | .19 | .848 | -.18 | .19 | -.15 | .21 |
| Patient Comfort: Gen. | -.05 | .07 | -.63 | .531 | -.18 | .10 | -.20 | .09 |
| Patient Comfort: Subs. | .05 | .05 | .96 | .338 | -.05 | .16 | -.07 | .16 |
| Total Indirect Effects | .02 | .05 | .40 | .689 | -.10 | .16 | -.10 | .14 |

Table 10.5. Mediation Model: The Effect of HIV Stigma Disclosure of Quantity of Alcohol Use through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship. (LOG)

| Path | Point Estimate | Product of Coefficients | | | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
|------------------------|----------------|-------------------------|---------|----------|-------------------|-------|----------------------------|-------|
| | | SE | Z | <i>p</i> | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | .004 | .04 | .09 (t) | .962 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Stigma Perceptions | -.02 | .08 | -.29 | .774 | -.17 | .12 | -.16 | .13 |
| Patient Comfort: Gen. | -.06 | .08 | -.83 | .409 | -.23 | .12 | -.24 | .10 |
| Patient Comfort: Subs. | .09 | .06 | 1.50 | .134 | -.07 | .24 | -.06 | .23 |
| Total Indirect Effects | .001 | .06 | .01 | .993 | -.13 | .16 | -.15 | .12 |

Table 10.6. Mediation Model: The Effect of HIV Stigma Disclosure of Lifetime Drug Use through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship.

| Path | Point Estimate | Product of Coefficients | | | <u>Bootstrapping</u> | | | |
|------------------------|----------------|-------------------------|----------|----------|----------------------|-------|----------------------------|-------|
| | | SE | Z | <i>p</i> | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
| | | | | | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | -.26 | .42 | -.62 (t) | .537 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Stigma Perceptions | -.65 | .48 | -1.36 | .174 | -1.71 | .35 | -1.65 | .36 |
| Patient Comfort: Gen. | 1.00 | .46 | 2.19 | .028 | .01 | 2.23 | -.12 | 2.09 |
| Patient Comfort: Subs. | -.05 | .34 | -.14 | .893 | -.71 | .66 | -.76 | .63 |
| Total Indirect Effects | .31 | .34 | .90 | .366 | -.38 | .98 | -.45 | .96 |

Table 10.7. Mediation Model: The Effect of HIV Stigma Disclosure of Drug Use in Past Three Months through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship. (LOG)

| Path | Point Estimate | Product of Coefficients | | | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
|------------------------|----------------|-------------------------|-----------|----------|-------------------|-------|----------------------------|-------|
| | | SE | Z | <i>p</i> | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | -.08 | .08 | -1.33 (t) | .323 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Stigma Perceptions | -.12 | .09 | -1.33 | .184 | -.28 | .04 | -.31 | .05 |
| Patient Comfort: Gen. | .20 | .08 | 2.36 | .018 | .05 | .39 | .05 | .38 |
| Patient Comfort: Subs. | -.04 | .06 | -.67 | .502 | -.06 | .14 | -.19 | .11 |
| Total Indirect Effects | .04 | .06 | .67 | .506 | -.06 | .14 | -.06 | .14 |

Table 10.8. Mediation Model: The Effect of HIV Stigma Disclosure of Recency of Missed HAART Doses through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship. (LOG)

| Path | Point Estimate | Product of Coefficients | | | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
|------------------------|----------------|-------------------------|-----------|------|-------------------|-------|----------------------------|-------|
| | | SE | Z | p | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | -.08 | .08 | -1.06 (t) | .293 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Stigma Perceptions | -.01 | .09 | -.06 | .949 | -.14 | .13 | -.13 | .13 |
| Patient Comfort: Gen. | .04 | .09 | .47 | .639 | -.14 | .25 | -.13 | .25 |
| Patient Comfort: Med | -.04 | .10 | -.40 | .693 | -.21 | .20 | -.23 | .18 |
| Total Indirect Effects | -.003 | .06 | -.05 | .960 | -.10 | .10 | -.11 | .10 |

Table 10.9. Mediation Model: The Effect of HIV Stigma Disclosure of HAART Non-Adherence through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship. (LOG)

| Path | Point Estimate | Product of Coefficients | | | <u>Bootstrapping</u> | | | |
|------------------------|----------------|-------------------------|----------|----------|----------------------|-------|----------------------------|-------|
| | | SE | Z | <i>p</i> | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
| | | | | | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | -.05 | .14 | -.35 (t) | .731 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Stigma Perceptions | .07 | .16 | .42 | .677 | -.23 | .39 | -.24 | .36 |
| Patient Comfort: Gen. | -.26 | .16 | -1.62 | .105 | -.58 | .06 | -.63 | 0.00 |
| Patient Comfort: Med | .24 | .18 | 1.34 | .180 | -.27 | .59 | -.15 | .62 |
| Total Indirect Effects | .04 | .11 | .40 | .689 | -.21 | .25 | -.15 | .26 |

Table 11.1 Alternate Single Mediator Models for Disclosure Outcomes-Model Fit Summary

| Dependent Variables | Model Summary | | |
|---|-------------------------|---------|-------|
| | Adjusted R ² | df | F |
| Disclosure of Lifetime Sexual Partners ^a | .058 | (2, 74) | 3.32* |
| Disclosure of Lifetime Drug Use | .027 | (2, 87) | 2.25 |
| Disclosure of Recent Drug Use ^a | .030 | (2, 85) | 1.69 |

Note: ^aAnalyses performed on Log transformations of these outcome measures.

Table 11.2 Alternate Single Mediator Model: The Effect of HIV Stigma on Disclosure of Lifetime Sexual Partners through Patients' Feelings of Disclosure-Specific Comfort. (LOG)

| Path | Point Estimate | Product of Coefficients | | | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
|----------------------|----------------|-------------------------|-----------|-----|-------------------|-------|----------------------------|-------|
| | | SE | Z | p | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | -.32 | .20 | -1.57 (t) | .12 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Patient Comfort: Sex | .35 | .14 | 2.47 | .01 | .14 | .6 | .12 | .61 |

Note: ^aAnalyses performed on Log transformations of these outcome measures.

Table 11.3 Alternate Single Mediator Model: The Effect of HIV Stigma Disclosure of Lifetime Drug Use through Patients' Feelings of General Comfort.

| Path | Point Estimate | Product of Coefficients | | | Bootstrapping | | | |
|-----------------------|----------------|-------------------------|-----------|-----|-------------------|-------|----------------------------|-------|
| | | SE | Z | p | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
| | | | | | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | -.54 | .37 | -1.44 (t) | .15 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Patient Comfort: Gen. | .58 | .28 | 2.09 | .04 | .09 | 1.12 | -.03 | 1.08 |

Table 11.4 Alternate Single Mediator Model: The Effect of HIV Stigma Disclosure of Recent Drug Use through Patients' Feelings of General Comfort. (LOG)

| Path | Point Estimate | Product of Coefficients | | | Bootstrapping | | | |
|-----------------------|----------------|-------------------------|-----------|----------|-------------------|-------|----------------------------|-------|
| | | SE | Z | <i>p</i> | Percentile 95% CI | | Bias Corr. & Accel. 95% CI | |
| | | | | | Lower | Upper | Lower | Upper |
| <i>Direct</i> | | | | | | | | |
| Stigma Condition | -.13 | .07 | -1.90 (t) | .06 | | | | |
| <i>Indirect</i> | | | | | | | | |
| Patient Comfort: Gen. | .09 | .05 | 1.86 | .06 | .01 | .19 | .01 | .19 |

Figure Captions

Figure 1. Interactional Model of Client Health Behavior

Figure 2. Mediation Model of Provider Stigma's Effects to HIV+ Patients' Engagement
in Care

Figure 3. Characterization of the "Non-Stigma" Treatment Vignette-Long Version

Figure 4. Characterization of the "Stigma" Treatment Vignette-Long Version

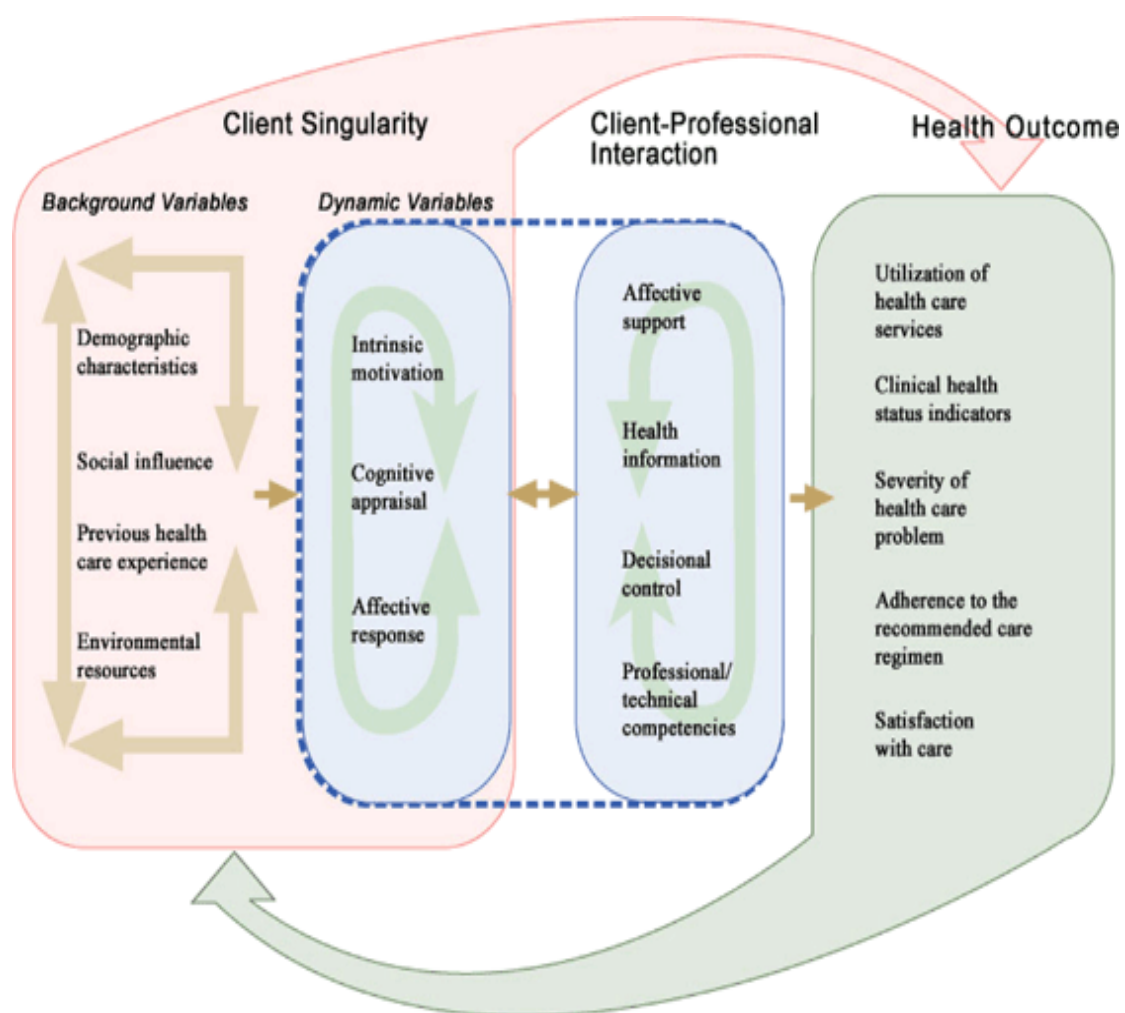
Figure 5. Characterization of the "Non-Stigma" Treatment Vignette-Short Version

Figure 6. Characterization of the "Stigma" Treatment Vignette-Short Version

Figures 7.1-7.4. Intention-Based Mediation Models

Figures 8.1-8.9. Disclosure-Based Mediation Models

Figure 1. Interaction Model of Client Health Behavior (Cox, 1982)



*Note: Specific diagram representation from Mathews, Secrest, & Muirhead (2008).

Figure 2. Mediation Model of Provider Stigma's Effects to HIV+ Patients' Engagement in Care

| <u>Predictor Variable</u> | <u>Mediation Variables</u> | <u>Dependent Variables</u> |
|---------------------------|--|----------------------------|
| Stigma Manipulation | Comfort and Perception of Stigmatization | Engagement in Care |

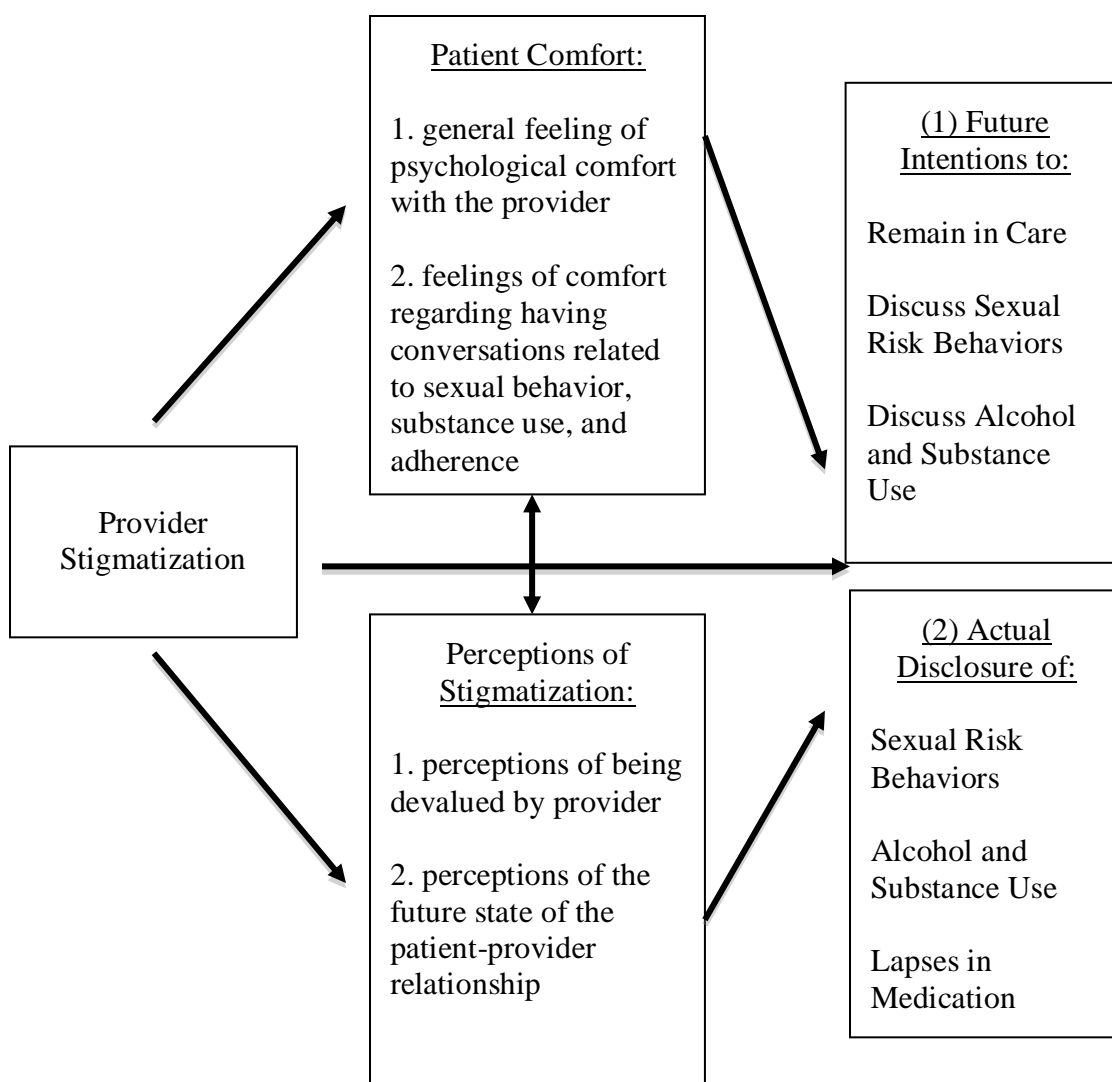


Figure 3. Characterization of the “Non-Stigma” Treatment Vignette-Long Version



1.

2.

*3.

*4.

Order of Computerized Protocol:

1. “non-stigma” Segment 1 Audio: (Narrator) Dr. Smith knocked on the door before entering into the room. She approached Mr. Johnson and shook his hand while introducing herself. Looking him in the eye, she asked, “How are you doing today?” (Actor)
Manipulated Independent Variables: touch (handshake), eye contact (maintained)

Comfort Measure: Imagine that you are the patient portrayed in this vignette. Now please rate you feelings of . . . comfort . . . worry

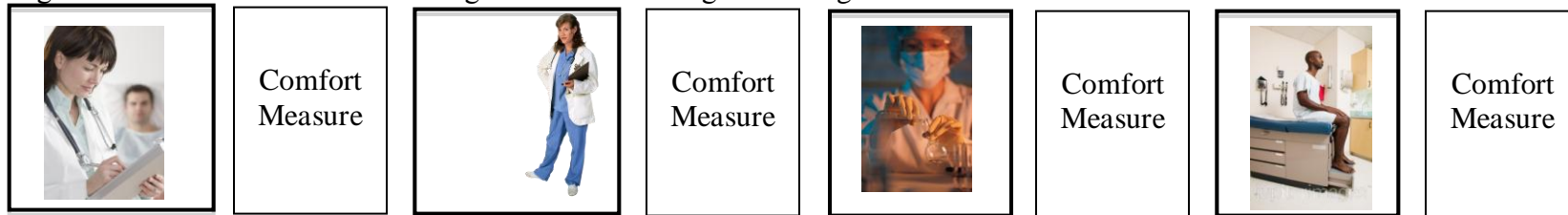
2. “non-stigma” Segment 2 Audio: (Narrator) Dr. Smith takes a seat in a chair a few feet away from the exam table where Mr. Johnson is sitting and begins reviewing his chart. She says (Actor: calm, pleasant tone), “Mr. Johnson I would like to confirm a few things in your medical history to make sure I have the most correct and current information. It says that you tested positive for HIV five years ago, most likely from sexual activity with men.” Mr. Johnson replied, “Yeah, that’s the story.” Dr. Smith (Actor: same calm, pleasant tone): “Ok, and it says that you began taking anti-retroviral medications pretty soon after the diagnosis.” Mr. Johnson replied: “Yeah it was within a few months.”
Manipulated Independent Variables: proximity in room (close), language and tone (non-judgmental)

Comfort Measure: Imagine that you are the patient portrayed in this vignette. Now please rate you feelings of . . . comfort . . . worry .

* Segments 3 and 4 proceed in similar fashion with comfort ratings following each segment.

Note: Pictures shown above are not exact representations. They are intended only to demonstrate the basic layout of the protocol.

Figure 4. Characterization of the “Stigma” Treatment Vignette-Long Version



1.

2.

*3.

*4.

Order of Computerized Protocol:

1. “stigma” Segment 1 Audio: (Narrator) Dr. Smith knocked on the door before entering into the room. She took a few steps into the room while introducing herself. While looking at the medical chart, she asked, “How are you doing today? (Actor)”.

Manipulated Independent Variables: touch (no handshake), eye contact (lacking)

Comfort Measure: Imagine that you are the patient portrayed in this vignette. Now please rate you feelings of . . . comfort . . . worry .

2. “stigma” Segment 2 Audio: (Narrator) Dr. Smith takes a seat in a chair across the room from the exam table where Mr. Johnson is sitting and begins reviewing his chart. She says (Actor: calm, unpleasant tone), “Mr. Johnson I would like to confirm a few things in your medical history to make sure I have the most correct and current information. It says that you tested positive for HIV five years ago, having gotten infected because you were sleeping with other men.” Mr. Johnson replied, “Yeah, that’s the story.” Dr. Smith (Actor: sarcastic tone): “Not surprising. It also says that you began taking anti-retroviral medications pretty soon after the diagnosis.” Mr. Johnson replied: “Yeah, it was within a few months.”

Manipulated Independent Variables: proximity in room (far), language and tone (judgmental)

Comfort Measure: Imagine that you are the patient portrayed in this vignette. Now please rate you feelings of . . . comfort . . . worry .

* Segments 3 and 4 proceed in similar fashion with comfort ratings following each segment.

Figure 5. Characterization of the “Non-Stigma” Treatment Vignette-Short Version



Order of Computerized Protocol:

1. “non-stigma” Segment 1 Audio: (Narrator) Dr. Smith knocked on the door before entering into the room. She approached Mr. Johnson and shook his hand while introducing herself. Looking him in the eye, she asked, “How are you doing today?” (Actor)
Manipulated Independent Variables: touch (handshake), eye contact (maintained)
2. “non-stigma” Segment 2 Audio: (Narrator) Dr. Smith takes a seat in a chair a few feet away from the exam table where Mr. Johnson is sitting and begins reviewing his chart. She says (Actor: calm, pleasant tone), “Mr. Johnson I would like to confirm a few things in your medical history to make sure I have the most correct and current information. It says that you tested positive for HIV five years ago, most likely from sexual activity with men.” Mr. Johnson replied, “Yeah, that’s the story.” Dr. Smith (Actor: same calm, pleasant tone): “Ok, and it says that you began taking anti-retroviral medications pretty soon after the diagnosis.” Mr. Johnson replied: “Yeah it was within a few months.”
Manipulated Independent Variables: proximity in room (close), language and tone (non-judgmental)

* Segments 3 and 4 proceed in similar fashion.

Comfort Measure: Imagine that you are the patient portrayed in this vignette. Now please rate you feelings of . . . comfort . . . worry .

Note: Pictures and narratives shown above are not exact representations. They are intended only to demonstrate the basic layout of the protocol.

Figure 6. Characterization of the “Stigma” Treatment Vignette-Short Version



Order of Computerized Protocol:

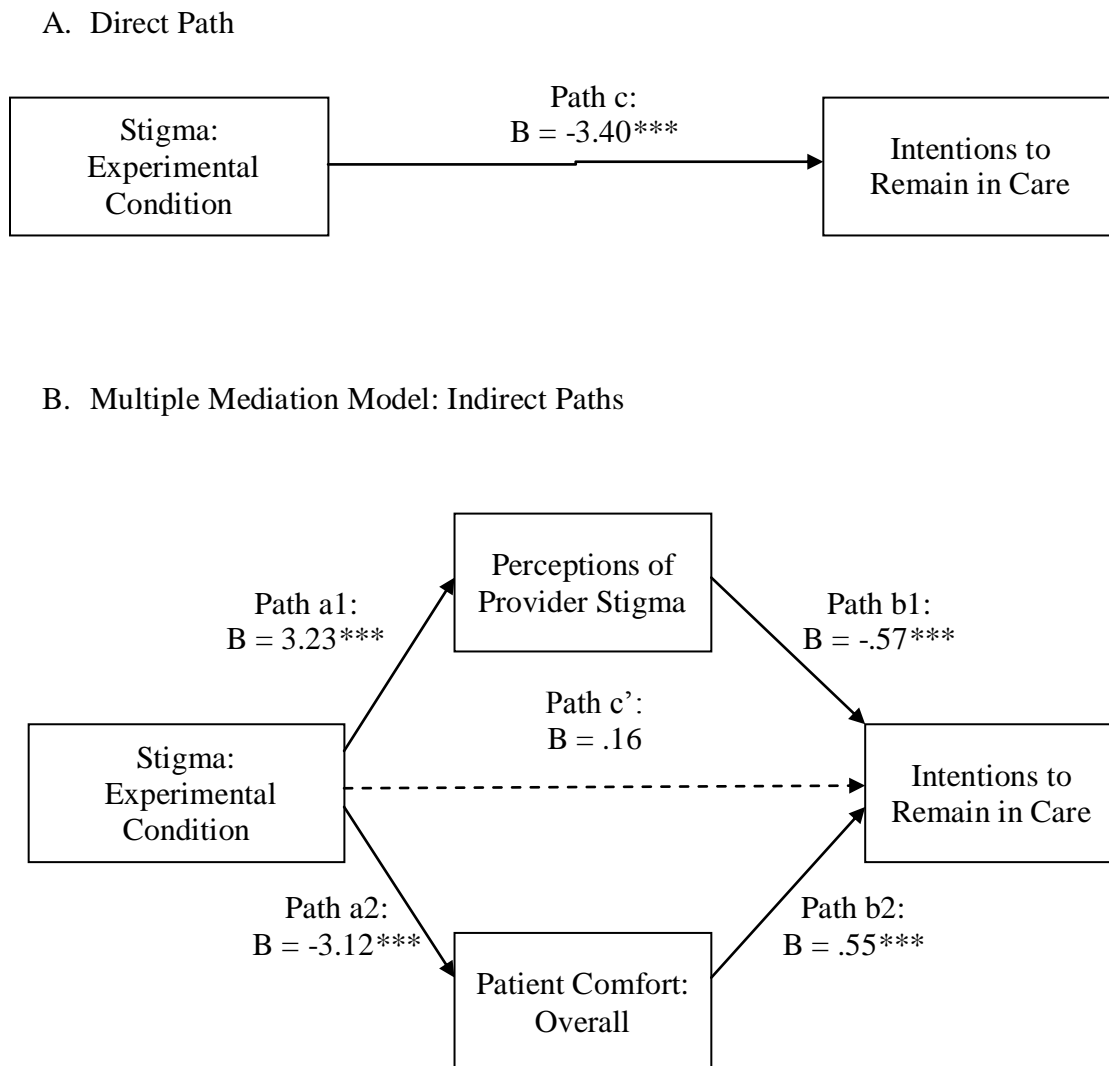
1. “stigma” Segment 1 Audio: (Narrator) Dr. Smith knocked on the door before entering into the room. She took a few steps into the room while introducing herself. While looking at the medical chart, she asked, “How are you doing today? (Actor)”.
Manipulated Independent Variables: touch (no handshake), eye contact (lacking)
2. “stigma” Segment 2 Audio: (Narrator) Dr. Smith takes a seat in a chair across the room from the exam table where Mr. Johnson is sitting and begins reviewing his chart. She says (Actor: calm, unpleasant tone), “Mr. Johnson I would like to confirm a few things in your medical history to make sure I have the most correct and current information. It says that you tested positive for HIV five years ago, having gotten infected because you were sleeping with other men.” Mr. Johnson replied, “Yeah, that’s the story.” Dr. Smith (Actor: sarcastic tone): “Not surprising. It also says that you began taking anti-retroviral medications pretty soon after the diagnosis.” Mr. Johnson replied: “Yeah, it was within a few months.”
Manipulated Independent Variables: proximity in room (far), language and tone (judgmental)

* Segments 3 and 4 proceed in similar fashion.

Comfort Measure: Imagine that you are the patient portrayed in this vignette. Now please rate you feelings of . . . comfort . . . worry

Note: Pictures and narratives shown above are not exact representations. They are intended only to demonstrate the basic layout of the protocol.

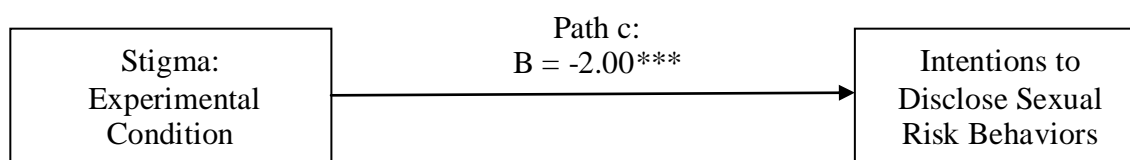
Figure 7.1. Mediation Model: The Effect of HIV Stigma on Intentions to Remain in Care through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship.



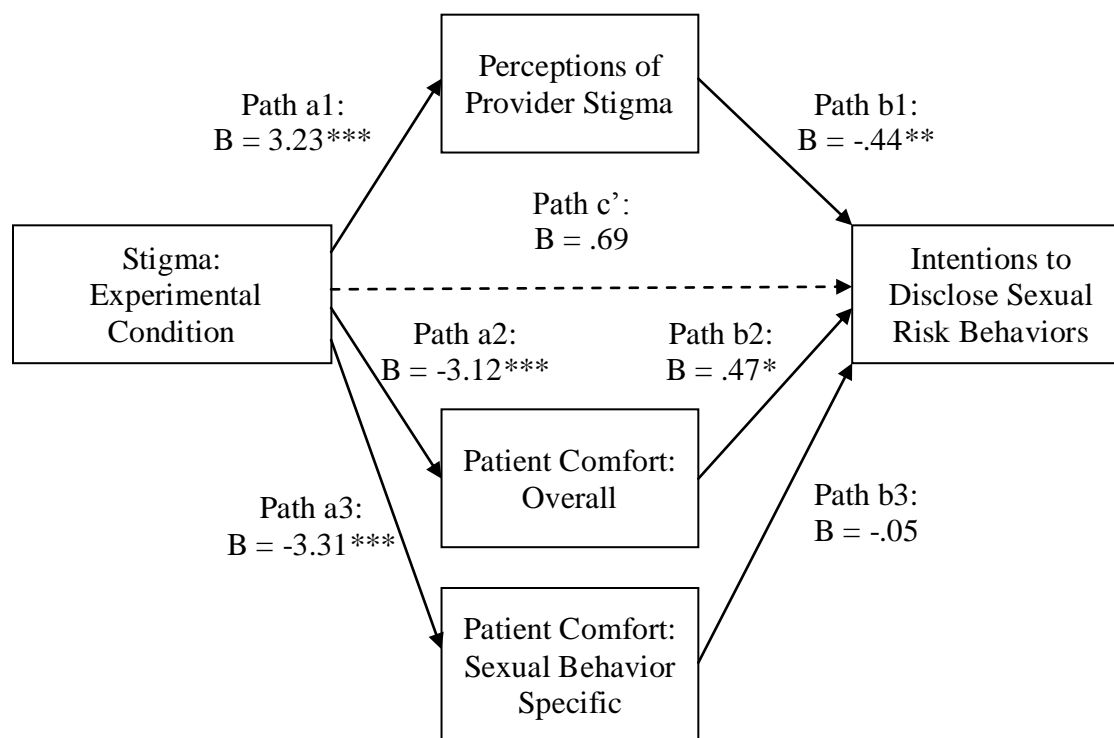
Note: [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Figure 7.2. Mediation Model: The Effect of HIV Stigma on Intentions to Disclose Sexual Risk Behavior through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship.

C. Direct Path

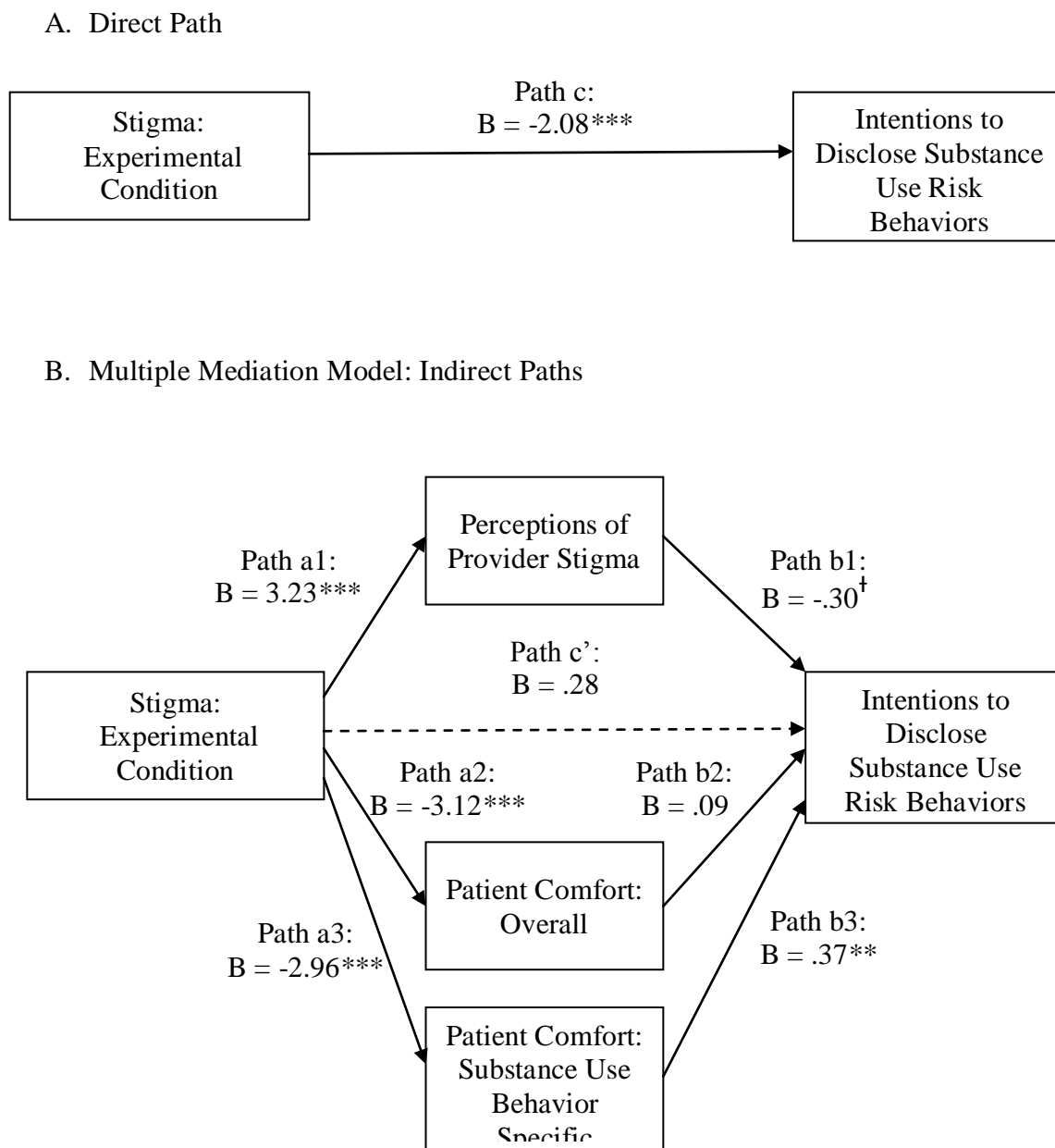


D. Multiple Mediation Model: Indirect Paths



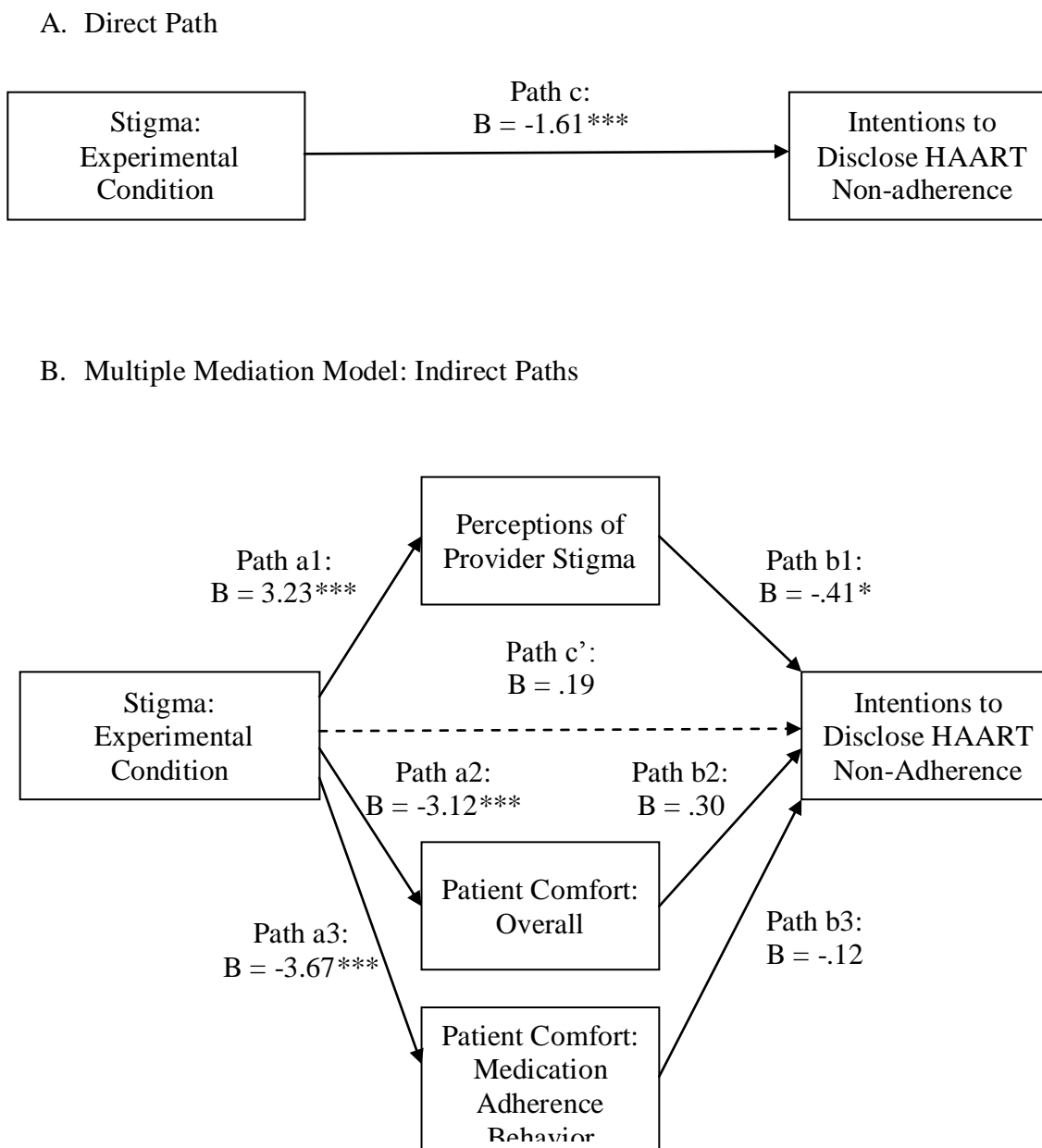
Note: [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Figure 7.3. Mediation Model: The Effect of HIV Stigma on Intentions to Disclose Substance Use Related Risk Behavior through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship.



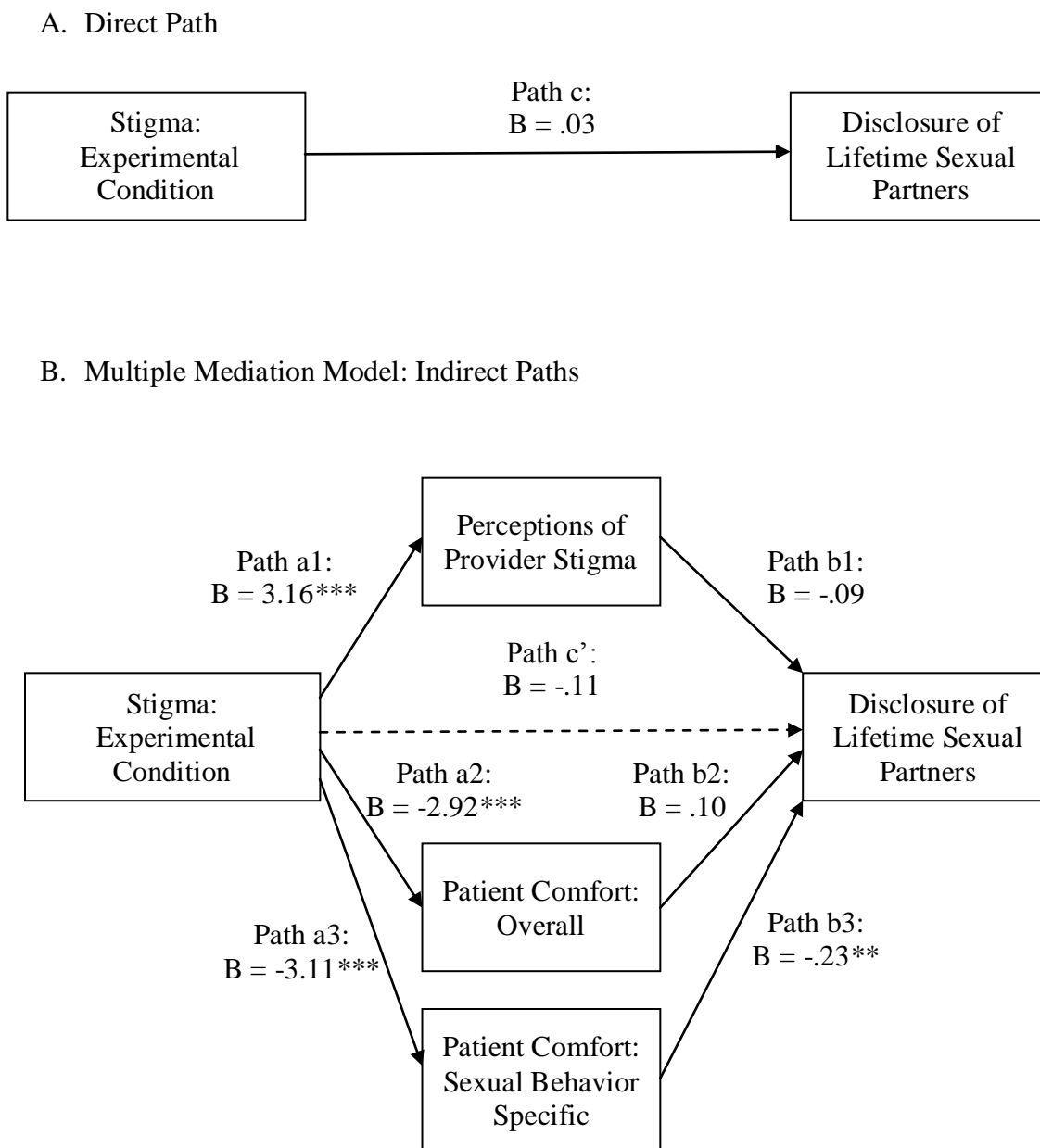
Note: [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Figure 7.4. Mediation Model: The Effect of HIV Stigma on Intentions to Disclose HAART Non-Adherence through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship.



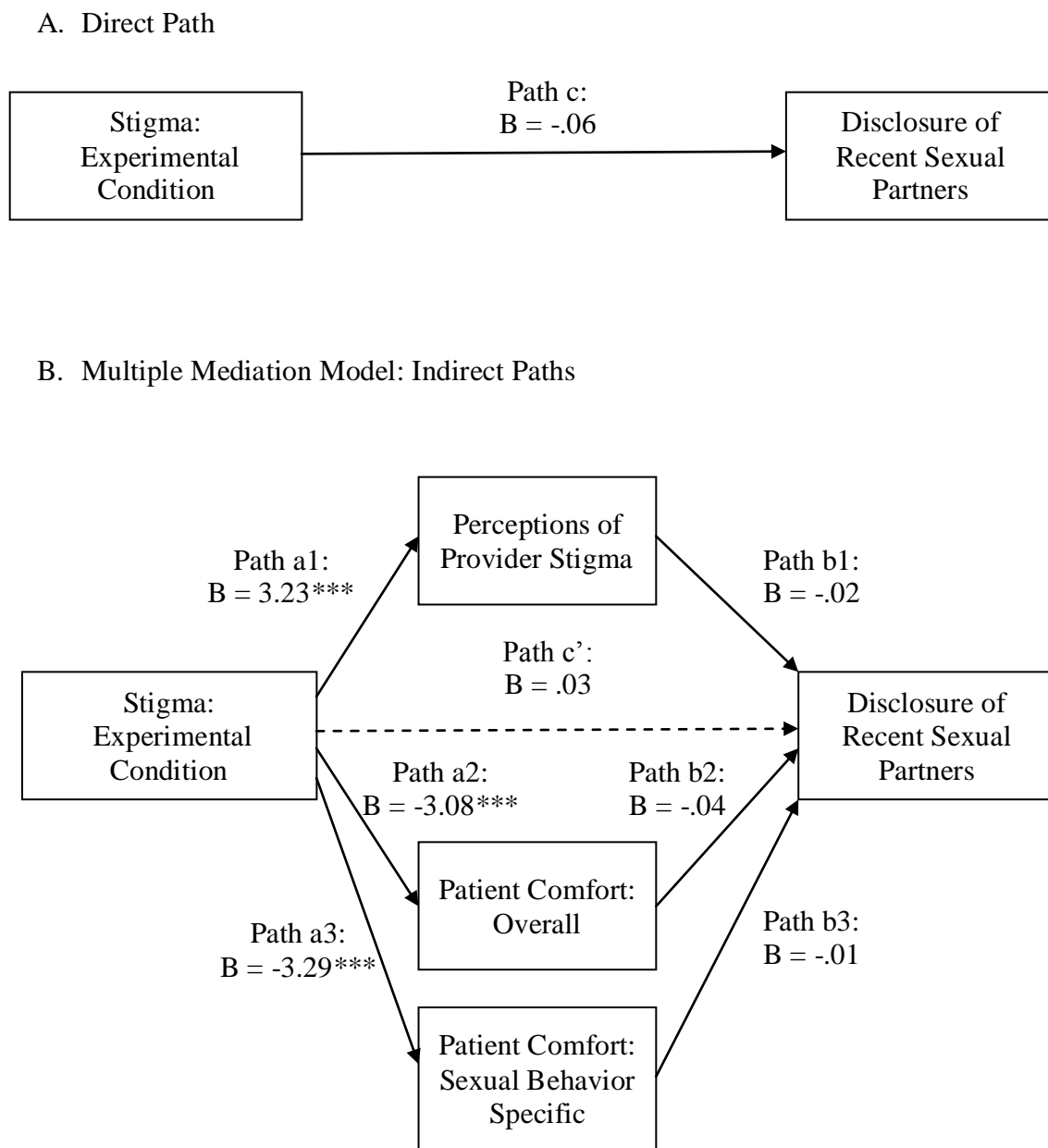
Note: [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Figure 8.1. Mediation Model: The Effect of HIV Stigma on Disclosure of Lifetime Sexual Partners through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship. (LOG)



Note: [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

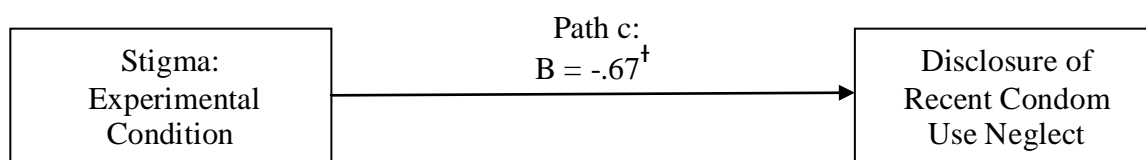
Figure 8.2. Mediation Model: The Effect of HIV Stigma on Disclosure of Sexual Partners in Past Three Months through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship. (LOG)



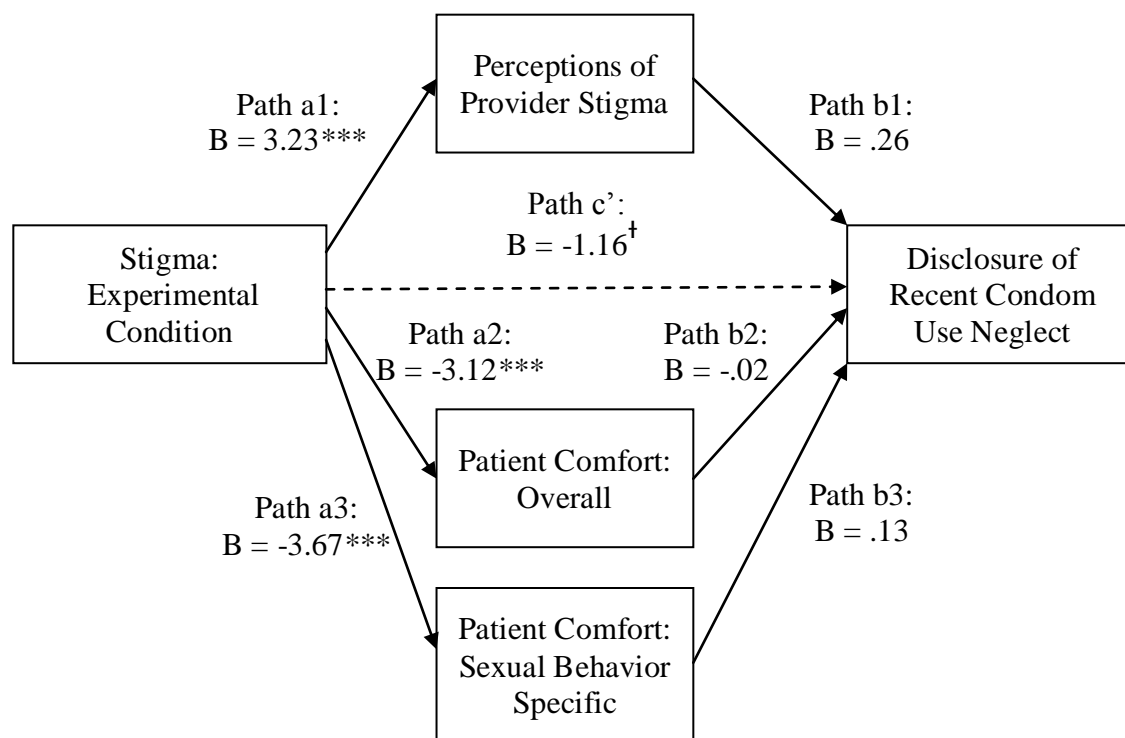
Note: [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Figure 8.3. Mediation Model: The Effect of HIV Stigma on Disclosure of Recent Condom Use Neglect through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship.

A. Direct Path

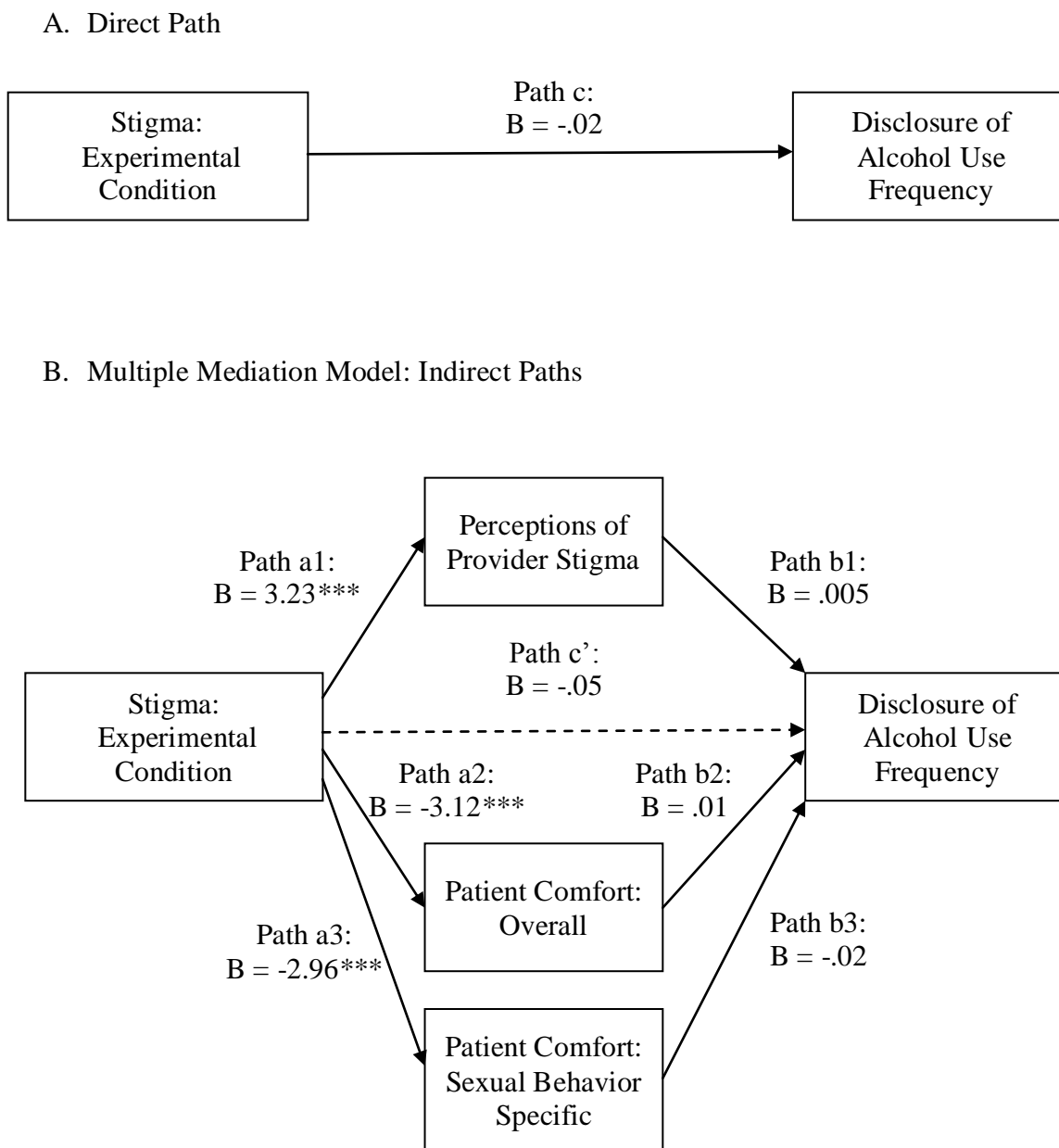


B. Multiple Mediation Model: Indirect Paths



Note: [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

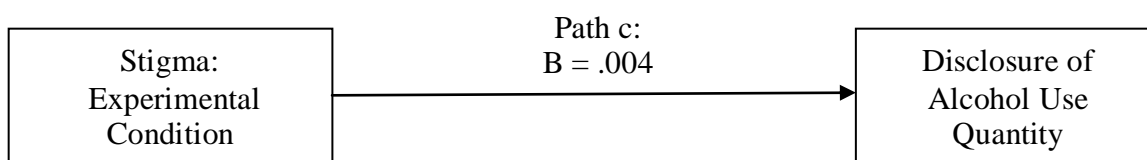
Figure 8.4. Mediation Model: The Effect of HIV Stigma Disclosure of Frequency of Alcohol Use through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship. (LOG)



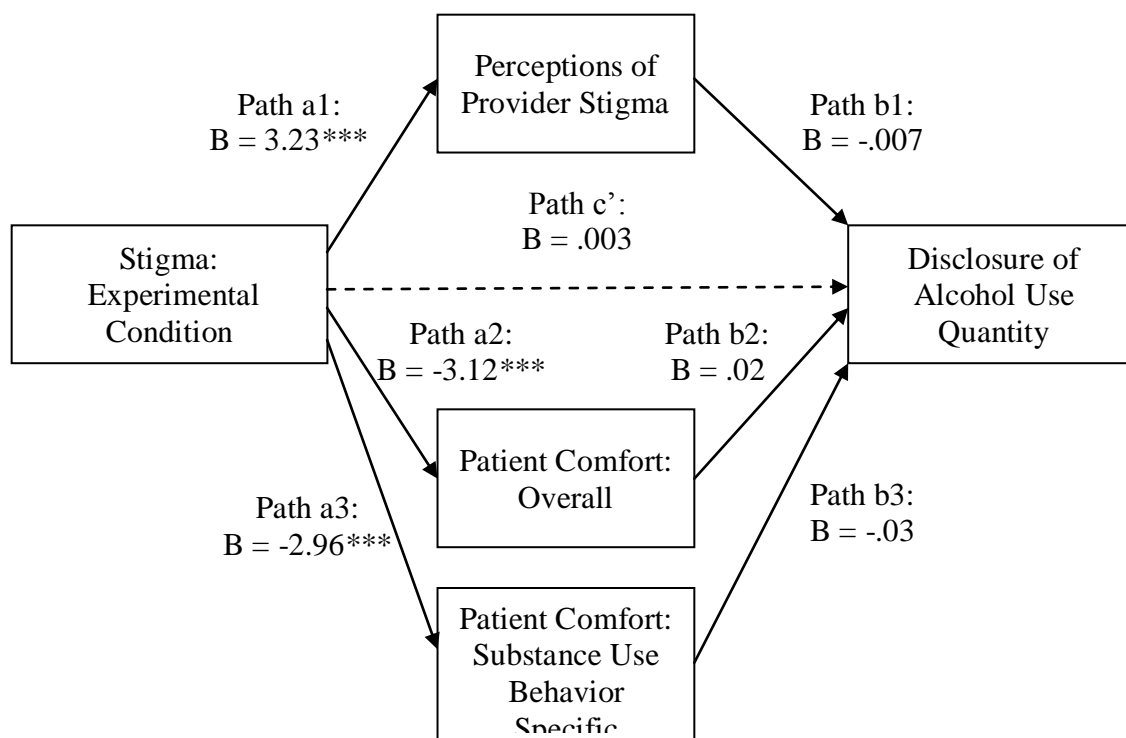
Note: [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Figure 8.5. Mediation Model: The Effect of HIV Stigma Disclosure of Quantity of Alcohol Use through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship. (LOG)

A. Direct Path



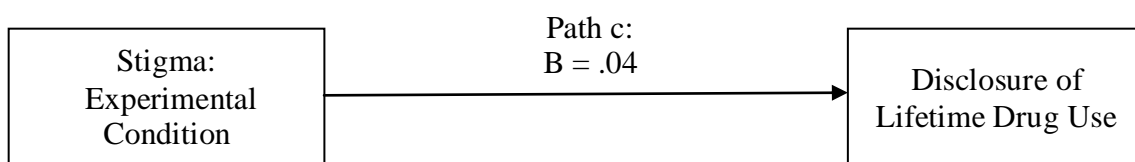
B. Multiple Mediation Model: Indirect Paths



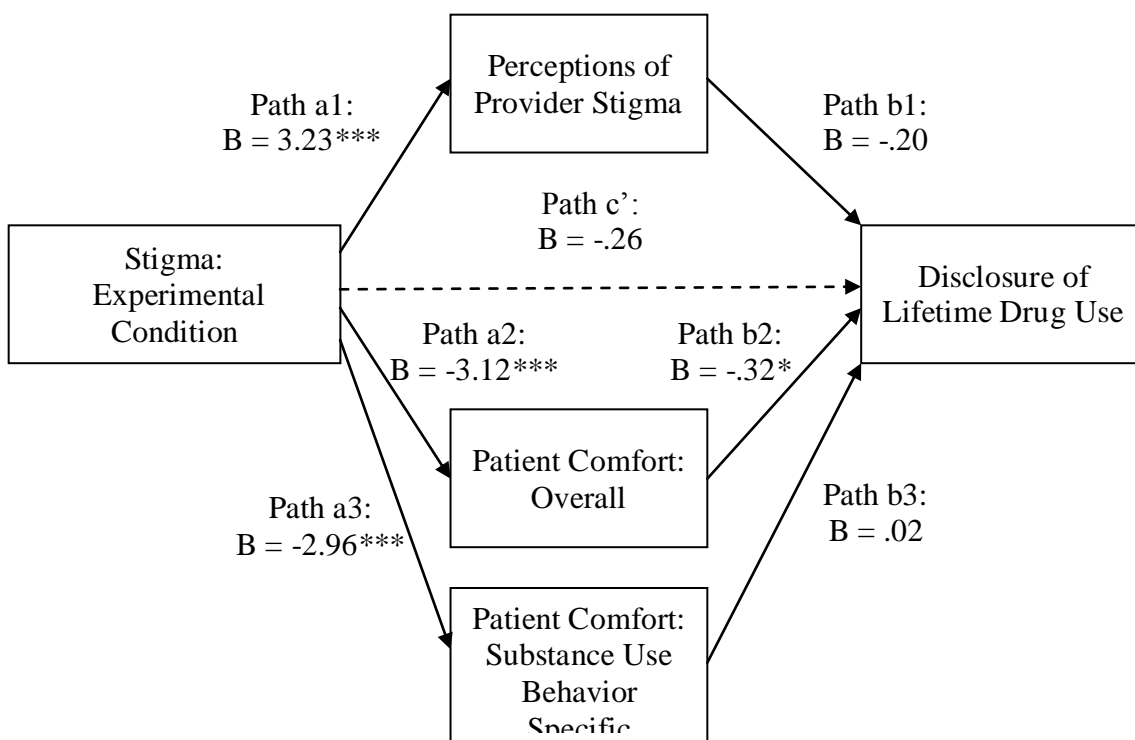
Note: [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Figure 8.6. Mediation Model: The Effect of HIV Stigma Disclosure of Lifetime Drug Use through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship.

A. Direct Path

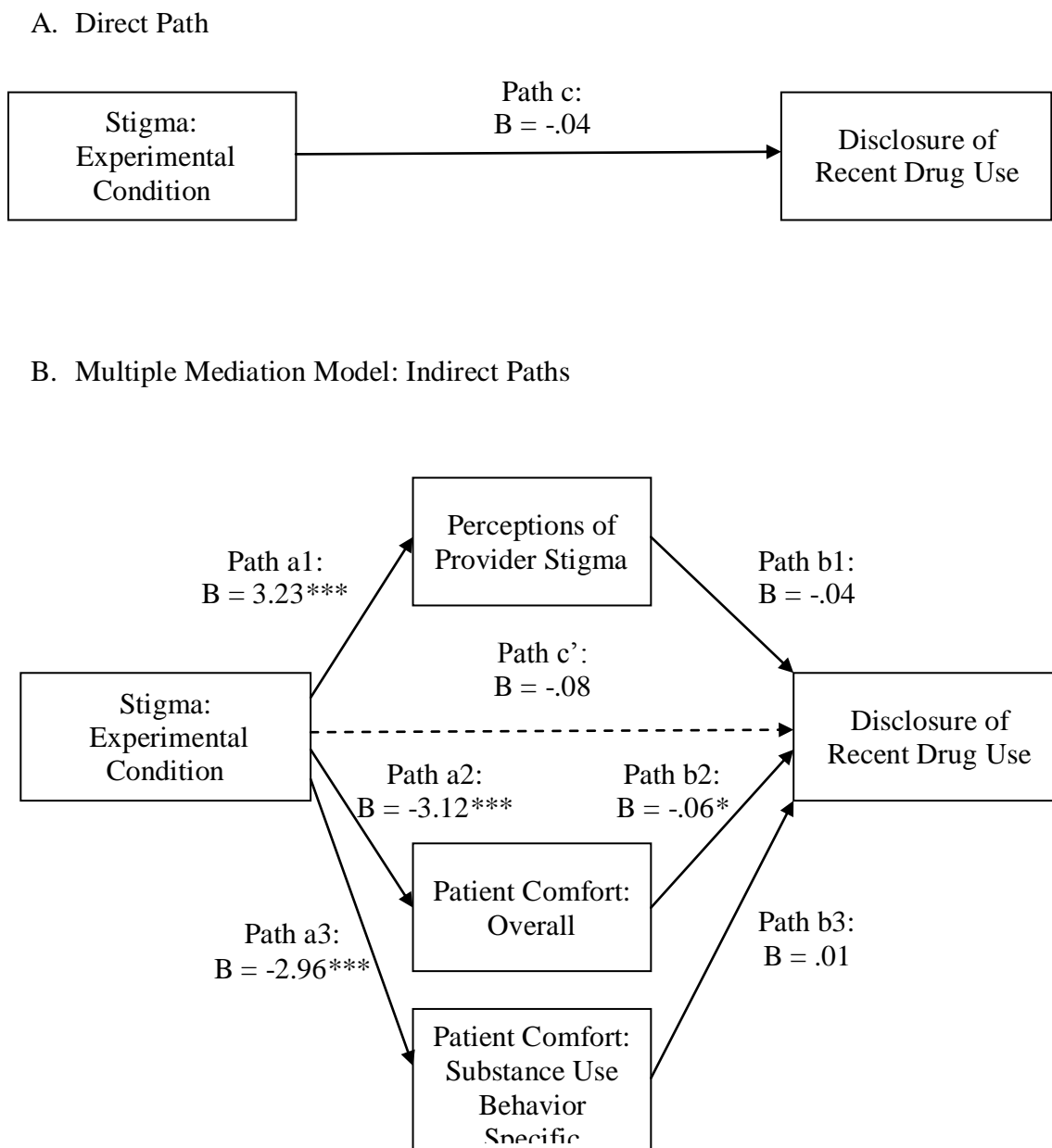


B. Multiple Mediation Model: Indirect Paths



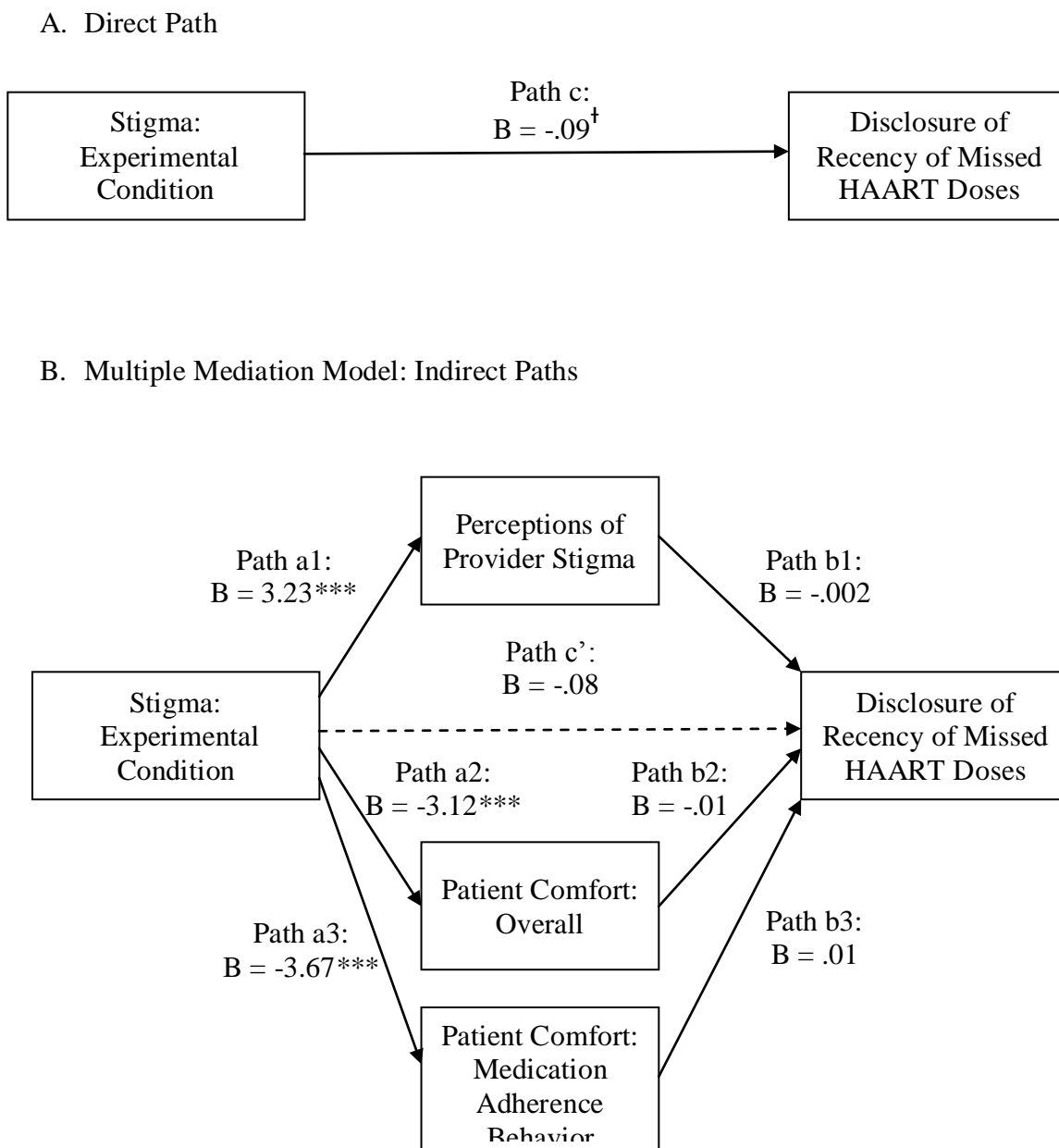
Note: [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Figure 8.7. Mediation Model: The Effect of HIV Stigma Disclosure of Drug Use in Past Three Months through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship. (LOG)



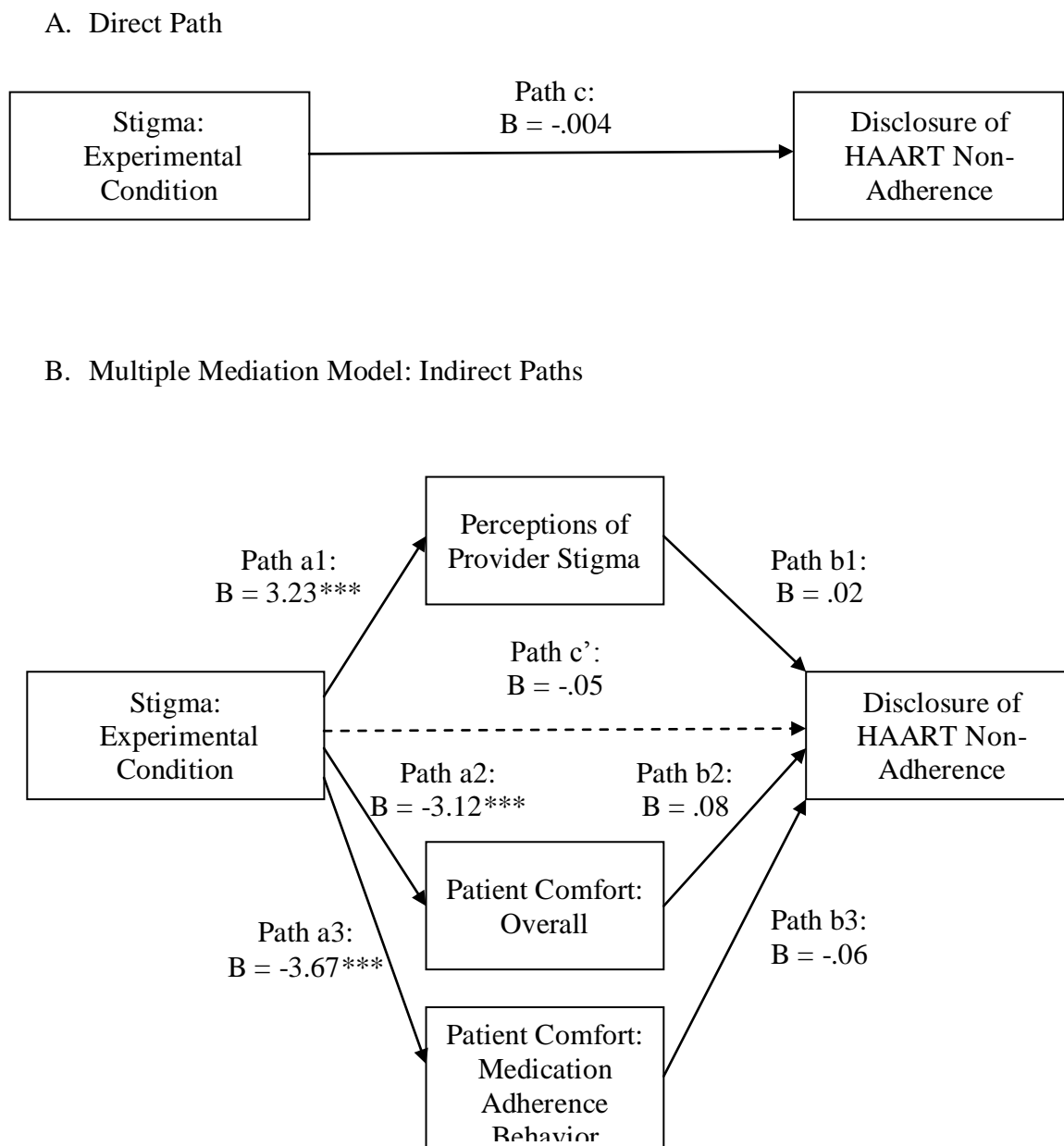
Note: [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Figure 8.8. Mediation Model: The Effect of HIV Stigma Disclosure of Recency of Missed HAART Doses through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship. (LOG)



Note: † trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Figure 8.9. Mediation Model: The Effect of HIV Stigma Disclosure of HAART Non-Adherence through Patients' Feelings of Comfort and their Perceptions of Stigmatization within the Patient Provider Relationship. (LOG)



Note: [†] trend at $p < .1$, * $p < .05$, ** $p < .01$, *** $p < .001$

Appendices

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Appendix A

Demographics and Medical Information

Background

These questions ask about your background. Please remember that all information you provide is completely confidential. Do not put your name on this form.

1. What is the highest grade in school that you have ever completed? (circle correct number below)

1 2 3 4 5 6 7 8 9 10 11 12 (12 = high school degree)

13 14 15 16(= bachelors' degree) 17 18(= masters' degree) 19

20(=doctoral degree)

2. What is your current age? _____

3. What is your Date of Birth ____ / ____ / ____

4. Do you consider yourself to be Hispanic/Latina/Latino? No Yes

5. Which of the following best describes your racial/ethnic background? Is it...

1 African-American or Black 4 American Indian or Alaska Native

2 White or Caucasian 5 Mixed or Multiracial

3 Asian or Pacific Islander 6 Other

6. Do you identify as:

1 2 3
female male transgender

7. Do you identify as

1 gay/homosexual 2 heterosexual/straight

3 bisexual 4 other

8. Based on your past behavior, which of the following statements applies best to you?

1 I have sex with men only.

2 I have sex mostly with men.

3 I have sex with men and women equally.

4 I have sex mostly with women.

5 I have sex with women only.

9. Are you currently employed?

no

yes → 10. How many hours per week do you work? _____

11. Which best describes your current relationship status?

1 I have a main or primary partner, and we live together

2 I have a main or primary partner, but we live separately

3 I don't currently have a primary partner

12. Is English your first language? No Yes

13. Where do you live?

1 My own apartment

2 My own home

3 My family's house or apartment

4 Someone else's house or apartment(not family)

5 A rooming house or single room hotel

6 A shelter

7 A group home or halfway house

8 Other: please specify other: _____

14. Approximately how much money do you have to live off of in an average month?

This includes money that goes toward paying your rent, utilities, and other
monthly bills. \$ _____

15. How old were you when you first learned that you were HIV+? _____ years old.

16. When were you first diagnosed? _____
month year

17. Have you ever been hospitalized for an HIV-related illness?

no

yes

(go to next question)

→ 17a. How many times? _____

18. Have you been diagnosed with AIDS?

no

yes

→ 18a. What was the approximate date? _____

19. What was your CD4 or helper t-cell count in your MOST RECENT test report? (If you are unsure of the exact number, please make as close an approximation as you can.)

CD4 count _____

I don't know

20. What was your MOST RECENT HIV viral load?

1

2

3

Undetectable Don't know Number: _____

21. Are you currently taking HIV medication(s)?

no

yes



21a. When did you start taking HIV meds? _____

22. Approximately how many medical appointments at the Infectious Disease Clinic have you missed in the past year? _____

23. What is the most likely way that you became infected with HIV?

1 Sex with a man who was HIV+

2 Sex with a woman who was HIV+

3 Blood Transfusion

4 Sharing Needles

5 Other

6 I don't know

Appendix B
Qualitative Interview Guide

Qualitative Focus Group Interview Guide

Introduction and Consent

Facilitator will introduce herself and review the major points of the consent form with the group as mentioned in the protocol:

- **WHO:** The project directors for this study are Jessie Heath, M.S., a clinical psychology doctoral student at Syracuse University and Dr. Peter Venable, an associate professor of psychology at Syracuse University and an adjunct assistant professor of medicine at SUNY Upstate Medical University.
- **PURPOSE & PROCEDURE:** You are being asked to participate in a research study designed to learn more about effects of positive and negative treatment experiences of persons living with HIV. Our goal is to identify what medical provider behaviors are viewed as stigmatizing by HIV+ patients and gain a better understanding of how stigmatizing behaviors of medical care providers can affect the HIV+ patients they treat. We will use the information obtained in this study to inform the development of strategies to reduce the stigmatization of HIV+ patients in medical care settings.
- **TIME & COMPENSATION:** Your participation involves a group discussion and filling out a short questionnaire, a total of 2 hours. You will receive \$20 for your time.
- **RISKS/BENEFITS:**
 - Embarrassment or discomfort: Some of the things we will talk about in the group discussion involved sensitive, private information. You are invited to share as much or as little information as you desire, you can refuse to answer any question you feel is too personal.
 - Breach of confidentiality: Because we will be meeting in a group, there is the potential for other group members to tell other people what you say during the discussion. We will try to prevent this from happening by asking group members to keep everything that is said in the group discussion confidential.
 - Benefits: You may learn more about your feelings and become aware of how your medical treatment experiences have affected you. In addition, because the information you provide assists in the development of stigma reducing strategies, your participation could benefit others living with HIV.
 - Questions?

Warm-Up

To start out, I'd like you to tell me a little about yourself.

- ❖ What was your experience like learning you have HIV? When were you diagnosed?
- ❖ Have you participated in research before? What do you think about research? What do you think about involving people with HIV?

I. Negative Experiences in Medical Care

I'd like to start by asking you a few questions about your experiences with in medical care.

- ❖ In thinking specifically about medical care, what have been some of your most negative experiences with providers like doctors, nurses, med students?
- ❖ Can you tell me about those experiences (what the provider specifically did or said, how you felt, when it occurred)?
- ❖ Why do you think they behaved that way towards you?

II. Stigmatization in Medical Care

Now I would like to talk to you about a specific kind of negative experience in medical care that HIV+ patients like yourself have reported in the past, namely stigmatization or stigma.

- ❖ When I say the word “stigma” or “stigmatization”, what comes to mind? How would you explain it to someone?
- ❖ If not reported: Other HIV+ patients have reported these stigmatizing experiences in medical care (e.g. poor eye contact, increased distance, etc.). Have you?
- ❖ How did you know that those experiences were related to being HIV+ vs. an alternative explanation like having a bad doctor or being treated poorly based on racial identity?
- ❖ What would you say are the biggest signs that you are being treated by a stigmatizing provider?

III. Effects of Provider Stigmatization

We've talked about your experiences with stigmatization in medical care. I'd now like to ask you about how you think those experiences have affected you.

- ❖ How do you think provider stigmatization affects you (physical health, mental health, relationships, etc.)?
- ❖ Do you think stigmatization affects your HIV disease progression?
- ❖ Do you think stigmatization affects your relationship with the provider? How?
- ❖ How does stigmatization affect your perceptions of your provider and your care?
- ❖ Have your experiences of provider stigmatization had any lasting effects in your life?
- ❖ If it weren't for my experiences of provider stigmatization, I would have . . .?

IV. Positive Treatment Experiences and Suggestions for Improved Care

Given that we've talked about your negative experiences with medical care, I would also like to know about your positive experiences with providers.

- ❖ Tell me about some of the most positive experiences you've have with medical providers.
- ❖ How did the providers talk to you, behave, and make you feel?
- ❖ What are some signs that your provider is not going to treat you in a stigmatizing way?
- ❖ How have providers gotten you to feel comfortable enough to open up about sensitive information like sexual risk behaviors, substance use, and medication non-adherence?
- ❖ What are some ways your providers could improve your treatment experiences?

V. Feedback

I really appreciate your participation in this study. As we are wrapping up, I would just like to get your feedback on how it felt to be a part of this group today.

- ❖ How did you feel talking with others about your experiences?
- ❖ What did you get out of today's group?
- ❖ Would you be interested in participating in future research projects?

Appendix C

Draft of Qualitative Focus Group Protocol

QUALITATIVE FOCUS GROUP PROCEDURES

I. INFORMED CONSENT

A. OVERVIEW OF CONSENT INFORMATION

A participant who gives their informed consent to participate in the focus group discussion should fully understand the nature of the research study, the purpose and pertinent procedures for the study, potential risks and benefits of participating, confidentiality and steps taken by research team to ensure confidentiality, and how the data will be used and stored.

B. FOCUS GROUP CONFIDENTIALITY CONCERNS

Although a number of steps are taken to ensure confidentiality for every participant, the nature of a discussion group limits our ability to ensure that who attends and what is said in the focus group remains confidential. Breach of confidentiality may occur if other group members choose to directly or indirectly disclose information regarding the identity of group members or the content of what is shared to people outside of the group. The facilitator of the focus group directly addresses this risk during the introduction. Specifically, she states that, “What is said here should stay here. Please respect the privacy of group members by not repeating what is said today outside of the group.”

C. PARTICIPANT CONSENT

After a brief introduction, the focus group facilitator leads the group through the informed consent form, highlighting the most important aspects of informed consent. The following outline illustrates the content that is verbally expressed by the facilitator during this process:

- **WHO:** The project directors for this study are Jessie Heath, M.S., a clinical psychology doctoral student at Syracuse University and Dr. Peter Venable, an associate professor of psychology at Syracuse University and an adjunct assistant professor of medicine at SUNY Upstate Medical University.
- **PURPOSE & PROCEDURE:** You are being asked to participate in a research study designed to learn more about effects of positive and negative treatment experiences of persons living with HIV. Our goal is to identify what medical provider behaviors are viewed as stigmatizing by HIV+ patients and gain a better understanding of how stigmatizing behaviors of medical care providers can affect the HIV+ patients they treat. We will use the information obtained in this study to inform the development of strategies to reduce the stigmatization of HIV+ patients in medical care settings.
- **TIME & COMPENSATION:** Your participation involves a group discussion and filling out a short questionnaire, a total of 2 hours. You will receive \$20 for your time.

- **RISKS/BENEFITS:**
 - Embarrassment or discomfort: Some of the things we will talk about in the group discussion involved sensitive, private information. You are invited to share as much or as little information as you desire, you can refuse to answer any question you feel is too personal.
 - Breach of confidentiality: Because we will be meeting in a group, there is the potential for other group members to tell other people what you say during the discussion. We will try to prevent this from happening by asking group members to keep everything that is said in the group discussion confidential.
 - Benefits: You may learn more about your feelings and become aware of how your medical treatment experiences have affected you. In addition, because the information you provide assists in the development of stigma reducing strategies, your participation could benefit others living with HIV.
- **CONFIDENTIALITY and HIPPA**
 - If you decide to participate, any information that you give us is strictly confidential. We will keep your information private, except under 2 circumstances.
 - First, if you tell us that you're planning to hurt yourself or someone else we would have to disclose that information.
 - Second, if officials were concerned that the research team was acting inappropriately, the research records might be audited to make sure the research was being conducted ethically; however, the auditors would be required to protect your privacy.
- **PROTECTION OF CONFIDENTIALITY**
 - All project staff receive extensive training and supervision on confidentiality procedures.
 - Your survey is given an identification number and only authorized research staff has access to the key that connects your information to your name. Your identity will not be included on the audiotapes and the tapes will be erased once we are finished with the project.
 - Certificate of Confidentiality from the Department of Health and Human services, which states that the investigators cannot be forced to release your information (for example, by subpoena) to any federal, state, or local, civil, criminal, administrative, legislative, or other proceedings. This Certificate does NOT prevent you or your family from voluntarily disclosing information about yourself or your involvement in this research.
- **PARTICIPATION IS VOLUNTARY:** You may refuse to participate or discontinue your participation at any time without penalty or loss of benefits.
- **PERMISSION TO BE RECONTACTED:** The participants are then asked to sign and date one copy of the consent form and keep a second copy for their own records. Participants are also given a copy of University Hospital's Privacy Practices Policy and asked to keep it for their records.

D. STORAGE OF CONSENT FORMS

After pertinent information from the completed consent forms has been entered into the secure Excel patient database, the completed focus group consent forms will be stored in a locked filing cabinet in the UPH office.

II. QUANTITATIVE DEMOGRAPHIC SURVEY ADMINISTRATION

A. ASSIGNMENT OF PARTICIPANT NUMBER

After participants consent to and complete the quantitative demographic questionnaire, they will be assigned a participant ID number.

B. SURVEY ADMINISTRATION

The quantitative demographic survey is administered following the informed consent. The participants are given clipboards to increase privacy in the group settings and are asked to complete the survey as accurately and honestly as possible. When everyone has completed the survey, the surveys are collected and the discussion portion of the focus group begins.

C. DATA ENTRY

Data from the completed quantitative questionnaire will be entered by the principle investigator into SPSS. The PI will then verify the accuracy of the initial data entry by double entering the data.

D. DATA STORAGE

Completed questionnaires will be stored in a locked filing cabinet in the UPH lab space in the CNY Medical Building. No identifying information will be on the completed questionnaire.

III. PROTOCOL FOR FOCUS GROUP ADMINISTRATION

A. RECORDING PROCEDURE

During the focus group, two handheld cassette recorders will be used to record the session. Prior to each focus group, the tape recorders will be tested to ensure that there are no technical problems.

B. FOCUS GROUP SCRIPT

The PC/focus group facilitator will follow the focus group script when leading focus group discussions.

C. PARTICIPANT REIMBURSEMENT

The PI will retrieve reimbursement funds from Sean Kelley prior to the start of the focus group. Participants will be reimbursed \$20 for their two hours of participation in the focus groups. After participants have received their reimbursement, the PI will complete a reimbursement receipt including only the participant's ID number and file it in the UPH filing cabinet under non-reconciled payment receipts. The original reimbursement form will then be turned in to Sean Kelley. A photocopy will be stored in the UPH filing cabinet under reconciled payment receipts.

D. STORAGE OF FOCUS GROUP TAPES

All focus group tapes will be labeled with the tape type (Master vs. Back-up), focus group date, interviewer's initials, and focus group number. Back-up tapes for each group will be stored in a locked filing cabinet in the UPH office.

E. FOCUS GROUP TRANSCRIPTS

The focus group tape will be transcribed, verbatim, by the facilitator. Once the focus group transcripts are completed, an electronic copy will be stored on the UPH computer. A paper copy will be stored in the locked UPH filing cabinet in the folder created specifically for that focus group.

Appendix D

Draft of Qualitative Focus Group Informed Consent Form

**SUNY UPSTATE MEDICAL UNIVERSITY AND
SYRACUSE UNIVERSITY**

Consent/Authorization Form

Title of Study: Treatment Experiences of HIV+ Patients Focus Group Study

Background/Purpose:

You are invited to participate in a research study designed to gain a better understanding of how the behaviors of medical care providers can affect the HIV+ patients they treat. We will use the information obtained in this study to inform the development of strategies to improve patient-provider relationships and the quality of medical care received HIV+ patients. The project directors for this study are Jessie Heath, M.S., a clinical psychology doctoral student at Syracuse University and Dr. Peter Venable, an Associate Professor of Psychology at Syracuse University and an adjunct assistant professor of medicine at SUNY Upstate Medical University. Other trained research staff will also be involved, and will be supervised by Dr. Peter Venable of Syracuse University. We are asking approximately 20 patients from this clinic to participate in the study.

You will be given enough time to read and understand the information provided in this consent and authorization form. Please ask the study staff to explain any words or information that you do not understand. You may keep an unsigned copy of this consent and authorization form to think about your decision or discuss with your family, friends, or doctors before making your decision to take part in this research study.

Study Procedures:

If you decide to take part, you will be asked to share some of your positive and negative medical treatment experiences in a small discussion group that includes other individuals who are HIV+. In the discussion group, we will seek your input about what provider behaviors are seen as stigmatizing to HIV+ individuals and how the experience of stigmatization in medical settings may have affected you. The discussion group will also include questions regarding your suggestions on how HIV care could be improved.

The discussion group will be tape recorded so that we can review all the suggestions and feedback provided by you and other participants. However, your identity will not be included on the audiotapes and the tapes will be erased once we are finished with the project. The discussion group will take approximately 2 hours to complete.

If you agree to participate in the study, you will also be asked to complete a brief survey with questions about your background and health information, including medical appointment attendance, hospitalizations, and recent indicators of health status (CD4 count, viral load).

Risks:

The risks of participating in this study include the possibility of experiencing uncomfortable feelings or distress when discussing your past treatment experiences. These risks will be minimized but not eliminated by our providing you with the opportunity to discuss any concerns that arise after completing the focus group. There is also a risk that information that you provide during this study could be inadvertently disclosed to others, or that a breach in confidentiality could occur regarding your involvement in the study. For example, other individuals who participate in the discussion group may tell other people what you say during the discussion group. However, we will try to prevent this from happening by asking group members not to disclose information that is discussed during the group.

Benefits:

The potential benefit to you is that you may learn more about your feelings and become aware of how your medical treatment experiences have affected you. In addition, because the information you provide may assist in educating health care providers about the best approaches to interacting with patients, your participation could benefit others living with HIV.

Voluntary Participation:

Your participation in this study is entirely voluntary and you may refuse to participate or discontinue participation at any time without penalty or loss of benefits to which you would be normally entitled. Your decision about whether or not to participate in the study will not affect the care you receive at SUNY Upstate Medical University.

Alternatives:

If you decide not to participate in this research study, you will continue to receive your usual care.

Costs/Payments:

There are no costs to you and/or your insurance carrier for participating in this study. You will receive \$20 for your participation.

If you choose to stop participating in the study before all study requirements are completed, you will be paid \$10 for each hour of time you devote to the study.

In addition, by accepting payment for participating in this study, certain identifying information about you may be made available to professional auditors to satisfy audit and Federal reporting requirements, but confidentiality will be preserved. Please note that if you earn \$600 or over in a calendar year as a research subject, you may have to pay taxes on these earnings.

Questions:

If you have any questions about the research, please contact Ms. Jessie Heath (315) 443-1052 or Dr. Peter Venable at (315) 443-2024. If you have any questions about your rights as a research subject, please contact the SUNY Upstate Medical University Institutional Review Board Office at (315) 464-4317 or the Syracuse University Institutional Review Board Office at (315) 443-3013.

Confidentiality of Records and Authorization to Use/Share Protected Health Information for Research:

If you agree to participate in this research, identifiable health information about you will be used and shared with others involved in this research. For you to be in this research we need your permission to collect and share this information. Federal law protects your right to privacy concerning this information.

When you sign this consent form at the end, it means that you have read this section and authorize the use and/or sharing of your protected health information as explained below. Your signature also means you have received a copy of Upstate's Notice of Privacy Practices.

Individually identifiable health information under the federal privacy law is considered to be any information from your medical record, or obtained from this study, that can be associated with you, and relates to your past, present, or future physical or mental health or condition. This is referred to as protected health information.

Your protected health information will be kept confidential. Research staff **will not** share the information you provide during the discussion group with your doctor or nurse here in the clinic. Further, you **will not** be identified in any publication or presentation resulting from this study. Several steps have been taken to protect the confidentiality of your responses and involvement in this research. Project staff has participated in extensive training and supervision regarding the importance of maintaining participant confidentiality. In addition, an identification number will be assigned to your focus group responses, and only the directors of this research (Jessie Heath, M.S., and Dr. Venable) will have access to the key that indicates which number belongs to which participant. The master list linking the participant ID number to the participant's identifying information will be maintained in a separate, secure computer database, and will be destroyed at the conclusion of the study.

To help us further protect your privacy, the investigators have received a Confidentiality Certificate from the Department of Health and Human Services. With this Certificate, the investigators cannot be forced (for example by court subpoena) to disclose research information that may identify you in any Federal, State, or local, civil, criminal, administrative, legislative, or other proceedings. The researchers will use the Certificate to resist any demands for information that would identify you, except as explained below.

The Certificate cannot be used to resist a request for information from personnel of the United States Department of Health and Human Services that is used for auditing or evaluation of federally funded projects.

In addition, the Confidentiality Certificate does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. Note however, that if an insurer or employer learns about your participation, and obtains your consent to receive research information, then the investigator may not use the Certificate of Confidentiality to withhold this information. This means that you and your family must also actively protect your own privacy.

Why is it necessary to use/share your protected health information with others?

The main reason to use and share your health information is to conduct the research as described in this consent form. Your information may also be shared with people and organizations that make sure the research is being done correctly, and to report unexpected or bad side effects you may have. In addition, we would be required to release protected health if you tell us of your intent to harm yourself or others.

What protected health information about you will be used or shared with others as part of this research?

We may use and share the results of the interviews. We will only collect information that is needed for the research.

Who will be authorized to use and/or share your protected health information?

The researchers, their staff and the staff of Upstate Medical University participating in the research will use your protected health information for this research study. In addition, the Upstate Institutional Review Board (IRB), a committee responsible for protecting the rights of research subjects, and other Upstate Medical University or University Hospital staff who supervise the way the research is done, may have access to your protected health information.

The researchers and their staff will determine if your protected health information will be used or shared with others outside of Upstate Medical University for purposes directly related to the conduct of the research.

With whom would the protected health information be shared?

Your protected health information may be shared with:

- Federal agencies that supervise the way the research is conducted, such as the Department of Health and Human Services' Office for Human Research Protections, the National Institutes of Health, or other governmental offices as required by law.
- Researchers from Syracuse University assisting in the study.

- The Syracuse University Institutional Review Board (a committee responsible for protecting the rights of research subjects).

All reasonable efforts will be used to protect the confidentiality of your protected health information. However, not all individuals or groups have to comply with the Federal privacy law. Therefore, once your protected health information is disclosed (leaves Upstate Medical University), the Federal privacy law may not protect it.

For how long will your protected health information be used or shared with others?

There is no scheduled date at which this information will be destroyed or no longer used. This is because information that is collected for research purposes continues to be used and analyzed for many years and it is not possible to determine when this will be complete.

Can you withdraw your authorization to collect/use/share your protected health information?

You always have the right to withdraw your permission (revoke authorization) for us to use and share your health information, by putting your request in writing to the investigator in charge of the study. This means that no further private health information will be collected. Once authorization is revoked, you may no longer participate in this research activity, but standard medical care and any other benefits to which you are entitled will not be affected. Revoking your authorization only affects uses and sharing of information obtained after your written request has been received, but not information obtained prior to that time.

Even after you withdraw your permission, Upstate Medical University may continue to use and share information needed for the integrity of the study; for example, information about an unexpected or bad side effect you experienced related to the study.

Can you have access to your health information?

At the end of the study, you have the right to see and copy health information about you in accordance with the SUNY Upstate Medical University policies; however, your access may be limited while the study is in progress.

Permission To Re-contact For Follow-Up Research

We may conduct additional research on this important topic. May we contact you about participation in future studies? Indicating you are willing to be contacted does not obligate you to participate in any other study, nor does it affect your participation in this study.

- No, I prefer not to be contacted about future studies.
 Yes, I am willing to be contacted about future studies.

Phone: _____ Mailing Address: _____

Consent To Participate In Research & Authorization To Use And Share Personal Health Information:

I hereby give my consent to participate in this research study and agree that my personal health information can be collected, used and shared by the researchers and staff for the research study described in this form. I will receive a signed copy of this consent form.

Signature of subject

Date

Printed Name of Research Participant

Signature of Person Obtaining Consent/Authorization

Date

Printed Name of Person Obtaining Consent/Authorization

Appendix E

Study Receipt

Receipt: Treatment Experiences of HIV+ Patients Study**Principle Investigator: Jessie Heath, M. S.****Date:** _____**Study:** **Focus Group** **Validity** **Experimental****ID:** _____**Money Received:** _____**Participant:**_____
Printed Name_____
Signed Name_____
Date**Research Assistant:**_____
Printed Name_____
Signed Name_____
Date

Appendix F

Validity Sub-study Questionnaire

Validity Sub-study Questionnaire

*Please answer the following items after each segment of the medical care visit is presented to you.

Vignette Segment 1.

a. Please imagine that you are the patient portrayed in this vignette. Now rate how you feel interacting with this provider in terms of feeling: Comfort, At Ease, Relaxed, Secure, Worried, Distressed, Serene, having Peace of Mind.

| | | | | | | |
|---------------------------------|----------------------------------|--------------------------------|--------------|------------------------------------|---|--|
| 1 Extremely Uncomfortable | 2 Moderately Uncomfortable | 3 Somewhat Uncomfortable | 4 Neutral | 5 Somewhat Comfortable | 6 Moderately Comfortable | 7 Extremely Comfortable |
| 1 Extremely Uneasy | 2 Moderately Uneasy | 3 Somewhat Uneasy | 4 Neutral | 5 Somewhat At Ease | 6 Moderately At Ease | 7 Extremely At Ease |
| 1 Extremely Tense | 2 Moderately Tense | 3 Somewhat Tense | 4 Neutral | 5 Somewhat Relaxed | 6 Moderately Relaxed | 7 Extremely Relaxed |
| 1 Extremely Insecure | 2 Moderately Insecure | 3 Somewhat Insecure | 4 Neutral | 5 Somewhat Secure | 6 Moderately Secure | 7 Extremely Secure |
| 1 Extremely Worried | 2 Moderately Worried | 3 Somewhat Worried | 4 Neutral | 5 Somewhat Worry-Free | 6 Moderately Worry-Free | 7 Extremely Worry-Free |
| 1 Extremely Distressed | 2 Moderately Distressed | 3 Somewhat Distressed | 4 Neutral | 5 Somewhat Calm | 6 Moderately Calm | 7 Extremely Calm |
| 1 Extremely Turbulent | 2 Moderately Turbulent | 3 Somewhat Turbulent | 4 Neutral | 5 Somewhat Serene | 6 Moderately Serene | 7 Extremely Serene |
| 1 Extremely Troubled | 2 Moderately Troubled | 3 Somewhat Troubled | 4 Neutral | 5 Have Some Peace of Mind | 6 Have Moderate Peace of Mind | 7 Have Extreme Peace of Mind |

b. Please imagine that you are the patient portrayed in this vignette and rate how much you agree or disagree with the following questions.

| | Strongly Disagree | Disagree | Slightly Disagree | Neutral | Slightly Agree | Agree | Strongly Agree |
|---|--------------------------|-----------------|--------------------------|----------------|-----------------------|--------------|-----------------------|
| 1. I felt devalued by this provider. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2. I believe this provider made negative judgments about me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3. I believe this provider treated me like an equal. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4. I believe this provider would prefer not to treat me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5. I believe this provider treated me the same as he treats his other patients. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6. I believe this provider thought I was a bad person. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7. I felt like this provider ignored or avoided me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8. I believe this provider was comfortable treating me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 9. I felt like this provider looked down on me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

***Thank you! Please click to watch next segment on the computer screen.

Vignette Segment 2.

a. Please imagine that you are the patient portrayed in this vignette. Now rate how you feel interacting with this provider in terms of feeling: Comfort, At Ease, Relaxed, Secure, Worried, Distressed, Serene, having Peace of Mind.

| | | | | | | |
|------------------------------|-------------------------------|-----------------------------|--------------|------------------------------|----------------------------------|---------------------------------|
| 1 Extremely Uncomfortable | 2 Moderately Uncomfortable | 3 Somewhat Uncomfortable | 4 Neutral | 5 Somewhat Comfortable | 6 Moderately Comfortable | 7 Extremely Comfortable |
| 1 Extremely Uneasy | 2 Moderately Uneasy | 3 Somewhat Uneasy | 4 Neutral | 5 Somewhat At Ease | 6 Moderately At Ease | 7 Extremely At Ease |
| 1 Extremely Tense | 2 Moderately Tense | 3 Somewhat Tense | 4 Neutral | 5 Somewhat Relaxed | 6 Moderately Relaxed | 7 Extremely Relaxed |
| 1 Extremely Insecure | 2 Moderately Insecure | 3 Somewhat Insecure | 4 Neutral | 5 Somewhat Secure | 6 Moderately Secure | 7 Extremely Secure |
| 1 Extremely Worried | 2 Moderately Worried | 3 Somewhat Worried | 4 Neutral | 5 Somewhat Worry-Free | 6 Moderately Worry-Free | 7 Extremely Worry-Free |
| 1 Extremely Distressed | 2 Moderately Distressed | 3 Somewhat Distressed | 4 Neutral | 5 Somewhat Calm | 6 Moderately Calm | 7 Extremely Calm |
| 1 Extremely Turbulent | 2 Moderately Turbulent | 3 Somewhat Turbulent | 4 Neutral | 5 Somewhat Serene | 6 Moderately Serene | 7 Extremely Serene |
| 1 Extremely Troubled | 2 Moderately Troubled | 3 Somewhat Troubled | 4 Neutral | 5 Have Some Peace of Mind | 6 Have Moderate Peace of Mind | 7 Have Extreme Peace of Mind |

b. Please imagine that you are the patient portrayed in this vignette and rate how much you agree or disagree with the following questions.

| | Strongly Disagree | Disagree | Slightly Disagree | Neutral | Slightly Agree | Agree | Strongly Agree |
|--|--------------------------|-----------------|--------------------------|----------------|-----------------------|--------------|-----------------------|
| 1. I felt devalued by this provider. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2. I believe this provider made negative judgments about me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3. I believe this provider treated me | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| like an equal. | | | | | | | |
| 4. I believe this provider would prefer not to treat me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5. I believe this provider treated me the same as he treats his other patients. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6. I believe this provider thought I was a bad person. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7. I felt like this provider ignored or avoided me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8. I believe this provider was comfortable treating me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 9. I felt like this provider looked down on me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

****Thank you! Please click to watch next segment on the computer screen.

Vignette Segment 3.

a. Please imagine that you are the patient portrayed in this vignette. Now rate how you feel interacting with this provider in terms of feeling: Comfort, At Ease, Relaxed, Secure, Worried, Distressed, Serene, having Peace of Mind.

| | | | | | | |
|------------------------------|-------------------------------|-----------------------------|--------------|------------------------------|----------------------------------|---------------------------------|
| 1 Extremely Uncomfortable | 2 Moderately Uncomfortable | 3 Somewhat Uncomfortable | 4 Neutral | 5 Somewhat Comfortable | 6 Moderately Comfortable | 7 Extremely Comfortable |
| 1 Extremely Uneasy | 2 Moderately Uneasy | 3 Somewhat Uneasy | 4 Neutral | 5 Somewhat At Ease | 6 Moderately At Ease | 7 Extremely At Ease |
| 1 Extremely Tense | 2 Moderately Tense | 3 Somewhat Tense | 4 Neutral | 5 Somewhat Relaxed | 6 Moderately Relaxed | 7 Extremely Relaxed |
| 1 Extremely Insecure | 2 Moderately Insecure | 3 Somewhat Insecure | 4 Neutral | 5 Somewhat Secure | 6 Moderately Secure | 7 Extremely Secure |
| 1 Extremely Worried | 2 Moderately Worried | 3 Somewhat Worried | 4 Neutral | 5 Somewhat Worry-Free | 6 Moderately Worry-Free | 7 Extremely Worry-Free |
| 1 Extremely Distressed | 2 Moderately Distressed | 3 Somewhat Distressed | 4 Neutral | 5 Somewhat Calm | 6 Moderately Calm | 7 Extremely Calm |
| 1 Extremely Turbulent | 2 Moderately Turbulent | 3 Somewhat Turbulent | 4 Neutral | 5 Somewhat Serene | 6 Moderately Serene | 7 Extremely Serene |
| 1 Extremely Troubled | 2 Moderately Troubled | 3 Somewhat Troubled | 4 Neutral | 5 Have Some Peace of Mind | 6 Have Moderate Peace of Mind | 7 Have Extreme Peace of Mind |

b. Please imagine that you are the patient portrayed in this vignette and rate how much you agree or disagree with the following questions.

| | Strongly Disagree | Disagree | Slightly Disagree | Neutral | Slightly Agree | Agree | Strongly Agree |
|--|--------------------------|-----------------|--------------------------|----------------|-----------------------|--------------|-----------------------|
| 1. I felt devalued by this provider. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2. I believe this provider made negative judgments about me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3. I believe this provider treated me | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| like an equal. | | | | | | | |
| 4. I believe this provider would prefer not to treat me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5. I believe this provider treated me the same as he treats his other patients. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6. I believe this provider thought I was a bad person. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7. I felt like this provider ignored or avoided me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8. I believe this provider was comfortable treating me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 9. I felt like this provider looked down on me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

****Thank you! Please click to watch next segment on the computer screen.

Part 4.

- a. Please imagine that you are the patient portrayed in this vignette. Now rate how you feel interacting with this provider in terms of feeling: Comfort, At Ease, Relaxed, Secure, Worried, Distressed, Serene, having Peace of Mind.

| | | | | | | |
|------------------------------|-------------------------------|-----------------------------|--------------|------------------------------|----------------------------------|---------------------------------|
| 1 Extremely Uncomfortable | 2 Moderately Uncomfortable | 3 Somewhat Uncomfortable | 4 Neutral | 5 Somewhat Comfortable | 6 Moderately Comfortable | 7 Extremely Comfortable |
| 1 Extremely Uneasy | 2 Moderately Uneasy | 3 Somewhat Uneasy | 4 Neutral | 5 Somewhat At Ease | 6 Moderately At Ease | 7 Extremely At Ease |
| 1 Extremely Tense | 2 Moderately Tense | 3 Somewhat Tense | 4 Neutral | 5 Somewhat Relaxed | 6 Moderately Relaxed | 7 Extremely Relaxed |
| 1 Extremely Insecure | 2 Moderately Insecure | 3 Somewhat Insecure | 4 Neutral | 5 Somewhat Secure | 6 Moderately Secure | 7 Extremely Secure |
| 1 Extremely Worried | 2 Moderately Worried | 3 Somewhat Worried | 4 Neutral | 5 Somewhat Worry-Free | 6 Moderately Worry-Free | 7 Extremely Worry-Free |
| 1 Extremely Distressed | 2 Moderately Distressed | 3 Somewhat Distressed | 4 Neutral | 5 Somewhat Calm | 6 Moderately Calm | 7 Extremely Calm |
| 1 Extremely Turbulent | 2 Moderately Turbulent | 3 Somewhat Turbulent | 4 Neutral | 5 Somewhat Serene | 6 Moderately Serene | 7 Extremely Serene |
| 1 Extremely Troubled | 2 Moderately Troubled | 3 Somewhat Troubled | 4 Neutral | 5 Have Some Peace of Mind | 6 Have Moderate Peace of Mind | 7 Have Extreme Peace of Mind |

- b. Please imagine that you are the patient portrayed in this vignette and rate how much you agree or disagree with the following questions.

| | Strongly Disagree | Disagree | Slightly Disagree | Neutral | Slightly Agree | Agree | Strongly Agree |
|--|--------------------------|-----------------|--------------------------|----------------|-----------------------|--------------|-----------------------|
| 1. I felt devalued by this provider. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2. I believe this provider made negative judgments about me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3. I believe this provider treated me like an | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| equal. | | | | | | | |
| 4. I believe this provider would prefer not to treat me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5. I believe this provider treated me the same as he treats his other patients. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6. I believe this provider thought I was a bad person. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7. I felt like this provider ignored or avoided me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8. I believe this provider was comfortable treating me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 9. I felt like this provider looked down on me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

c. Taking into consideration this entire treatment experience, how comfortable would you feel having a conversation about risky sexual behaviors with this provider?

| | | | | | | |
|------------------------------|-------------------------------|-----------------------------|--------------|---------------------------|-----------------------------|----------------------------|
| 1 Extremely Uncomfortable | 2 Moderately Uncomfortable | 3 Somewhat Uncomfortable | 4 Neutral | 5 Somewhat Comfortable | 6 Moderately Comfortable | 7 Extremely Comfortable |
|------------------------------|-------------------------------|-----------------------------|--------------|---------------------------|-----------------------------|----------------------------|

d. Taking into consideration this entire treatment experience, how comfortable would you feel having a conversation about alcohol and substance use with this provider?

| | | | | | | |
|------------------------------|-------------------------------|-----------------------------|--------------|---------------------------|-----------------------------|----------------------------|
| 1 Extremely Uncomfortable | 2 Moderately Uncomfortable | 3 Somewhat Uncomfortable | 4 Neutral | 5 Somewhat Comfortable | 6 Moderately Comfortable | 7 Extremely Comfortable |
|------------------------------|-------------------------------|-----------------------------|--------------|---------------------------|-----------------------------|----------------------------|

e. Taking into consideration this entire treatment experience, how comfortable would you feel having a conversation about HIV medication adherence difficulties with this provider?

| | | | | | | |
|---------------------------------|----------------------------------|--------------------------------|--------------|------------------------------|--------------------------------|-------------------------------|
| 1 Extremely Uncomfortable | 2 Moderately Uncomfortable | 3 Somewhat Uncomfortable | 4 Neutral | 5 Somewhat Comfortable | 6 Moderately Comfortable | 7 Extremely Comfortable |
|---------------------------------|----------------------------------|--------------------------------|--------------|------------------------------|--------------------------------|-------------------------------|

***Thank you! Please ring bell for research assistant.

Appendix G

Draft of Validity Phase Protocol

VALIDITY STUDY PROCEDURES

I. INFORMED CONSENT

A. OVERVIEW OF CONSENT INFORMATION

A participant who gives their informed consent to participate in the study should fully understand the nature of the research study, the purpose and pertinent procedures for the study, potential risks and benefits of participating, confidentiality and steps taken by research team to ensure confidentiality, and how the data will be used and stored.

B. PARTICIPANT CONSENT

After a brief introduction, the principle investigator (PI) leads the participant through the informed consent form, highlighting the most important aspects of informed consent. The following outline illustrates the content that is verbally expressed by the PI during this process:

- **WHO:** The project directors for this study are Jessie Heath, M.S., a clinical psychology doctoral student at Syracuse University and Dr. Peter Venable, an associate professor of psychology at Syracuse University and an adjunct assistant professor of medicine at SUNY Upstate Medical University.
- **PURPOSE & PROCEDURE:** You are being asked to participate in a research study designed to learn more about how aspects of patient-provider relationships can affect the medical treatment of persons living with HIV. Our goal is to gain a better understanding of how the behaviors of medical care providers within medical appointments can affect the HIV+ patients they treat. We will use the information obtained in this study to inform the development of strategies to improve patient-provider relationships and the quality of medical care received HIV+ patients.
- **TIME & COMPENSATION:** Your participation involves viewing two vignettes of hypothetical medical care visits, responding to questions using an interactive computer program, and briefly discussing your opinions with a research assistant. The study takes approximately one half hour, and you will receive \$10 for your time.
- **RISKS/BENEFITS:**
 - Risks: There are three risks associated with this study. First, you may feel uncomfortable answering personal questions. If this occurs, you may choose not to answer any question. Second, you may find some aspects of the vignette mildly upsetting. A third risk involves the risk of disclosing private information to our research team. However, all information that you share with members of our team is considered strictly confidential, and we are obligated to protect your privacy.
 - Benefits: You may learn more about your feelings and become aware of how aspects of medical treatment experiences can affect you. In addition, because the information you provide assists in the development of

strategies to improve patient-provider relationships, your participation could benefit others living with HIV.

- **CONFIDENTIALITY and HIPPA**
 - If you decide to participate, any information that you give us is strictly confidential. We will keep your information private, except under 2 circumstances.
 - First, if you tell us that you're planning to hurt yourself or someone else we would have to disclose that information.
 - Second, if officials were concerned that the research team was acting inappropriately, the research records might be audited to make sure the research was being conducted ethically; however, the auditors would be required to protect your privacy.
- **PROTECTION OF CONFIDENTIALITY**
 - All project staff receive extensive training and supervision on confidentiality procedures.
 - Your survey is given an identification number and only authorized research staff has access to the key that connects your information to your name. Your identity will not be included on the audiotapes and the tapes will be erased once we are finished with the project.
 - Certificate of Confidentiality from the Department of Health and Human services, which states that the investigators cannot be forced to release your information (for example, by subpoena) to any federal, state, or local, civil, criminal, administrative, legislative, or other proceedings. This Certificate does NOT prevent you or your family from voluntarily disclosing information about yourself or your involvement in this research.
- **PARTICIPATION IS VOLUNTARY:** You may refuse to participate or discontinue your participation at any time without penalty or loss of benefits.
- **PERMISSION TO BE RECONTACTED:** The participants are then asked to sign and date one copy of the consent form and keep a second copy for their own records. Participants are also given a copy of University Hospital's Privacy Practices Policy and asked to keep it for their records.

C. STORAGE OF CONSENT FORMS

After pertinent information from the completed consent forms has been entered into the Excel patient database, the completed focus group consent forms will be stored in a locked filing cabinet in the UPH office.

II. VALIDITY STUDY PROTOCOL ADMINISTRATION

A. ASSIGNMENT OF PARTICIPANT NUMBER AND CONDITION

After participants consent, they will be assigned a participant ID number and randomized to a view either the "high stigma" or "no stigma" study condition first using a random number generator.

B. VIGNETTE AND SURVEY ADMINISTRATION

The quantitative survey is administered following the informed consent. The participants will be seated in front of a computer, where the PI will introduce the computerized study protocol and briefly describe how the computer program works. The PI will answer any questions the participant has and ensure the participant's ability to successfully interact with the computer program. For participants with limited computer exposure, the principle investigator will provide additional instruction on the use of the mouse and keyboard as necessary. Participants will also be instructed that if they have any difficulties with the computer program to ring a bell on the desk and the principle investigator will assist them. Participants will then follow the audio instructions on the ACASI program to complete the small battery of self-report assessments and respond to the visual and audio treatment vignettes. The ordering of the protocol will be as follows: (1) reporting of background and health information, (2) step-by-step presentation of treatment vignettes with ratings of comfort and stigmatization assessed at several points throughout the presented patient-provider interaction, and (3) a brief discussion with the research assistant to elicit feedback about the vignettes.

C. DATA ENTRY AND STORAGE

Data from the ACASI program will be automatically stored upon completion of the protocol and then transformed into an SPSS format for analyses. There will be no hard copies of data in the experimental phase of the study and no identifying information will present in the ACASI or SPSS files.

D. PARTICIPANT REIMBURSEMENT

The PI will retrieve reimbursement funds from Sean Kelley prior to the start of the focus group. Participants will be reimbursed \$10 for their one half hour of participation in the focus groups. After participants have received their reimbursement, the PI will complete a reimbursement receipt including only the participant's ID number and file it in the UPH filing cabinet under non-reconciled payment receipts. The original reimbursement form will then be turned in to Sean Kelley. A photocopy will be stored in the UPH filing cabinet under reconciled payment receipts.

Appendix H

Draft of Validity Phase Informed Consent Form

**SUNY UPSTATE MEDICAL UNIVERSITY AND
SYRACUSE UNIVERSITY**

Consent/Authorization Form

Title of Study: Treatment Experiences of HIV+ Patients Validity Sub-Study

Background/Purpose:

You are invited to participate in a research study designed to learn more about how aspects of patient-provider relationships can affect the medical treatment of persons living with HIV. Our goal is to gain a better understanding of how the behaviors of medical care providers can affect the HIV+ patients they treat. We will use the information obtained in this study to inform the development of strategies to improve patient-provider relationships and the quality of medical care received HIV+ patients. The directors of this study are Jessie Heath, M.S., a clinical psychology doctoral student and Dr. Peter Vanable, an Associate Professor of Psychology at Syracuse University and an Adjunct Assistant Professor of Medicine at SUNY Upstate Medical University. Other trained research staff will also be involved, and will be supervised by Drs. Peter Vanable of Syracuse University. We are asking approximately 20 patients to participate in the study.

You will be given enough time to read and understand the information provided in this consent and authorization form. Please ask the study staff to explain any words or information that you do not understand. You may keep an unsigned copy of this consent and authorization form to think about your decision or discuss with your family, friends, or doctors before making your decision to take part in this research study.

Study Procedures:

If you decide to take part in this study, you will listen and respond to information that is presented individually to you on a computer. You will view two vignettes representing typical, first-time medical care visits of an HIV+ patient. On the computer, you will hear audio descriptions of the medical visits, conversations between the hypothetical patient and provider, and also view pictures of the interaction. Throughout the presentation of the vignettes, you will answer questions presented on the computer screen regarding your feelings and opinions about what you are viewing. Following the presentation of the vignettes, you will give verbal feedback to a research assistant about your experience in the study and suggestions for improving the vignettes. The study takes approximately one half hour to complete, and your participation is completely voluntary.

If you agree to participate in the study, you will also be asked to complete a brief survey with questions about your background and health information, including medical appointment attendance, hospitalizations, and recent indicators of health status (CD4 count, viral load).

Risks:

There are three risks associated with this study. First, you may feel uncomfortable answering personal questions. If this occurs, you may choose not to answer any question. Second, you may find some aspects of the treatment vignette mildly upsetting. A third risk involves the risk of disclosing private information to our research team. However, all information that you share with members of our team is considered strictly confidential, and we are obligated to protect your privacy.

Benefits:

The potential benefits are that you may learn more about your feelings and become aware of how aspects of medical treatment experiences can affect you. In addition, because the information you provide assists in the development of strategies to improve patient-provider relationships, your participation could benefit others living with HIV.

Voluntary Participation:

Your participation in this study is entirely voluntary and you may refuse to participate or stop participation at any time without penalty or loss of benefits to which you would normally be entitled. Your decision about whether or not to participate in the study will not affect the care you receive at SUNY Upstate Medical University.

Alternatives:

If you decide not to participate in this research study, you will continue to receive your usual care and will not complete the surveys for research purposes.

Costs/Payments:

There are no costs to you and/or your insurance carrier for participating in this study. After completing the study, you will receive \$10 to offset your expenses and to thank you for your time.

If you choose to stop participating in the study before all study requirements are completed, you will be paid \$5 for each ¼ hour of time you devote to the study.

In addition, by accepting payment for participating in this study, certain identifying information about you may be made available to professional auditors to satisfy audit and Federal reporting requirements, but confidentiality will be preserved. Please note that if you earn \$600 or over in a calendar year as a research subject, you may have to pay taxes on these earnings.

Questions:

If you have any questions about the research, please contact Ms. Jessie Heath at (315) 443-1052 or Dr. Peter Vanable at (315) 443-2024. If you have any questions about your rights as a research subject, please contact the SUNY Upstate Medical University Institutional Review Board Office at (315) 464-4317 or the Syracuse University Institutional Review Board Office at (315) 443-3013.

Confidentiality of Records and Authorization to Use/Share Protected Health Information for Research:

If you agree to participate in this research, identifiable health information about you will be used and shared with others involved in this research. For you to be in this research we need your permission to collect and share this information. Federal law protects your right to privacy concerning this information.

When you sign this consent form at the end, it means that you have read this section and authorize the use and/or sharing of your protected health information as explained below. Your signature also means you have received a copy of Upstate's Notice of Privacy Practices.

Individually identifiable health information under the federal privacy law is considered to be any information from your medical record, or obtained from this study, that can be associated with you, and relates to your past, present, or future physical or mental health or condition. This is referred to as protected health information.

Your protected health information will be kept confidential. Research staff will not share the information you provide during the discussion group and on the survey with your doctor or nurse here in the clinic. Further, you will not be identified in any publication or presentation resulting from this study. Several steps have been taken to protect the confidentiality of your responses and involvement in this research. Project staff has participated in extensive training and supervision regarding the importance of maintaining participant confidentiality. In addition, an identification number will be assigned to your survey, and only the directors of this research (Jessie Heath, M.S. and Dr. Vanable) will have access to the key that indicates which number belongs to which participant. The master list linking the participant ID number to the participant's identifying information will be maintained in a separate, secure computer database, and will be destroyed at the conclusion of the study. Your name or other identifying information will not be kept with your survey, and your survey information will be stored in a secure computer database.

To help us further protect your privacy, the investigators have received a Confidentiality Certificate from the Department of Health and Human Services. With this Certificate, the investigators cannot be forced (for example by court subpoena) to disclose research information that may identify you in any Federal, State, or local, civil, criminal, administrative, legislative, or other proceedings. The researchers will use the Certificate to resist any demands for information that would identify you, except as explained below.

The Certificate cannot be used to resist a request for information from personnel of the United States Department of Health and Human Services that is used for auditing or evaluation of federally funded projects.

In addition, the Confidentiality Certificate does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. Note however, that if an insurer or employer learns about your participation, and obtains your consent to receive research information, then the investigator may not use the Certificate of Confidentiality to withhold this information. This means that you and your family must also actively protect your own privacy.

Why is it necessary to use/share your protected health information with others? The main reason to use and share your health information is to conduct the research as described in this consent form. Your information may also be shared with people and organizations that make sure the research is being done correctly, and to report unexpected or bad side effects you may have. In addition, we will release protected health information about you if we learn about your intent to harm yourself or others.

What protected health information about you will be used or shared with others as part of this research? We may use and share the results of tests, questionnaires, and interviews. We will only collect information that is needed for the research.

Who will be authorized to use and/or share your protected health information? The researchers, their staff and the staff of Upstate Medical University participating in the research will use your protected health information for this research study. In addition, the Upstate Medical University and Syracuse University Institutional Review Boards (IRB), committees responsible for protecting the rights of research subjects, and other Upstate Medical University, Syracuse University, or University Hospital staff who supervise the way the research is done, may have access to your protected health information.

The researchers and their staff will determine if your protected health information will be used or shared with others outside of Upstate Medical University and Syracuse University for purposes directly related to the conduct of the research.

With whom would the protected health information be shared? Your protected health information may be shared with:

- Federal agencies that supervise the way the research is conducted, such as the Department of Health and Human Services' Office for Human Research Protections or the National Institutes of Health.
- Researchers from Syracuse University assisting in the study.

- The Syracuse University Institutional Review Board (a committee responsible for protecting the rights of research subjects).

All reasonable efforts will be used to protect the confidentiality of your protected health information. However, not all individuals or groups have to comply with the Federal privacy law. Therefore, once your protected health information is disclosed (leaves Upstate Medical University), the Federal privacy law may not protect it.

For how long will your protected health information be used or shared with others? There is no scheduled date at which this information will be destroyed or no longer used. This is because information that is collected for research purposes continues to be used and analyzed for many years and it is not possible to determine when this will be complete.

Can you withdraw your authorization to collect/use/share your protected health information? You always have the right to withdraw your permission (revoke authorization) for us to use and share your health information, by putting your request in writing to the investigator in charge of the study. This means that no further private health information will be collected. Once authorization is revoked, you may no longer participate in this research activity, but standard medical care and any other benefits to which you are entitled will not be affected. Revoking your authorization only affects uses and sharing of information obtained after your written request has been received, but not information obtained prior to that time.

Even after you withdraw your permission, Upstate Medical University may continue to use and share information needed for the integrity of the study; for example, information about an unexpected or bad side effect you experienced related to the study.

Can you have access to your health information? At the end of the study, you have the right to see and copy health information about you in accordance with the SUNY Upstate Medical University policies; however, your access may be limited while the study is in progress.

Permission To Contact For Follow-Up Research

We may conduct additional research on this important topic. May we contact you about participation in future studies? Indicating you are willing to be contacted does not obligate you to participate in any other study, nor does it affect your participation in this study.

- No, I prefer not to be contacted about future studies.
 Yes, I am willing to be contacted about future studies.

Phone: _____

Mailing Address: _____

Consent To Participate In Research & Authorization To Use And Share Personal Health Information:

I hereby give my consent to participate in this research study and agree that my personal health information can be collected, used and shared by the researchers and staff for the research study described in this form. I will receive a signed copy of this consent form.

Signature of subject

Date

Printed Name of Research Participant

Signature of Person Obtaining Consent/Authorization

Date

Printed Name of Person Obtaining Consent/Authorization

Appendix I
Experiences of HIV-related Stigmatization in Healthcare

Experiences of HIV-related Stigmatization in Healthcare

Directions: Please indicate the extent to which you have experienced these behaviors from a healthcare provider (doctor, nurse, intern, medical student) because you were HIV+.

| Item: | Never | Once or Twice | 3-6 Times | 7-10 Times | More than 10 Times |
|--|--------------|----------------------|------------------|-------------------|---------------------------|
| <u>A healthcare provider . . .</u> | | | | | |
| 1. has refused to treat me because I am HIV+ | 0 | 1 | 2 | 3 | 4 |
| 2. has appeared angry or irritated while treating me | 0 | 1 | 2 | 3 | 4 |
| 3. has avoided touching me because I am HIV+ | 0 | 1 | 2 | 3 | 4 |
| 4. has rushed me through an appointment because I am HIV+ | 0 | 1 | 2 | 3 | 4 |
| 5. has blamed me for my infection because of my lifestyle | 0 | 1 | 2 | 3 | 4 |
| 6. has given me a lower quality of care because I am HIV+ | 0 | 1 | 2 | 3 | 4 |
| 7. would not maintain eye contact with me because I am HIV+ | 0 | 1 | 2 | 3 | 4 |
| 8. has sat/stood very far away from me in the treatment room because I am HIV+ | 0 | 1 | 2 | 3 | 4 |
| 9. has made me wait longer for care than other patients because I am HIV+ | 0 | 1 | 2 | 3 | 4 |

| | | | | | |
|--|---|---|---|---|---|
| 10. has appeared nervous or uncomfortable while treating me | 0 | 1 | 2 | 3 | 4 |
| 11. has treated me rudely or disrespectfully because I am HIV+ | 0 | 1 | 2 | 3 | 4 |
| 12. has told me that I deserved to become infected | 0 | 1 | 2 | 3 | 4 |
| 13. referred me to another provider because I am HIV+ | 0 | 1 | 2 | 3 | 4 |
| 14. has worn extra gloves to examine me when it was unnecessary | 0 | 1 | 2 | 3 | 4 |
| 15. has told me or acted as if I was a waste of his/her time because I am HIV+ | 0 | 1 | 2 | 3 | 4 |

Appendix J

Patient Comfort Measure

Patient Comfort Measure

1. Please imagine that you are the patient portrayed in this vignette. Now rate how you feel interacting with this provider in terms of feeling: Comfort, At Ease, Relaxed, Secure, Worried, Distressed, Serene, having Peace of Mind.

| | | | | | | |
|------------------------------|-------------------------------|-----------------------------|--------------|------------------------------|----------------------------------|---------------------------------|
| 1 Extremely Uncomfortable | 2 Moderately Uncomfortable | 3 Somewhat Uncomfortable | 4 Neutral | 5 Somewhat Comfortable | 6 Moderately Comfortable | 7 Extremely Comfortable |
| 1 Extremely Uneasy | 2 Moderately Uneasy | 3 Somewhat Uneasy | 4 Neutral | 5 Somewhat At Ease | 6 Moderately At Ease | 7 Extremely At Ease |
| 1 Extremely Tense | 2 Moderately Tense | 3 Somewhat Tense | 4 Neutral | 5 Somewhat Relaxed | 6 Moderately Relaxed | 7 Extremely Relaxed |
| 1 Extremely Insecure | 2 Moderately Insecure | 3 Somewhat Insecure | 4 Neutral | 5 Somewhat Secure | 6 Moderately Secure | 7 Extremely Secure |
| 1 Extremely Worried | 2 Moderately Worried | 3 Somewhat Worried | 4 Neutral | 5 Somewhat Worry-Free | 6 Moderately Worry-Free | 7 Extremely Worry-Free |
| 1 Extremely Distressed | 2 Moderately Distressed | 3 Somewhat Distressed | 4 Neutral | 5 Somewhat Calm | 6 Moderately Calm | 7 Extremely Calm |
| 1 Extremely Turbulent | 2 Moderately Turbulent | 3 Somewhat Turbulent | 4 Neutral | 5 Somewhat Serene | 6 Moderately Serene | 7 Extremely Serene |
| 1 Extremely Troubled | 2 Moderately Troubled | 3 Somewhat Troubled | 4 Neutral | 5 Have Some Peace of Mind | 6 Have Moderate Peace of Mind | 7 Have Extreme Peace of Mind |

2. How comfortable would you feel having a conversation about risky sexual behaviors with the provider shown in the computer program?

| | | | | | | |
|------------------------------|-------------------------------|-----------------------------|--------------|---------------------------|-----------------------------|----------------------------|
| 1 Extremely Uncomfortable | 2 Moderately Uncomfortable | 3 Somewhat Uncomfortable | 4 Neutral | 5 Somewhat Comfortable | 6 Moderately Comfortable | 7 Extremely Comfortable |
|------------------------------|-------------------------------|-----------------------------|--------------|---------------------------|-----------------------------|----------------------------|

3. How comfortable would you feel having a conversation about alcohol and substance use with the provider shown in the computer program?

| | | | | | | |
|---------------------------------|----------------------------------|--------------------------------|--------------|------------------------------|--------------------------------|-------------------------------|
| 1 Extremely Uncomfortable | 2 Moderately Uncomfortable | 3 Somewhat Uncomfortable | 4 Neutral | 5 Somewhat Comfortable | 6 Moderately Comfortable | 7 Extremely Comfortable |
|---------------------------------|----------------------------------|--------------------------------|--------------|------------------------------|--------------------------------|-------------------------------|

4. How comfortable would you feel having a conversation about HIV medication adherence difficulties with the provider shown in the computer program?

| | | | | | | |
|---------------------------------|----------------------------------|--------------------------------|--------------|------------------------------|--------------------------------|-------------------------------|
| 1 Extremely Uncomfortable | 2 Moderately Uncomfortable | 3 Somewhat Uncomfortable | 4 Neutral | 5 Somewhat Comfortable | 6 Moderately Comfortable | 7 Extremely Comfortable |
|---------------------------------|----------------------------------|--------------------------------|--------------|------------------------------|--------------------------------|-------------------------------|

Appendix K

Perceptions of Stigmatization within the Patient-Provider Interaction

Perceptions of Stigmatization within the Patient-Provider Interaction

Directions: Please indicate the extent to which you agree or disagree with each of the following statements regarding your beliefs about the provider shown in the computer program.

| | Strongly Disagree | Disagree | Slightly Disagree | Neutral | Slightly Agree | Agree | Strongly Agree |
|---|-------------------|----------|-------------------|---------|----------------|-------|----------------|
| 1. I felt devalued by this provider. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2. I believe this provider made negative judgments about me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3. I believe this provider treated me like an equal. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4. I believe this provider would prefer not to treat me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5. I believe this provider treated me the same as he treats his other patients. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6. I believe this provider thought I was a bad person. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7. I felt like this provider ignored or avoided me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8. I believe this provider was comfortable treating me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 9. I felt like this provider looked down on me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

| Patient-Provider Relationship Items | Strongly Disagree | Disagree | Slightly Disagree | Neutral | Slightly Agree | Agree | Strongly Agree |
|--|--------------------------|-----------------|--------------------------|----------------|-----------------------|--------------|-----------------------|
| 10. I believe this provider would listen to me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 11. I believe this provider would care about me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 12. I believe this provider would answer my questions. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 13. I believe this provider would spend enough time with me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 14. I believe this provider would involve me in treatment decisions. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 15. I believe this provider would respect my choices. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 16. I believe this provider would effectively deal with my problems. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 17. I believe this provider would engage me in my care. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 18. I believe this provider would be helpful to me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 19. I believe this provider would respect me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 20. I believe this provider would support my decisions. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 21. I believe this provider would see me when I ask. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 22. I believe this provider would give me important information. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Appendix L

Engagement in Care Measure

Engagement in Care Measures

A. Intentions to Remain in HIV Care Measure

1. How likely is it that you would remain in care with the provider shown in the computer program?

| | | | | | | |
|----------------------------|-----------------------------|---------------------------|--------------|-------------------------|---------------------------|--------------------------|
| 1 Extremely Unlikely | 2 Moderately Unlikely | 3 Somewhat Unlikely | 4 Neutral | 5 Somewhat Likely | 6 Moderately Likely | 7 Extremely Likely |
|----------------------------|-----------------------------|---------------------------|--------------|-------------------------|---------------------------|--------------------------|

B. Intentions to Discuss Sexual Risk Behavior Measure

***Please answer the following questions as if you have had unprotected anal or vaginal sex since becoming HIV+. In other words, even if you have not had unprotected sex since becoming HIV+, please imagine that you have when you are answering these next questions.**

1. If the provider shown in the computer program asked, how likely is it that you would tell them you had unprotected anal or vaginal sex with a **STEADY PARTNER**:

| | Extremely Unlikely | Moderately Unlikely | Somewhat Unlikely | Neutral | Somewhat Likely | Moderately Likely | Extremely Likely |
|---|--------------------|---------------------|-------------------|---------|-----------------|-------------------|------------------|
| a. who was <u>HIV- or unknown status,</u> and it happened <u>more than</u> 3 months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| b. who was <u>HIV- or unknown status,</u> and it happened <u>less than</u> 3 months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

2. If the provider shown in the computer program asked, how likely is it that you would tell them you had unprotected anal or vaginal sex with a **CASUAL PARTNER**:

| | Extremely Unlikely | Moderately Unlikely | Somewhat Unlikely | Neutral | Somewhat Likely | Moderately Likely | Extremely Likely |
|---|--------------------|---------------------|-------------------|---------|-----------------|-------------------|------------------|
| c. who was <u>HIV- or unknown status,</u> and it happened <u>more than</u> 3 months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| d. who was <u>HIV- or unknown status,</u> and it happened | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

| | | | | | | | |
|----------------------------------|--|--|--|--|--|--|--|
| less than 3 months ago | | | | | | | |
|----------------------------------|--|--|--|--|--|--|--|

3. In the event that you were having difficulties achieving and maintaining safer sex practices, how likely is it that **you would start** a conversation about this with the provider?

| | | | | | | |
|----------------------------|-----------------------------|---------------------------|--------------|-------------------------|---------------------------|--------------------------|
| 1 Extremely Unlikely | 2 Moderately Unlikely | 3 Somewhat Unlikely | 4 Neutral | 5 Somewhat Likely | 6 Moderately Likely | 7 Extremely Likely |
|----------------------------|-----------------------------|---------------------------|--------------|-------------------------|---------------------------|--------------------------|

C. Intentions to Discuss Substance Use Risk Behavior Measure

***Please answer the following questions as if you have drunk alcohol or used drugs (not prescribed to you) since becoming HIV+. In other words, even if you have not drunk alcohol or used drugs since becoming HIV+, please imagine that you have when you are answering these next questions.**

1. If the provider shown in the computer program asked, how likely is it that you would tell them you have consumed **ALCOHOL**:

| | Extremely Unlikely | Moderately Unlikely | Some- what Unlikely | Neutr al | Some- what Likely | Moderately Likely | Extremely Likely |
|---|-----------------------|------------------------|---------------------------|-------------|-------------------------|----------------------|---------------------|
| a. at <u>low</u> levels <u>more than 3</u> months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| b. at <u>low</u> levels <u>less than 3</u> months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| c. at <u>high</u> levels or <u>problematically more than 3</u> months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| d. at <u>high</u> levels or <u>problematically less than 3</u> months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

2. If the provider shown in the computer program asked, how likely is it that you would tell them you have used **ILLEGAL DRUGS** or those **NOT PRESCRIBED TO YOU:**

| | Extremely Unlikely | Moderately Unlikely | Somewhat Unlikely | Neutral | Somewhat Likely | Moderately Likely | Extremely Likely |
|---|--------------------|---------------------|-------------------|---------|-----------------|-------------------|------------------|
| a. at <u>low</u> levels <u>more than 3</u> months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| b. at <u>low</u> levels <u>less than 3</u> months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| c. at <u>high</u> levels or <u>problematically more than 3</u> months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| d. at <u>high</u> levels or <u>problematically less than 3</u> months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

3. In the event that you were **SHARING NEEDLES** during drug use, and the provider shown in the computer program asked, how likely is it that you would tell them?

| | | | | | | |
|-------------------------|--------------------------|------------------------|--------------|----------------------|------------------------|-----------------------|
| 1 Extremely Unlikely | 2 Moderately Unlikely | 3 Somewhat Unlikely | 4 Neutral | 5 Somewhat Likely | 6 Moderately Likely | 7 Extremely Likely |
|-------------------------|--------------------------|------------------------|--------------|----------------------|------------------------|-----------------------|

4. In the event that you were interested in receiving alcohol or substance abuse treatment, how likely is it that **you would start** a conversation about this with this provider?

| | | | | | | |
|----------------------------|-----------------------------|---------------------------|--------------|-------------------------|---------------------------|--------------------------|
| 1 Extremely Unlikely | 2 Moderately Unlikely | 3 Somewhat Unlikely | 4 Neutral | 5 Somewhat Likely | 6 Moderately Likely | 7 Extremely Likely |
|----------------------------|-----------------------------|---------------------------|--------------|-------------------------|---------------------------|--------------------------|

D. Intentions to Discuss Medication Adherence Difficulties Measure

***Please answer the following questions as if you are taking HIV MEDICATIONS and HAVE NOT had perfect 100% adherence. In other words, even if you are not on HIV medications or have never missed a dose, please imagine that you have when you are answering these next questions.**

1. If the provider shown in the computer program asked, how likely is it that you would tell them that you had **UNINTENTIONALLY** missed doses of your HIV medications (examples: forgetting, misplacing medications, sleeping through doses, etc.) if:

| | Extremely Unlikely | Moderately Unlikely | Some-what Unlikely | Neutral | Some-what Likely | Moderately Likely | Extremely Likely |
|--|---------------------------|----------------------------|---------------------------|----------------|-------------------------|--------------------------|-------------------------|
| a. it only happened <u>a few</u> times and <u>more than</u> 3 months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| b. it happened <u>many</u> times and <u>more than</u> 3 months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| c. it only happened <u>a few</u> times and <u>less than</u> 3 months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| d. it happened <u>many</u> times and <u>less than</u> 3 months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

2. If the provider shown in the computer program asked, how likely is it that you would tell them you had **INTENTIONALLY** missed doses of your HIV medications (examples: purposely skipping doses, medication vacations, taking meds not as prescribed, etc.) if:

| | Extremely Unlikely | Moderately Unlikely | Some-what Unlikely | Neutral | Some-what Likely | Moderately Likely | Extremely Likely |
|--|--------------------|---------------------|--------------------|---------|------------------|-------------------|------------------|
| a. it only happened <u>a few</u> times and <u>more than 3</u> months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| b. it happened <u>many</u> times and <u>more than 3</u> months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| c. it only happened <u>a few</u> times and <u>less than 3</u> months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| d. it happened <u>many</u> times and <u>less than 3</u> months ago | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

3. In the event that you were having difficulties with medication adherence (not taking your meds exactly how you are supposed to), how likely is it that **you would start** a conversation about this with the provider?

| | | | | | | |
|----------------------------|-----------------------------|---------------------------|--------------|-------------------------|---------------------------|--------------------------|
| 1 Extremely Unlikely | 2 Moderately Unlikely | 3 Somewhat Unlikely | 4 Neutral | 5 Somewhat Likely | 6 Moderately Likely | 7 Extremely Likely |
|----------------------------|-----------------------------|---------------------------|--------------|-------------------------|---------------------------|--------------------------|

E. Disclosure of Personal Risk Behaviors Measure

***For these next questions, please imagine that you are at a clinic appointment with Dr. XXX, the provider previously shown on the computer. You are sitting on the exam table when Dr. XXX enters the room and states that he will be asking you a series of questions regarding sensitive health behaviors such sexual activities, alcohol and drug use, and HIV medication adherence. Please answer the provider based on your own actual, real life experiences.**

1. How many sexual partners have you had in your lifetime?

2. How many sexual partners have you had in the **past 3 months**?

3. **In the past 3 months**, what percentage of time have you used condoms?

| | | | | |
|-------------|----------------------------|----------------------------|----------------------------|----------------|
| 0% Never | 25% Some of the Time | 50% Half of the Time | 75% Most of the Time | 100% Always |
|-------------|----------------------------|----------------------------|----------------------------|----------------|

4. Thinking of the past 3 months, how many days a week did you drink alcohol?

| | | | | |
|--------|----------|----------|----------|--------|
| 0 days | 1-2 days | 3-4 days | 5-6 days | 7 days |
|--------|----------|----------|----------|--------|

5. Thinking of times when you have drank in the past three months, how many alcoholic drinks did you typically have at one time?

| | | | | |
|------|------------|------------|------------|-----------------------|
| None | 1-2 drinks | 3-4 drinks | 5-6 drinks | More than 6 drinks |
|------|------------|------------|------------|-----------------------|

6. Have you ever used illegal drugs?

| | | | |
|----|----------------------------|---|--|
| No | Yes, but only a few times. | Yes, I have used drugs frequently but did not have problems related to my use. | Yes, I have used drugs frequently and did have problems related to my use. |
|----|----------------------------|---|--|

7. In the **past three months**, how often have you used illegal drugs?

| | | | | |
|-------|---------------|----------------------|----------------------|-----------------|
| Never | Once or Twice | Once or Twice a Week | Several Times a Week | Almost Everyday |
|-------|---------------|----------------------|----------------------|-----------------|

8. When was the last time you purposely **SKIPPED** taking any of your HIV medications?

| | | | | | |
|-------|------------------------|----------------|---------------|---------------|----------------------|
| Never | More than 3 months ago | 1-3 months ago | 2-4 weeks ago | 1-2 weeks ago | within the past week |
|-------|------------------------|----------------|---------------|---------------|----------------------|

9. What percentage of your HIV medication doses have you taken **in the past week**?

| | | | | | | | | | | |
|--|-----|-----|-----|-----|-----|-----|-----|-----|-----|--|
| 0% I have not taken any of my meds. | 10% | 20% | 30% | 40% | 50% | 60% | 70% | 80% | 90% | 100% I have taken all the doses of my meds. |
|--|-----|-----|-----|-----|-----|-----|-----|-----|-----|--|

Appendix M
Vignette Scripts

Non-Stigma Vignette Female

1. Segment 1:

Narrator: Dr. Everheart knocked on the door before entering into the room. He approached Ms. Johnson and shook her hand while introducing himself.

Actor 1 (provider): Hello Ms. Johnson my name is Dr. Actor 1 (provider) Everheart and I'll be your primary physician here at the clinic. I understand that you are new to the area. I hope you are enjoying our lovely city. How are you doing?

Narrator: Dr. Everheart takes a seat in a chair near the exam table where Ms. Johnson is sitting and begins reviewing her chart.

Actor 2 (patient): Pretty good, I'm feeling healthy. I'm just a little stressed with having to start all over at a new clinic with new doctors.

Actor 1 (provider): Well that's understandable, we'll try to make the process as easy as possible for you. Basically all we are going to be doing today is going over your medical history, completing a physical exam, and discussing any questions or concerns that you or I might have about your health. I like to be thorough with all my new patients, and double check some of the information in their files just to be sure it's up to date and correct. Your last treatment center sent us your file yesterday, I just have few pieces of information that I would like to confirm with you.

Actor 2 (patient): ok

Actor 1 (provider): Your chart says that you tested positive for HIV about five years ago in February of 2006.

Actor 2 (patient): Yeah, that's the story.

Actor 1 (provider): It says that you most likely became infected from sexual activity with men, and more specifically your boyfriend at the time.

Actor 2 (patient): Yeah. He didn't realize that he was positive and after 5 or 6 months together we weren't as strict about using condoms all the time. One day he found out one of his past hook-ups was positive and we both went in and got tested. Both of us found out that we were positive. We're still together though and he moved here with me.

Actor 1 (provider): It seems like you have really been there for each other. You know, it's so common for people to not know that they are positive. It seems like both of you got blind-sided in that situation. It's really good that you both decided to come in and get tested when you did.

Actor 2 (patient): Thanks.

2. Segment 2:

Actor 1 (provider): So it also says that you began taking anti-retroviral medications pretty soon after you received your diagnosis.

Actor 2 (patient): Yeah it was within a few months.

Actor 1 (provider): And other than a couple bouts of pneumonia in 2007 and 2008, you have been pretty healthy. Looks like your viral load and CD4 counts have been pretty stable ever since you started taking meds, except for the summer of last year when your viral load became detectable again and your CD4 count dropped by 30%. Do you remember what was going on around that time that caused these changes?

Actor 2 (patient): Yeah, my last doctors tried to switch my meds because they were making me nauseas and tired throughout the day. The new combination didn't work, so they put me back on the old meds after a few months. I was actually upset about it because physically I felt really great on the new meds. I mean is it really that big of deal if my numbers change a little?

Actor 1 (provider): You know it can often be a fairly complicated process to find the right combination of meds for patients. We try to balance out the experience of side effects with the effectiveness of the medications, and every patient responds a bit differently. Unfortunately, it is a big deal if your viral load and CD4 count change. Those are our best indicators of how the HIV virus is progressing in your body, and they can even be better indicators than how your body is physically feeling. I actually have a great brochure about some of the important information about viral load and CD4 counts. Would you like me to go over some of it with you?

Actor 2 (patient): That would actually be really helpful.

Narrator: Dr. Everheart stood up from his chair and grabbed a brochure. After walking over to the exam table, Dr. Everheart pointed out the key points of the brochure to Ms. Johnson and answered any remaining questions that she had.

Actor 2 (patient): Ok, so I get now why they took me off the new meds, but is there anything that you can do to help with the side effects. I can't be feeling sick all day at my new job. I don't want to make that type of impression.

Actor 1 (provider): For now, there are a few prescriptions to lessen your symptoms that haven't been tried by your last doctors. And after I get some more detailed results from your blood draw today, I will look into the possibility of other medication regimens that might be as effective as your current meds but with less side effects. I don't know if the new HIV medications on market will turn out to be a good fit for you, but we can definitely look into the possibility.

Actor 2 (patient): Ok, fair enough.

3. Segment 3:

Narrator: Dr. Everheart handed the brochure to Ms. Johnson and explained that he would now be performing a physical examination.

Actor 1 (provider): Alright, well I am now going to give you a brief physical examination to check your heart rate, blood pressure, breathing, and also check out your throat, ears, and eyes for normal functioning.

Narrator: Dr. Everheart approached Ms. Johnson, placing the stethoscope in his ears. He stood close to Ms. Johnson, placed the stethoscope on her chest, and listened to her breathing for approximately 10 seconds. He then placed the stethoscope on his back and listened for another 10 seconds. Dr. Everheart removed the stethoscope from her ears, reached for the blood pressure cuff, and placed it on Ms. Johnson's arm. After taking Ms. Johnson's blood pressure, Dr. Everheart, stood up and walked to the supply cabinet in the exam room. Dr. Everheart returned with a tongue depressor and asked Ms. Johnson to open her mouth. Dr. Everheart leaned towards Ms. Johnson and examined the inside of her throat thoroughly. Dr. Everheart then felt her lymph nodes on the side of her neck for a few moments before returning to his seat near the exam table.

4. Segment 4:

Actor 1 (provider): Well everything looks good as far as blood pressure and heart rate. And no signs of temperature or cold symptoms. How have you been feeling recently?

Actor 2 (patient): Pretty good, but I've been having a lot of headaches lately.

Actor 1 (provider): Has anything happened recently to trigger these headaches? Any changes in medication, diet, activity level?

Actor 2 (patient): Not really.

Actor 1 (provider): Have you been experiencing a lot of stress lately? Everything been going ok with friends/family?

Actor 2 (patient): You know I have been stressed out a lot due to the move, but I really don't think it's just that. They're pretty bad. I get shooting pains right behind my eyes, and it's happening at least twice a week.

Actor 1 (provider): Ok, well I have some ideas for what might be causing these types headaches. Those pain symptoms are pretty common for a lot of people especially those with a family history of migraines. I'll check to see if we have some medication samples to for you take home and see if they help. They shouldn't interact with any of your HIV

meds, just make sure to take them with food. If after a week you're still having problems we can do some more extensive tests to see what's going on. Sound okay to you?

Actor 2 (patient): Sounds good.

Actor 1 (provider): Great. Well I'm going to go grab those medication samples.

Narrator: Dr. Everheart left the exam room and returned in several minutes with the medication samples.

Actor 1 (provider): Well we're just about finished with today's appointment. But before you leave, I'd like to chat with you a little about your current sexual practices and also any previous or current alcohol or drug use. I know these types of topics are sensitive in nature and can seem a little out of the blue for a regular medical appointment. Basically new national standards of medical practice have been created, calling for health care providers to assess these types of things at all medical care visits to improve prevention of new infections and also to allow for the best care possible for current HIV+ patients. It's important to me that you feel comfortable, so is it okay for me to ask you a few questions?

Stigma Vignette Female

1. Segment 1:

Narrator: Dr. Everheart knocked on the door before entering into the room. He walked through door looking at Ms. Johnson's file and did not look up while introducing himself.

Actor 1 (provider): Hello Ms. Johnson my name is Dr. Everheart and I'll be your primary physician here at the clinic. How are you doing?

Narrator: Dr. Everheart takes a seat in a chair on the far side of the room from where Ms. Johnson is sitting and begins reviewing her chart.

Actor 2 (patient): Pretty good, I'm feeling healthy. I'm just a little stressed with having to start all over at a new clinic with new doctors.

Narrator: Dr. Everheart continues to look down at Ms. Johnson's chart as he speaks.

Actor 1 (provider): Well, nothing to worry about. Basically all we are going to be doing today is going over your medical history and completing a physical exam. I like to be thorough with all my new patients, and double check some of the information in their files. Your last treatment center sent us your file yesterday, I just have few pieces of information that I would like to confirm with you.

Actor 2 (patient): ok

Actor 1 (provider): Your chart says that you tested positive for HIV about five years ago in February of 2006.

Actor 2 (patient): Yeah, that's the story.

Actor 1 (provider): It says that you most likely became infected from having sex with HIV+ men. Hopefully becoming positive has motivated you to be more careful with reducing your number of sexual partners, using condoms, and staying away from drugs. Oh wait, I see here that you were infected by your boyfriend at the time.

Actor 2 (patient): Yeah. He didn't realize that he was positive and after 5 or 6 months together we weren't as strict about using condoms all the time. One day he found out one of his past hook-ups was positive and we both went in and got tested. Both of us found out that we were positive. We're still together though and he moved here with me.

Actor 1 (provider): That's surprising. You really don't see that nowadays. But, I guess you learned your lesson, and at least you both decided to come in and get tested when you did.

Actor 2 (patient): Thanks.

2. Segment 2:

Actor 1 (provider): So it also says that you began taking anti-retroviral medications pretty soon after you received your diagnosis.

Actor 2 (patient): Yeah it was within a few months.

Actor 1 (provider): And other than a couple bouts of pneumonia in 2007 and 2008, you have been pretty healthy. Looks like your viral load and CD4 counts have been pretty stable ever since you started taking meds. That is except for the summer of last year when your viral load became detectable again and your CD4 count dropped by 30%. Did you stop taking your meds?

Actor 2 (patient): No, actually my last doctors tried to switch my meds because they were making me nauseas and tired throughout the day. The new combination didn't work, so they put me back on the old meds after a few months. I was actually upset about it because physically I felt really great on the new meds. I mean is it really that big of deal if my numbers change a little?

Actor 1 (provider): Unfortunately, Ms. Johnson it is a big deal if your viral load and CD4 count change. Those are our best indicators of how the HIV virus is progressing in your body. You've been positive a while, I assumed you knew all this. I think I have a brochure that can explain viral load and CD4 counts to you. Let me grab it.

Narrator: Dr. Everheart rose from his chair and grabbed a brochure. Without approaching the exam table, he leaned over to hand the brochure to Ms. Johnson.

Actor 1 (provider): I strongly suggest you review this material.

Actor 2 (patient): I'll check this out later, but is there anything that you can do to help with the side effects. I can't be feeling sick all day at my new job. I don't want to make that type of impression.

Actor 1 (provider): For now, there are a few prescriptions to lessen your symptoms that haven't been tried by your last doctors.

Actor 2 (patient): What about changing my HIV meds? Can we try something new? I've been reading a lot about a one-a-day pill. Could we try that?

Actor 1 (provider): I really don't think that's necessary at this point. Your current meds are working great, other than a few side effects. But if it's that important to you, after I get some more detailed results from your blood draw today, I will look into the possibility of other medication regimens.

Actor 2 (patient): Ok.

3. Segment 3:

Narrator: Dr. Everheart explained that he would now be performing a physical examination.

Actor 1 (provider): Alright, well I am now going to give you a brief physical examination to check your heart rate, blood pressure, breathing, and also check out your throat, ears, and eyes for normal functioning.

Narrator: Dr. Everheart walked to the supply cabinet and grabbed two pairs of latex gloves. He put them on his hands and approached Ms. Johnson, placing the stethoscope in his ears. He maintained an arm's length distance from Ms. Johnson, having to stretch his arm to place the stethoscope on her chest. Leaning away from Ms. Johnson, he listened to his breathing for a few seconds, and then placed the stethoscope on her back and listened for another couple seconds. Dr. Everheart removed the stethoscope from his ears, reached for the blood pressure cuff, and asked Ms. Johnson's to place it on her own arm. After taking Ms. Johnson's blood pressure, Dr. Everheart, stood up and again walked to the supply cabinet in the exam room. Dr. Everheart returned with a tongue depressor and asked Ms. Johnson to open her mouth. Dr. Everheart again maintained an arm's length distance from Ms. Johnson and had a strained look on his face while examining the inside of her throat. Dr. Everheart then felt her lymph nodes on the side of her neck for a few moments before returning to his seat on the far side of the exam room.

4. Segment 4:

Actor 1 (provider): Well everything looks good as far as blood pressure and heart rate. And no signs of temperature or cold symptoms. How have you been feeling recently?

Actor 2 (patient): Pretty good, but I've been having a lot of headaches lately.

Actor 1 (provider): Has anything happened recently to trigger these headaches? Any changes in medication, diet, activity level?

Actor 2 (patient): Not really.

Actor 1 (provider): Then it's probably just HIV-related.

Actor 2 (patient): Well maybe. But they're pretty bad. I get shooting pains right behind my eyes, and it's happening at least twice a week.

Actor 1 (provider): Ok, well it sounds like you might be experiencing migraines. I think we have some med samples here in the clinic that you could try out, but I'm not really sure if migraine medications with interact negatively with your HIV medications. Let me check with your nurse practitioner.

Narrator: Dr. Everheart walked to the door and opened it far enough to stick his head out into the hall. In a moderately loud voice, he called for Ms. Johnson's nurse practitioner.

Actor 1 (provider): Christine, will Imitrex interact with Ms. Regina Johnson's HIV regimen?

Narrator: After Dr. Everheart talked with Christine, he closed the door and turned to face Ms. Johnson.

Actor 1 (provider): Ok, well they shouldn't interact with any of your HIV meds, just make sure to take them with food. If after a week you're still having problems we can do some more extensive tests to see what else might be going on. Sound okay to you?

Actor 2 (patient): Sounds good.

Actor 1 (provider): Great. Well I'm going to go grab those medication samples.

Narrator: Dr. Everheart left the exam room and returned in 15 minutes with the medication samples.

Actor 1 (provider): Well we're just about finished with today's appointment. But before you leave, I need to ask you a series of questions about your current sexual practices and also any previous or current alcohol or drug use.

Non-Stigma Vignette Male

1. Segment 1:

Narrator: Dr. Everheart knocked on the door before entering into the room. He approached Mr. Johnson and shook his hand while introducing himself.

Actor 1 (provider): Hello Mr. Johnson my name is Dr. Actor 1 (provider) Everheart and I'll be your primary physician here at the clinic. I understand that you are new to the area. I hope you are enjoying our lovely city. How are you doing?

Narrator: Dr. Everheart takes a seat in a chair near the exam table where Mr. Johnson is sitting and begins reviewing his chart.

Actor 2 (patient): Pretty good, I'm feeling healthy. I'm just a little stressed with having to start all over at a new clinic with new doctors.

Actor 1 (provider): Well that's understandable, we'll try to make the process as easy as possible for you. Basically all we are going to be doing today is going over your medical history, completing a physical exam, and discussing any questions or concerns that you or I might have about your health. I like to be thorough with all my new patients, and double check some of the information in their files just to be sure it's up to date and correct. Your last treatment center sent us your file yesterday, I just have few pieces of information that I would like to confirm with you.

Actor 2 (patient): ok

Actor 1 (provider): Your chart says that you tested positive for HIV about five years ago in February of 2006.

Actor 2 (patient): Yeah, that's the story.

Actor 1 (provider): It says that you most likely became infected from sexual activity with men, and more specifically your partner at the time.

Actor 2 (patient): Yeah. He didn't realize that he was positive and after 5 or 6 months together we weren't as strict about using condoms all the time. One day he found out one of his past hook-ups was positive and we both went in and got tested. Both of us found out that we were positive. We're still together though and he moved here with me.

Actor 1 (provider): It seems like you have really been there for each other. You know, it's so common for people to not know that they are positive. It seems like both of you got blind-sided in that situation. It's really good that you both decided to come in and get tested when you did.

Actor 2 (patient): Thanks.

2. Segment 2:

Actor 1 (provider): So it also says that you began taking anti-retroviral medications pretty soon after you received your diagnosis.

Actor 2 (patient): Yeah it was within a few months.

Actor 1 (provider): And other than a couple bouts of pneumonia in 2007 and 2008, you have been pretty healthy. Looks like your viral load and CD4 counts have been pretty stable ever since you started taking meds, except for the summer of last year when your viral load became detectable again and your CD4 count dropped by 30%. Do you remember what was going on around that time that caused these changes?

Actor 2 (patient): Yeah, my last doctors tried to switch my meds because they were making me nauseas and tired throughout the day. The new combination didn't work, so they put me back on the old meds after a few months. I was actually upset about it because physically I felt really great on the new meds. I mean is it really that big of deal if my numbers change a little?

Actor 1 (provider): You know it can often be a fairly complicated process to find the right combination of meds for patients. We try to balance out the experience of side effects with the effectiveness of the medications, and every patient responds a bit differently. Unfortunately, it is a big deal if your viral load and CD4 count change. Those are our best indicators of how the HIV virus is progressing in your body, and they can even be better indicators than how your body is physically feeling. I actually have a great brochure about some of the important information about viral load and CD4 counts. Would you like me to go over some of it with you?

Actor 2 (patient): That would actually be really helpful.

Narrator: Dr. Everheart stood up from his chair and grabbed a brochure. After walking over to the exam table, Dr. Everheart pointed out the key points of the brochure to Mr. Johnson and answered any remaining questions that he had.

Actor 2 (patient): Ok, so I get now why they took me off the new meds, but is there anything that you can do to help with the side effects. I can't be feeling sick all day at my new job. I don't want to make that type of impression.

Actor 1 (provider): For now, there are a few prescriptions to lessen your symptoms that haven't been tried by your last doctors. And after I get some more detailed results from your blood draw today, I will look into the possibility of other medication regimens that might be as effective as your current meds but with less side effects. I don't know if the new HIV medications on market will turn out to be a good fit for you, but we can definitely look into the possibility.

Actor 2 (patient): Ok, fair enough.

3. Segment 3:

Narrator: Dr. Everheart handed the brochure to Mr. Johnson and explained that he would now be performing a physical examination.

Actor 1 (provider): Alright, well I am now going to give you a brief physical examination to check your heart rate, blood pressure, breathing, and also check out your throat, ears, and eyes for normal functioning.

Narrator: Dr. Everheart approached Mr. Johnson, placing the stethoscope in his ears. He stood close to Mr. Johnson, placed the stethoscope on his chest, and listened to his breathing for approximately 10 seconds. He then placed the stethoscope on his back and listened for another 10 seconds. Dr. Everheart removed the stethoscope from his ears, reached for the blood pressure cuff, and placed it on Mr. Johnson's arm. After taking Mr. Johnson's blood pressure, Dr. Everheart, stood up and walked to the supply cabinet in the exam room. Dr. Everheart returned with a tongue depressor and asked Mr. Johnson to open his mouth. Dr. Everheart leaned towards Mr. Johnson and examined the inside of his throat thoroughly. Dr. Everheart then felt his lymph nodes on the side of his neck for a few moments before returning to his seat near the exam table.

4. Segment 4:

Actor 1 (provider): Well everything looks good as far as blood pressure and heart rate. And no signs of temperature or cold symptoms. How have you been feeling recently?

Actor 2 (patient): Pretty good, but I've been having a lot of headaches lately.

Actor 1 (provider): Has anything happened recently to trigger these headaches? Any changes in medication, diet, activity level?

Actor 2 (patient): Not really.

Actor 1 (provider): Have you been experiencing a lot of stress lately? Everything been going ok with friends/family?

Actor 2 (patient): You know I have been stressed out a lot due to the move, but I really don't think it's just that. They're pretty bad. I get shooting pains right behind my eyes, and it's happening at least twice a week.

Actor 1 (provider): Ok, well I have some ideas for what might be causing these types headaches. Those pain symptoms are pretty common for a lot of people especially those with a family history of migraines. I'll check to see if we have some medication samples to for you take home and see if they help. They shouldn't interact with any of your HIV

meds, just make sure to take them with food. If after a week you're still having problems we can do some more extensive tests to see what's going on. Sound okay to you?

Actor 2 (patient): Sounds good.

Actor 1 (provider): Great. Well I'm going to go grab those medication samples.

Narrator: Dr. Everheart left the exam room and returned in several minutes with the medication samples.

Actor 1 (provider): Well we're just about finished with today's appointment. But before you leave, I'd like to chat with you a little about your current sexual practices and also any previous or current alcohol or drug use. I know these types of topics are sensitive in nature and can seem a little out of the blue for a regular medical appointment. Basically new national standards of medical practice have been created, calling for health care providers to assess these types of things at all medical care visits to improve prevention of new infections and also to allow for the best care possible for current HIV+ patients. It's important to me that you feel comfortable, so is it okay for me to ask you a few questions?

Stigma Vignette Male

1. Segment 1:

Narrator: Dr. Everheart knocked on the door before entering into the room. He walked through door looking at Mr. Johnson's file and did not look up while introducing himself.

Actor 1 (provider): Hello Mr. Johnson my name is Dr. Everheart and I'll be your primary physician here at the clinic. How are you doing?

Narrator: Dr. Everheart takes a seat in a chair on the far side of the room from where Mr. Johnson is sitting and begins reviewing his chart.

Actor 2 (patient): Pretty good, I'm feeling healthy. I'm just a little stressed with having to start all over at a new clinic with new doctors.

Narrator: Dr. Everheart continues to look down at Mr. Johnson's chart as he speaks.

Actor 1 (provider): Well, nothing to worry about. Basically all we are going to be doing today is going over your medical history and completing a physical exam. I like to be thorough with all my new patients, and double check some of the information in their files. Your last treatment center sent us your file yesterday, I just have few pieces of information that I would like to confirm with you.

Actor 2 (patient): ok

Actor 1 (provider): Your chart says that you tested positive for HIV about five years ago in February of 2006.

Actor 2 (patient): Yeah, that's the story.

Actor 1 (provider): It says that you most likely became infected from having sex with other men. Hopefully becoming positive has motivated you to be more careful with reducing your number of sexual partners and using condoms. Oh wait, I see here that you were infected by your partner at the time.

Actor 2 (patient): Yeah. He didn't realize that he was positive and after 5 or 6 months together we weren't as strict about using condoms all the time. One day he found out one of his past hook-ups was positive and we both went in and got tested. Both of us found out that we were positive. We're still together though and he moved here with me.

Actor 1 (provider): That's surprising. You really don't see that nowadays. But, I guess you learned your lesson, and at least you both decided to come in and get tested when you did.

Actor 2 (patient): Thanks.

2. Segment 2:

Actor 1 (provider): So it also says that you began taking anti-retroviral medications pretty soon after you received your diagnosis.

Actor 2 (patient): Yeah it was within a few months.

Actor 1 (provider): And other than a couple bouts of pneumonia in 2007 and 2008, you have been pretty healthy. Looks like your viral load and CD4 counts have been pretty stable ever since you started taking meds. That is except for the summer of last year when your viral load became detectable again and your CD4 count dropped by 30%. Did you stop taking your meds?

Actor 2 (patient): No, actually my last doctors tried to switch my meds because they were making me nauseas and tired throughout the day. The new combination didn't work, so they put me back on the old meds after a few months. I was actually upset about it because physically I felt really great on the new meds. I mean is it really that big of deal if my numbers change a little?

Actor 1 (provider): Unfortunately, Mr. Johnson it is a big deal if your viral load and CD4 count change. Those are our best indicators of how the HIV virus is progressing in your body. You've been positive a while, I assumed you knew all this. I think I have a brochure that can explain viral load and CD4 counts to you. Let me grab it.

Narrator: Dr. Everheart rose from his chair and grabbed a brochure. Without approaching the exam table, he leaned over to hand the brochure to Mr. Johnson.

Actor 1 (provider): I strongly suggest you review this material.

Actor 2 (patient): I'll check this out later, but is there anything that you can do to help with the side effects. I can't be feeling sick all day at my new job. I don't want to make that type of impression.

Actor 1 (provider): For now, there are a few prescriptions to lessen your symptoms that haven't been tried by your last doctors.

Actor 2 (patient): What about changing my HIV meds? Can we try something new? I've been reading a lot about a one-a-day pill. Could we try that?

Actor 1 (provider): I really don't think that's necessary at this point. Your current meds are working great, other than a few side effects. But if it's that important to you, after I get some more detailed results from your blood draw today, I will look into the possibility of other medication regimens.

Actor 2 (patient): Ok.

3. Segment 3:

Narrator: Dr. Everheart explained that he would now be performing a physical examination.

Actor 1 (provider): Alright, well I am now going to give you a brief physical examination to check your heart rate, blood pressure, breathing, and also check out your throat, ears, and eyes for normal functioning.

Narrator: Dr. Everheart walked to the supply cabinet and grabbed two pairs of latex gloves. He put them on his hands and approached Mr. Johnson, placing the stethoscope in his ears. He maintained an arm's length distance from Mr. Johnson, having to stretch his arm to place the stethoscope on his chest. Leaning away from Mr. Johnson, he listened to his breathing for a few seconds, and then placed the stethoscope on his back and listened for another couple seconds. Dr. Everheart removed the stethoscope from his ears, reached for the blood pressure cuff, and asked Mr. Johnson's to place it on his own arm. After taking Mr. Johnson's blood pressure, Dr. Everheart, stood up and again walked to the supply cabinet in the exam room. Dr. Everheart returned with a tongue depressor and asked Mr. Johnson to open his mouth. Dr. Everheart again maintained an arm's length distance from Mr. Johnson and had a strained look on his face while examining the inside of his throat. Dr. Everheart then felt his lymph nodes on the side of his neck for a few moments before returning to his seat on the far side of the exam room.

4. Segment 4:

Actor 1 (provider): Well everything looks good as far as blood pressure and heart rate. And no signs of temperature or cold symptoms. How have you been feeling recently?

Actor 2 (patient): Pretty good, but I've been having a lot of headaches lately.

Actor 1 (provider): Has anything happened recently to trigger these headaches? Any changes in medication, diet, activity level?

Actor 2 (patient): Not really.

Actor 1 (provider): Then it's probably just HIV-related.

Actor 2 (patient): Well maybe. But they're pretty bad. I get shooting pains right behind my eyes, and it's happening at least twice a week.

Actor 1 (provider): Ok, well it sounds like you might be experiencing migraines. I think we have some med samples here in the clinic that you could try out, but I'm not really sure if migraine medications with interact negatively with your HIV medications. Let me check with your nurse practitioner.

Narrator: Dr. Everheart walked to the door and opened it far enough to stick his head out into the hall. In a moderately loud voice, he called for Mr. Johnson's nurse practitioner.

Actor 1 (provider): Christine, will Imitrex interact with Mr. Robert Johnson's HIV regimen?

Narrator: After Dr. Everheart talked with Christine, he closed the door and turned to face Mr. Johnson.

Actor 1 (provider): Ok, well they shouldn't interact with any of your HIV meds, just make sure to take them with food. If after a week you're still having problems we can do some more extensive tests to see what else might be going on. Sound okay to you?

Actor 2 (patient): Sounds good.

Actor 1 (provider): Great. Well I'm going to go grab those medication samples.

Narrator: Dr. Everheart left the exam room and returned in 15 minutes with the medication samples.

Actor 1 (provider): Well we're just about finished with today's appointment. But before you leave, I need to ask you a series of questions about your current sexual practices and also any previous or current alcohol or drug use.

Appendix N

Draft of Experimental Phase Protocol

EXPERIMENTAL PROCEDURES

I. INFORMED CONSENT

A. OVERVIEW OF CONSENT INFORMATION

A participant who gives their informed consent to participate in the study should fully understand the nature of the research study, the purpose and pertinent procedures for the study, potential risks and benefits of participating, confidentiality and steps taken by research team to ensure confidentiality, and how the data will be used and stored.

B. PARTICIPANT CONSENT

After a brief introduction, the principle investigator (PI) leads the participant through the informed consent form, highlighting the most important aspects of informed consent. The following outline illustrates the content that is verbally expressed by the PI during this process:

- **WHO:** The project directors for this study are Jessie Heath, M.S., a clinical psychology doctoral student at Syracuse University and Dr. Peter Venable, an associate professor of psychology at Syracuse University and an adjunct assistant professor of medicine at SUNY Upstate Medical University.
- **PURPOSE & PROCEDURE:** You are being asked to participate in a research study designed to learn more about how aspects of patient-provider relationships can affect the medical treatment of persons living with HIV. Our goal is to gain a better understanding of how the behaviors of medical care providers within medical appointments can affect the HIV+ patients they treat. We will use the information obtained in this study to inform the development of strategies to improve patient-provider relationships and the quality of medical care received HIV+ patients.
- **TIME & COMPENSATION:** Your participation involves viewing a vignette of a hypothetical medical care visit and responding to questions using an interactive computer program. The study takes approximately one hour, and you will receive \$20 for your time.
- **RISKS/BENEFITS:**
 - Risks: There are three risks associated with this study. First, you may feel uncomfortable answering personal questions. If this occurs, you may choose not to answer any question. Second, you may find some aspects of the vignette mildly upsetting. A third risk involves the risk of disclosing private information to our research team. However, all information that you share with members of our team is considered strictly confidential, and we are obligated to protect your privacy.
 - Benefits: You may learn more about your feelings and become aware of how aspects of medical treatment experiences can affect you. In addition, because the information you provide assists in the development of strategies to improve patient-provider relationships, your participation could benefit others living with HIV.

- **CONFIDENTIALITY and HIPPA**
 - If you decide to participate, any information that you give us is strictly confidential. We will keep your information private, except under 2 circumstances.
 - First, if you tell us that you're planning to hurt yourself or someone else we would have to disclose that information.
 - Second, if officials were concerned that the research team was acting inappropriately, the research records might be audited to make sure the research was being conducted ethically; however, the auditors would be required to protect your privacy.
- **PROTECTION OF CONFIDENTIALITY**
 - All project staff receive extensive training and supervision on confidentiality procedures.
 - Your survey is given an identification number and only authorized research staff has access to the key that connects your information to your name. Your identity will not be included on the audiotapes and the tapes will be erased once we are finished with the project.
 - Certificate of Confidentiality from the Department of Health and Human services, which states that the investigators cannot be forced to release your information (for example, by subpoena) to any federal, state, or local, civil, criminal, administrative, legislative, or other proceedings. This Certificate does NOT prevent you or your family from voluntarily disclosing information about yourself or your involvement in this research.
- **PARTICIPATION IS VOLUNTARY:** You may refuse to participate or discontinue your participation at any time without penalty or loss of benefits.
- **PERMISSION TO BE RECONTACTED:** The participants are then asked to sign and date one copy of the consent form and keep a second copy for their own records. Participants are also given a copy of University Hospital's Privacy Practices Policy and asked to keep it for their records.

C. STORAGE OF CONSENT FORMS

After pertinent information from the completed consent forms has been entered into the Excel patient database, the completed focus group consent forms will be stored in a locked filing cabinet in the UPH office.

II. EXPERIMENTAL PROTOCOL ADMINISTRATION

A. ASSIGNMENT OF PARTICIPANT NUMBER AND CONDITION

After participants consent, they will be assigned a participant ID number and randomized to a "high stigma," "moderate stigma," or "no stigma" study condition using a random number generator.

B. VIGNETTE AND SURVEY ADMINISTRATION

The quantitative survey is administered following the informed consent. The participants will be seated in front of a computer, where the PI will introduce the computerized study protocol and briefly describe how the computer program works. The PI will answer any questions the participant has and ensure the participant's ability to successfully interact with the computer program. For participants with limited computer exposure, the principle investigator will provide additional instruction on the use of the mouse and keyboard as necessary. Participants will also be instructed that if they have any difficulties with the computer program to ring a bell on the desk and the principle investigator will assist them. Participants will then follow the audio instructions on the ACASI program to complete the small battery of self-report assessments and respond to the visual and audio treatment vignettes. The ordering of the protocol will be as follows: (1) reporting of background and health information, (2) step-by-step presentation of treatment vignette with ratings of comfort assessed at several points throughout the presented patient-provider interaction, (3) ratings on the Perceptions of Stigmatization within the Patient-Provider Interaction scale, (4) ratings on measures assessing intentions to engage in care, and (5) ratings on the Experiences of HIV-related Stigmatization in Healthcare Settings measure.

C. DATA ENTRY AND STORAGE

Data from the ACASI program will be automatically stored upon completion of the protocol and then transformed into an SPSS format for analyses. There will be no hard copies of data in the experimental phase of the study and no identifying information will present in the ACASI or SPSS files.

D. PARTICIPANT REIMBURSEMENT

The PI will retrieve reimbursement funds from Sean Kelley prior to the start of the focus group. Participants will be reimbursed \$20 for their one hour of participation in the focus groups. After participants have received their reimbursement, the PI will complete a reimbursement receipt including only the participant's ID number and file it in the UPH filing cabinet under non-reconciled payment receipts. The original reimbursement form will then be turned in to Sean Kelley. A photocopy will be stored in the UPH filing cabinet under reconciled payment receipts.

Appendix O

Draft of Experimental Phase Informed Consent Form

**SUNY UPSTATE MEDICAL UNIVERSITY AND
SYRACUSE UNIVERSITY**

Consent/Authorization Form

Title of Study: Treatment Experiences of HIV+ Patients Study

Background/Purpose:

You are invited to participate in a research study designed to learn more about how aspects of patient-provider relationships can affect the medical treatment of persons living with HIV. Our goal is to gain a better understanding of how the behaviors of medical care providers within medical appointments can affect the HIV+ patients they treat. We will use the information obtained in this study to inform the development of strategies to improve patient-provider relationships and the quality of medical care provided to persons living with HIV. The directors of this study are Jessie Heath, M.S., a clinical psychology doctoral student and Dr. Peter Venable, an Associate Professor of Psychology at Syracuse University and an Adjunct Assistant Professor of Medicine at SUNY Upstate Medical University. Other trained research staff will also be involved, and will be supervised by Drs. Peter Venable of Syracuse University. We are asking approximately 150 patients to participate in the study.

You will be given enough time to read and understand the information provided in this consent and authorization form. Please ask the study staff to explain any words or information that you do not understand. You may keep an unsigned copy of this consent and authorization form to think about your decision or discuss with your family, friends, or doctors before making your decision to take part in this research study.

Study Procedures:

If you decide to take part in this study, you will listen and respond to information that is presented individually to you on a computer. You will be randomly assigned to view one of two vignettes representing a typical, first-time medical care visit of an HIV+ patient. On the computer, you will hear audio descriptions of the medical visit, conversations between the hypothetical patient and provider, and also view pictures of the interaction. Throughout, and following the presentation of the vignette, you will answer questions presented on the computer screen regarding your feelings and opinions about what you are viewing. You will then respond to questions related to health, sexual behavior, and substance use. The study takes approximately one hour to complete, and your participation is completely voluntary.

If you agree to participate in the study, you will also be asked to complete a brief survey with questions about your background and health information, including medical appointment attendance, hospitalizations, and recent indicators of health status (CD4 count, viral load).

Risks:

There are three risks associated with this study. First, you may feel uncomfortable answering personal questions. If this occurs, you may choose not to answer any question. Second, you may find some aspects of the vignette mildly upsetting. A third risk involves the risk of disclosing private information to our research team. However, all information that you share with members of our team is considered strictly confidential, and we are obligated to protect your privacy.

Benefits:

The potential benefits are that you may learn more about your feelings and become aware of how aspects of medical treatment experiences can affect you. In addition, because the information you provide assists in the development of strategies to improve patient-provider relationships, your participation could benefit others living with HIV.

Voluntary Participation:

Your participation in this study is entirely voluntary and you may refuse to participate or stop participation at any time without penalty or loss of benefits to which you would normally be entitled. Your decision about whether or not to participate in the study will not affect the care you receive at SUNY Upstate Medical University.

Alternatives:

If you decide not to participate in this research study, you will continue to receive your usual care and will not complete the surveys for research purposes.

Costs/Payments:

There are no costs to you and/or your insurance carrier for participating in this study. After completing the study, you will receive \$20 to offset your expenses and to thank you for your time.

If you choose to stop participating in the study before all study requirements are completed, you will be paid \$10 for each ½ hour of time you devote to the study.

In addition, by accepting payment for participating in this study, certain identifying information about you may be made available to professional auditors to satisfy audit and Federal reporting requirements, but confidentiality will be preserved. Please note that if you earn \$600 or over in a calendar year as a research subject, you may have to pay taxes on these earnings.

Questions:

If you have any questions about the research, please contact Ms. Jessie Heath at (315) 443-1052 or Dr. Peter Vanable at (315) 443-2024. If you have any questions about your rights as a research subject, please contact the SUNY Upstate Medical University

Institutional Review Board Office at (315) 464-4317 or the Syracuse University Institutional Review Board Office at (315) 443-3013.

Confidentiality of Records and Authorization to Use/Share Protected Health Information for Research:

If you agree to participate in this research, identifiable health information about you will be used and shared with others involved in this research. For you to be in this research we need your permission to collect and share this information. Federal law protects your right to privacy concerning this information.

When you sign this consent form at the end, it means that you have read this section and authorize the use and/or sharing of your protected health information as explained below. Your signature also means you have received a copy of Upstate's Notice of Privacy Practices.

Individually identifiable health information under the federal privacy law is considered to be any information from your medical record, or obtained from this study, that can be associated with you, and relates to your past, present, or future physical or mental health or condition. This is referred to as protected health information.

Your protected health information will be kept confidential. Research staff will not share the information you provide during the discussion group and on the survey with your doctor or nurse here in the clinic. Further, you will not be identified in any publication or presentation resulting from this study. Several steps have been taken to protect the confidentiality of your responses and involvement in this research. Project staff has participated in extensive training and supervision regarding the importance of maintaining participant confidentiality. In addition, an identification number will be assigned to your survey, and only the directors of this research (Jessie Heath, M.S. and Dr. Vanable) will have access to the key that indicates which number belongs to which participant. The master list linking the participant ID number to the participant's identifying information will be maintained in a separate, secure computer database, and will be destroyed at the conclusion of the study. Your name or other identifying information will not be kept with your survey, and your survey information will be stored in a secure computer database.

To help us further protect your privacy, the investigators have received a Confidentiality Certificate from the Department of Health and Human Services. With this Certificate, the investigators cannot be forced (for example by court subpoena) to disclose research information that may identify you in any Federal, State, or local, civil, criminal, administrative, legislative, or other proceedings. The researchers will use the Certificate to resist any demands for information that would identify you, except as explained below.

The Certificate cannot be used to resist a request for information from personnel of the United States Department of Health and Human Services that is used for auditing or evaluation of federally funded projects.

In addition, the Confidentiality Certificate does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. Note however, that if an insurer or employer learns about your participation, and obtains your consent to receive research information, then the investigator may not use the Certificate of Confidentiality to withhold this information. This means that you and your family must also actively protect your own privacy.

Why is it necessary to use/share your protected health information with others? The main reason to use and share your health information is to conduct the research as described in this consent form. Your information may also be shared with people and organizations that make sure the research is being done correctly, and to report unexpected or bad side effects you may have. In addition, we will release protected health information about you if we learn about your intent to harm yourself or others.

What protected health information about you will be used or shared with others as part of this research? We may use and share the results of tests, questionnaires, and interviews. We will only collect information that is needed for the research.

Who will be authorized to use and/or share your protected health information? The researchers, their staff and the staff of Upstate Medical University participating in the research will use your protected health information for this research study. In addition, the Upstate Medical University and Syracuse University Institutional Review Boards (IRB), committees responsible for protecting the rights of research subjects, and other Upstate Medical University, Syracuse University, or University Hospital staff who supervise the way the research is done, may have access to your protected health information.

The researchers and their staff will determine if your protected health information will be used or shared with others outside of Upstate Medical University and Syracuse University for purposes directly related to the conduct of the research.

With whom would the protected health information be shared? Your protected health information may be shared with:

- Federal agencies that supervise the way the research is conducted, such as the Department of Health and Human Services' Office for Human Research Protections or the National Institutes of Health.
- Researchers from Syracuse University assisting in the study.
- The Syracuse University Institutional Review Board (a committee responsible for protecting the rights of research subjects).

All reasonable efforts will be used to protect the confidentiality of your protected health information. However, not all individuals or groups have to comply with the Federal privacy law. Therefore, once your protected health information is disclosed (leaves Upstate Medical University), the Federal privacy law may not protect it.

For how long will your protected health information be used or shared with others? There is no scheduled date at which this information will be destroyed or no longer used. This is because information that is collected for research purposes continues to be used and analyzed for many years and it is not possible to determine when this will be complete.

Can you withdraw your authorization to collect/use/share your protected health information? You always have the right to withdraw your permission (revoke authorization) for us to use and share your health information, by putting your request in writing to the investigator in charge of the study. This means that no further private health information will be collected. Once authorization is revoked, you may no longer participate in this research activity, but standard medical care and any other benefits to which you are entitled will not be affected. Revoking your authorization only affects uses and sharing of information obtained after your written request has been received, but not information obtained prior to that time.

Even after you withdraw your permission, Upstate Medical University may continue to use and share information needed for the integrity of the study; for example, information about an unexpected or bad side effect you experienced related to the study.

Can you have access to your health information? At the end of the study, you have the right to see and copy health information about you in accordance with the SUNY Upstate Medical University policies; however, your access may be limited while the study is in progress.

Permission To Contact For Follow-Up Research

We may conduct additional research on this important topic. May we contact you about participation in future studies? Indicating you are willing to be contacted does not obligate you to participate in any other study, nor does it affect your participation in this study.

- No, I prefer not to be contacted about future studies.
 Yes, I am willing to be contacted about future studies.

Phone: _____

Mailing Address: _____

Consent To Participate In Research & Authorization To Use And Share Personal Health Information:

I hereby give my consent to participate in this research study and agree that my personal health information can be collected, used and shared by the researchers and staff for the research study described in this form. I will receive a signed copy of this consent form.

Signature of subject

Date

Printed Name of Research Participant

Signature of Person Obtaining Consent/Authorization

Date

Printed Name of Person Obtaining Consent/Authorization

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Jessica.Naughton@va.gov

Education

Ph.D., Clinical Psychology, Syracuse University (2012)

Degree: Clinical Psychology Ph.D.

Graduate Advisor: Peter A. Venable, Ph.D.

Qualifying Exam Title: *HIV Stigmatization among Providers: Review of the Evidence and Implications for HIV Care*

Dissertation Title: *HIV-Related Stigmatization in Treatment Settings: Effects on Patient Comfort, Risk Disclosure, and Treatment Decisions*

M.S., Clinical Psychology, Syracuse University (2008)

Master's Thesis Title: *Adjustments in HIV-related Stigma Responses: An Examination of a Dual Process Model*

B.A., Psychology, University of Missouri-Kansas City (2004)

Graduated *Summa Cum Laude*, with Departmental Honors

Senior Honors Thesis: *The Down Low: Attitudes, Identity, and HIV Implications*

Clinical Training and Practicum Experience

VA Long Beach Healthcare System

2011-2012

(APA Accredited Internship in Clinical Psychology)

Long Beach, CA

Training Director: Kenneth, Cole, Ph.D.

- Rotations
 - PTSD and Mindfulness (Supervisor: John Huang, Ph.D.)
 - Conducted psychological intake assessments and provided time-limited therapy to OIF/OEF, Gulf War, and Vietnam-era veteran patients using integrative therapeutic approaches, CPT, and PE protocols to treat PTSD and comorbid psychological disorders.
 - Received training in mindfulness practices for the treatment of PTSD, incorporating its techniques and principles of present-focused, non-judgmental awareness into my clinical work with patients suffering from trauma-related difficulties.
 - Co-facilitated multiple psychotherapy and psychoeducation groups including: Mindfulness/Meditation Group for Combat Veterans (ongoing), Combat PTSD Group (12 week, topic-based with focus on

- coping), CBT for Insomnia (6 sessions), and several CPT Groups for Combat-related PTSD (13 sessions)
- Substance Abuse Treatment Center (Supervisor: Henry Benedict, Ph.D.)
 - Worked as part of a multi-disciplinary team to conduct psychological intake assessments and provide time-limited therapy to veteran patients recovering from alcohol and substance dependence.
 - Co-facilitated two supportive psychotherapy groups focusing on maintaining long-term sobriety through discussion of current and previous life struggles, relapse prevention strategies, and individual successes and positive life changes.
 - Women's Mental Health Treatment Center (Supervisor: Lori Katz, Ph.D.)
 - Introduced to a holistic, integrated team approach to treating female veterans with psychological difficulties related to sexual trauma.
 - Conducted short-term individual and group therapy modalities including: DBT, Seeking Safety, PE, goal-oriented dynamic approaches, and holographic reprocessing.
 - Conducted individual and group therapies as part of interdisciplinary treatment team for Renew program, an intensive 12-week residential treatment program for female sexual trauma survivors focusing on psychological, as well as holistic healing.
 - Outpatient Psychotherapy and Assessment (Supervisor: Leigh Messinides, Ph.D.)
 - Conducted cognitive and personality assessments and provided time-limited individual and couples' therapy for veterans and/or their significant others.
 - Utilized a variety of therapeutic approaches (psychodynamic, CBT, mindfulness, CPT) in the treatment of a wide range of affective, anxiety, and relation-based psychological difficulties.
 - Co-facilitated a 16-week structured psychotherapy group for survivors of non-combat related trauma. Group incorporates principles of Acceptance and Commitment Therapy, mindfulness, coping skill development, and mantram repetition.
 - HIV and Hospice Care (Supervisor: Adrienne House, Ph.D.)
 - Infectious Disease Program: Conducted psychological screenings for new patients in ID Clinic, as well as assessed potential difficulties in maintaining non-compliance with medication regimens and safer sex practices. Also provided crisis intervention and psychotherapy for outpatients to address psychological and substance-related difficulties.
 - Hematology/Oncology Service: Provided consultation services to veterans receiving inpatient and outpatient treatment for cancer. Also provided psychotherapy and family support for veterans coping with issues related to life-threatening and chronic illness, changes in body image or functioning, chronic pain, side effects of chemotherapy and radiation, and communication with medical team.
 - Completed transplant evaluations examining patients' psychological readiness for the surgery and recovery process, including barriers to

aftercare compliance, pre-existing mental health difficulties, and strength of support system.

**Syracuse Vet Center
Syracuse, New York**

2008-2011

Supervised by: Douglas Scaturro, Ph.D.

- Practicum Student Therapist
 - Conducted psychological intake assessments and provided therapy to OIF/OEF and Vietnam-era veteran clients in individual and couples settings using an integrative therapeutic approach to treat PTSD symptoms and associated marital and life difficulties.
 - Facilitated a Vietnam-era veterans' support group and a time-limited, couples' group for Vietnam-era veterans and their significant others using both supportive and CBT-based approaches.

**Psychological Services Center
Syracuse University**

2007-2011

Supervised by: Mark Ginsberg, Ph.D. (Director), Joseph Himmelsbach, Ph.D., Thomas Krisher, Ph.D., Lisa Cromer, Ph.D.

- Student Therapist
 - Conducted psychological intake assessments and provided individual therapy to student and community clients with a wide range of mental health diagnoses.
 - Developed and honed clinical skills pertaining to diagnosis, treatment planning, therapy, assessment, case presentations, and report writing.
 - Received individual supervision from clinicians belonging to multiple theoretical backgrounds.

**SUNY Upstate Medical University Infectious Disease Clinic
Syracuse, New York**

2009-2010

Supervised by: Jennifer Funderburk, Ph.D. & Brian Amidon, LMSW

- Practicum Student Therapist
 - Worked as part of an interdisciplinary team conducting psychological intake assessments and providing individual therapy to HIV+ clients from diverse demographic backgrounds.
 - Advanced clinical skills pertaining to diagnosis, treatment planning, therapy, assessment, case conceptualization, and report writing as a therapist within a medical setting.
 - Co-facilitated a skills-based, Coping Effectiveness Group for HIV+ men.

**The Center for Health and Behavior
Syracuse, New York**

2010

Supervised by: Peter Vanable, Ph.D.

- Facilitator
 - Gained experience in implementing brief, community-based interventions to promote sexual health and decrease risk behaviors related to alcohol and substance use among 9th graders in an urban school district.
 - Developed and conducted single session workshops by incorporating elements of psycho-education, motivational interviewing techniques, and behavioral skills training.

Clinical Trainings and Professional Development Activities

Child Abuse Seminar for Licensure (Psychiatry 615)

October 29th, 2011

Taught by: Margaret Dominguez, Ph.D.

- Presented by UCLA Dept of Psychiatry and Biobehavioral Sciences
 - Participated in 8 hour training seminar focusing on the recognition, assessment, effects, and reporting of child abuse.
 - Training completed as one of the requirements for clinical licensure in California (certificate provided).

Prolonged Exposure Therapy Seminar

October 12, 19, 26th, 2011

Taught by: Diedre Lopez, Ph.D.

- Presented by the Long Beach VA as part of an intern seminar series
 - Participated in 6 hour training seminar providing instruction for conducting Prolonged Exposure Therapy for the treatment of PTSD.
 - Currently participating in ongoing supervision/consultation process.

**Cognitive Processing Therapy Training
for Certification**

September 29-30th, 2011

Taught by: Diane Sakal-Guttierrez, LCSW

- Presented by Loma Linda VA
 - Participated in two-day training seminar (16 hrs) providing instruction for conducting Cognitive Processing Therapy for the treatment of PTSD.
 - Currently participating in six month supervision/consultation process on individual and group CPT cases for purposes of attaining status as a certified CPT provider.

**Workshop in Time-Limited Dynamic Psychotherapy:
Attachment-Based, Emotionally-Focused, Interpersonal Approach**

May 23rd, 2010

Taught by: Hannah Levenson, Ph.D.

- Presented by Department of Psychiatry at SUNY Upstate Medical University

- Participated in one-day workshop offering an introduction to the history, theoretical bases, basic principles, strategies, and process of conducting integrated, time-limited dynamic psychotherapy.

A Rorschach Workshop

October 15th, 2010

Taught by: Michael Miller, Ph.D. (SUNY Upstate Medical University)

- Presented by Syracuse University
 - Participated in one-day workshop offering a basic and brief introduction to the history, theoretical bases, administration, and scoring of the Rorschach.
 - Primary emphasis on Exner's Comprehensive System, working from the "Rorschach Workbook for the Comprehensive System".

Cognitive Behavioral Therapy Seminar

January 2008-May 2008

Taught by: Lisa Cromer, Ph.D., Lenny Vartanian, Ph.D.

- Presented by Syracuse University
 - Participated in semester-long training seminar in cognitive behavioral theory, skills, materials, and therapeutic application.
 - Received individual supervision on a client treated using a strict CBT approach, formulating case conceptualizations and demonstrating competence in case presentation.

Prolonged Exposure Therapy for PTSD Training Seminar

December 2007

Taught by: Shawn Cahill, Ph.D.

- Presented by Psychological HealthCare, P. L. L. C. and the Onondaga County Mental Health Association (Syracuse, NY)
 - Received training in Prolonged Exposure Therapy (PET) for patients presenting with PTSD (3 day seminar).
 - Instruction and practice in using in-vivo exposure exercises, the Subjective Units of Distress Scale, and imaginal exposure techniques.

Publications

Naughton, J., & Vanable, P. (2012). An experimental investigation of a dual process model of HIV related stigma. *Basic and Applied Social Psychology*, 43, 8-19.

Heath, J., Lanoye, A., & Maisto, S. (2012). The role of substance use in risky sexual behavior among older men who have sex with men: Review of current literature. *Aids and Behavior*, 16, 578-589.

Maisto, S. A., Palfai, T., Vanable, P. A., **Heath, J.**, & Woolf-King, S. E. (2011, e-pub ahead of print). The effects of alcohol and sexual arousal on determinants of sexual risk in men who have sex with men. *Archives of Sexual Behavior*.

Naughton, J. & Vanable, P. A. (2012). HIV stigmatization among healthcare providers: Review of the evidence and implications for HIV care. Chapter in P. Liamputong (Ed.), *Stigma, Discrimination and Living With HIV/AIDS: A Cross-Cultural Perspective*. Springer, New York.

Heath, J., & Goggin, K. (2009). Attitudes towards male homosexuality, bisexuality, and the down low lifestyle: Demographic differences and HIV implications. *Journal of Bisexuality*, 9, 17-31.

Research Presentations and Symposia

Naughton, J. D., & Vanable, P. A. (2012, April). *HIV-Related Stigmatization in Treatment Settings: Effects on Patient Comfort, Risk Disclosure, and Treatment Decisions*. Poster selected to receive a mentored poster at the 33rd Society of Behavioral Medicine Annual Meeting and Scientific Sessions, New Orleans, Louisiana.

Bonafide, K. E., Vanable, P. A., Carey, M. P., **Naughton, J. D.**, & Brown, J. L. (2012, March), *The Impact of Parental Attitudes and Beliefs on the Decision to Vaccinate Daughters with the HPV Vaccine*. Poster accepted to the annual CDC National STD Prevention Conference, Minneapolis, Minnesota.

Vanable, P. A., Carey, M. P., Bonafide, K. E., Brown, J. L., **Heath, J. D.**, & Bostwick, R. A. (2011, April). *Barriers to Male Human Papillomavirus Vaccination among African-American Mothers and their Adolescent Sons*. Paper presented at the annual meeting of the Society of Behavioral Medicine, Washington, D.C.

Wyatt, J., Vanable, P. A., Bonafide, K. A., **Heath, J. D.**, Carey, M. P., Brown, J. L., & Bostwick, R. A. (2011, April). *The Relationship of Parent-Child Communication about Sexual Health to Sexual Risk Taking among African American Adolescents*. Poster presented at the annual meeting of the Society of Behavioral Medicine, Washington, D.C.

Heath, J. D., & Vanable, P. A. (2010, April). *HIV Stigmatization among Providers: A Systematic Review of the Evidence and Implications for HIV Care*. Poster presented at the annual meeting of the Society of Behavioral Medicine, Seattle, WA.

Heath, J. D., & Vanable, P. A. (2009, April). *Testing a Two-Phased Model of HIV Related Stigma: The Role of Homophobia, Contagion Myths, and Motivation to Control Prejudices*. Poster presented at the annual meeting of the Society of Behavioral Medicine, Montreal, Quebec, Canada.

Brown, J. L., Vanable, P. A., Carey, M. P., & **Heath, J. D.** (2009, April). *Identifying the Stressors and Coping Strategies of HIV-Positive Women: Findings from a Qualitative Study*. Poster presented at the annual meeting of the Society of Behavioral Medicine, Montreal, Quebec, Canada.

- Brown, J. L., Vanable, P. A., Carey, M. P., Elin, L., & **Heath, J. D.** (2009, August). *Development of a Computerized Stress Management Training Program for HIV+ Women*. Poster presented at the Center for Disease Control 2009 National HIV Prevention Conference, Atlanta, GA.
- Ouimette, P., Carnrike, J., Martino, S., Rothong, N. D., **Heath, J.**, Najavits, J., et al. (2009, July). *Telephone Screening of Mental Health Problems Among Community Veterans*. Poster presented at the annual VA Mental Health Conference, Baltimore, MD.
- Heath, J. D.**, Vanable, P. A., Carey, M. P., Bostwick, R. A., Brown, J., & Littlewood, R. (2008, March). *The Association of Stigma to Unprotected Sex and Partner Communication Among HIV+ MSM*. Poster presented at the annual meeting of the Society of Behavioral Medicine, San Diego, CA.
- Biondolillo, M. J., Arcidiacono, S. J., **Heath, J. D.**, & Vanable, P. (2008, May). *Evidence of Ethnic Difference in Homophobia*. Poster presented at the annual Syracuse University Mayfest Poster Session, Syracuse, NY.
- Arcidiacono, S. J., Biondolillo, M. J., **Heath, J. D.**, & Vanable, P. (2008, May). *Church Attendance as a Predictor of Motivations to Control Prejudice Towards HIV+ Individuals*. Poster presented at the annual Syracuse University Mayfest Poster Session, Syracuse, NY.
- Heath, J. D.**, Vanable, P. A., & Evans, C. (2006, November). *The Perpetuation of AIDS Stigma Among Young Adults: The Role of Casual Contact Myths and Homophobia*. Poster presented at the annual meeting of the Association for Behavioral and Cognitive Therapies, Chicago, IL.
- Naughton, J.**, & Goggin, K. (2004, April). *Attitudes Towards the "Down Low" Lifestyle: Differences Among Genders, Age Groups, and Recruitment Sources*. Poster presented at the National Conferences on Undergraduate Research, Indianapolis, IN.
- Naughton, J.**, & Goggin, K. (2004, April). *Attitudes Towards the "Down Low" Lifestyle*. Poster presented at The 4th Annual SEARCH Undergraduate Research Symposium, Kansas City, MO.

Funded Grants and Research Awards

American Psychological Association, Division 38 Student Research Award.

Funded by the American Psychological Association.

Title: *Examining the Impact of Provider Stigmatization on the Care of HIV+*

Patients: Effects to Engagement in Care, Comfort, and Perceptions of Healthcare Providers

Role: Principle Investigator

Co-Investigator: Peter A. Venable, Ph.D.

Awarded: 3/15/10

Syracuse University Psychology Department Dissertation Research Award.

Funded by the Psychology Department of Syracuse University.

Title: *Examining the Impact of Provider Stigmatization on the Care of HIV+ Patients: Effects to Engagement in Care, Comfort, and Perceptions of Healthcare Providers*

Role: Principle Investigator

Co-Investigator: Peter A. Venable, Ph.D.

Awarded: 3/15/11

SEARCH (Students Engaged in Artistic and Academic Research) Grant

Funded by the University of Missouri-Kansas City.

Grant # K9321: *Life on the "Down Low": Attitudes Towards Homosexuality and Sexual Disclosure*

Role: Principle Investigator

Faculty Sponsor: Kathy Goggin, Ph.D.

Awarded: 2004

Research Positions

Research Assistant: Center for Integrated Health

2008-2011

Syracuse Veterans Affairs Medical Center

Supervisors: Kyle Possemato, Ph.D. and Paige Ouimette, Ph.D.

- NIAAA R03 Grant: *Assessing Naturalistic Course of PTSD Among Patients with Alcohol Use Disorders*
 - Principal Investigator: Paige Ouimette, Ph.D. (Syracuse VAMC, Center for Integrated Health)
- NIAAA R21 Grant: *Daily Fluctuations in PTSD Symptoms and Alcohol Use: A Test of Self-Medication*
 - Principal Investigator: Paige Ouimette, Ph.D. (Syracuse VAMC, Center for Integrated Health)
- VA Clinical Sciences Research & Development Merit Grant: *Daily Fluctuations of PTSD Symptoms and Alcohol Use among OEF/OIF Veterans*
 - Principal Investigator: Kyle Possemato, Ph.D. (Syracuse VAMC, Center for Integrated Health)
- Experiences:
 - Member of a health psychology laboratory specializing in the study of Posttraumatic Stress Disorder and Substance Dependence.
 - Performed structured clinical interviews for three longitudinal studies assessing the presence of current and lifetime posttraumatic stress

symptoms (Clinician Administered PTSD Scale) and substance use difficulties (SCID).

- Gained assessment experience working with OEF/OIF veterans and persons receiving care at chemical dependency treatment centers.
- Received training in multiple assessments including the SCID (by Michael First, Ph.D.), CAPS, LIFE, and Time-line Follow-back procedures.

**Research Assistant: Upstate Partnership for Health
Syracuse University**

2005-2011

Supervisor: Peter A. Vanable, Ph.D.

- NIH/NIMH R21 Grant: *Reducing High-Risk Sexual Behavior Among HIV+ Men*
 - Principal Investigator: Peter A. Vanable, Ph.D. (Syracuse University)
- NIMH U01 Grant: *A Multi-Level HIV Prevention Strategy for High-Risk Youth*
 - Principal Investigator: Peter A. Vanable, Ph.D. (Syracuse University)
- Experiences:
 - Member of a health psychology laboratory studying risk behaviors related to HIV transmission, prevention strategies, and intervention work with HIV+ men who have sex with men (MSM) and African American adolescents.
 - Participation in participant recruitment, screening, longitudinal data collection, data entry, data analysis, and manuscript preparation.
 - Assisted in managing intervention workshops for HIV+ MSM and co-facilitated focus groups pertaining to stress management strategies among HIV+ women and qualitative focus groups pertaining to HIV-related stigma experiences in healthcare settings.

**Research Assistant: Alcohol Research Lab
Syracuse University**

2009-2010

Supervisor: Stephen Maisto, Ph.D.

- NIH/NIAAA R01 Grant: *Alcohol, Risky Behavior, and AIDS in Men*
 - Principal Investigator: Stephen A. Maisto, Ph.D. (Syracuse University)
- Experiences:
 - Member of a health psychology laboratory studying risk behaviors related to substance use and HIV transmission among MSM.
 - Participation in experimental data collection involving alcohol administration, data entry, data analysis, and manuscript drafting.
 - Experience with participant recruitment and screening via telephone interviews and outreach events with the LGBT community.

**Undergraduate Research Assistant: HIV Research Group
University of Missouri-KC**

2003-2005

Advisor and Principle Investigator: Kathy Goggin, Ph.D.

- Experiences:

- Research assistant in an active health psychology lab studying risk behaviors related to HIV transmission, HIV medication adherence, and alcohol and condom use among at-risk populations.
- Completed interviews with clients at the Kansas City Free Health Clinic regarding their experience with the HIV Counseling and Testing program at the clinic. Reported findings in quarterly evaluations.

Teaching and Training Experience

PTSD and Substance-related Disorders Assessment Training **2011**
Syracuse VAMC-Center for Integrated Health

- Supervisor of Clinical Assessment Training for Research Staff
 - Organized content and developed the structure of a 4 day seminar to train new research staff in the clinical assessment of PTSD and substance-related disorders.
 - Trained staff on the background and implementation of the Clinician Administered PTSD Scale (CAPS) and Substance Use Disorders SCID module using verbal instruction, training videos, role plays, and step-by-step analysis of audio recordings of actual clinical interviews.

Psychology 395: Abnormal Psychology **2008-2009**
Syracuse University

Supervised by Peter A. Vanable, Ph.D.

- Teaching Assistant: Primary Instructor
 - Organized content and developed the structure of an advanced level undergraduate course.
 - Taught classes of 60-80 students using PowerPoint presentations, class discussions and activities, and video representations of mental health disorders and treatment.

Mentoring Experience

Psychology 470: Experience Credit **2007-2008, 2010-2011**
Syracuse University

Supervised by Peter A. Vanable, Ph.D.

- Graduate Student Mentor
 - Mentored two undergraduates in carrying out experimental research protocol.
 - Trained students in data collection and analysis procedures and also supervised the development of several poster presentations.

Syracuse University Summer PRIDE (Psychology Research and Diversity Enhancement) Program **2010, 2011**

Supervised by Peter A. Vanable, Ph.D.

- Graduate Student Mentor

- Mentored two undergraduates from ethnically diverse backgrounds in data collection and analysis procedures and also supervised the development of oral presentations.

Program Evaluation Services

SUNY Upstate Medical University Infectious Disease Clinic, Syracuse, New York

- Consultant
 - Conducted focus groups and analyzed data from patient feedback surveys regarding mental health, case management, and treatment adherence services provided to HIV+ patients through funding from Ryan White Care grants.
 - Created reports informing clinic staff of patients' perceptions of quality of care, impact of services received, and suggestions for further improvement.
 - Completed phone interviews with young (17-25), HIV+ men who have sex with men regarding current sexual practices, partner seeking behaviors, and condom use to create a qualitative report for New York Department of Health.

Awards and Honors

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|--|-----------|
| APA Division 38 Student Research Award | 2010 |
| Summa Cum Laude, University of Missouri-Kansas City | 2004 |
| Graduation with Honors, University of Missouri-Kansas City | 2004 |
| Excellence in Research Award – SEARCH 1 st place (UMKC) | 2004 |
| University of Missouri – Kansas City Honors College Scholar | 2004 |
| University of Missouri – Kansas City Honors Student | 2002-2004 |
| Dean's List at University of Missouri – Kansas City | 2002-2004 |
| Dean's List at University of Miami | 2001-2002 |
| President's and Provost's Honor Roll at University of Miami | 2001-2002 |
| Bank of America Joe Martin Scholarship | 2001-2004 |
| Hersch Norman Memorial Scholarship | 2001 |
| Wal-Mart All American Scholarship | 2001 |
| Henry King Stanford Scholarship | 2001-2002 |

Professional Memberships

Society of Behavioral Medicine (SBM)
 American Psychological Association (APA)
 Division 38, Health Psychology
 Association of Behavior and Cognitive Therapies (ABCT)

Honorary Memberships

The National Honor Society in Psychology (Psi Chi)

Golden Key International Honor Society
National Society of Collegiate Scholars

Editorial Service

Ad-hoc reviewer: *Journal of Social and Clinical Psychology*

Ad-hoc reviewer: *BioMedCentral*

Ad-hoc reviewer: *Archives of Women's Health*

Ad-hoc reviewer: *Basic and Applied Social Psychology*

Professional Service

Psychology Action Committee (PAC) Co-President, Syracuse University (2007-2008)

Volunteer Activities

Kansas City Free Health Clinic, Kansas City, MO

2004-2005

Supervised by: Jamie Stevens, MA

- Certified Counselor in HIV Testing
 - Received state certification for HIV Counseling and Testing in June of 2004.
 - Conducted psycho-education counseling sessions with persons being tested for HIV by assessing client's risk level, creating personalized risk reduction plans, and educating clients about HIV and sexually transmitted diseases
 - Administered Orasure HIV tests.

Metropolitan Organization to Counter Sexual Assault Kansas City, MO

2004

- Support Group Facilitator
 - Facilitated a support group for adult survivors of childhood sexual abuse entitled Survivors United Reaching Empowerment (SURE).
 - Received training in supportive counseling techniques, emergency response intervention, and in giving community education presentations regarding sexual abuse and assault.