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Understanding Mediators of the Relationship Between HIV-Related Stigma and Medication Adherence Among People Living with HIV (HIV)

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Abstract

Although accumulated research demonstrates that HIV-related stigma is associated with medication adherence difficulties for PLWH, this literature is limited by inconsistencies in the conceptualization and assessment of both stigma and adherence. Additionally, few empirical research studies provide tests of the psychosocial mechanisms that may account for the stigma-adherence relationship. The present study sought to clarify these relationships using more refined measures, which assessed multiple domains of stigma (i.e., internalized, anticipated, and enacted stigmas) and multiple domains of adherence (i.e., global and intentional nonadherence). It was further hypothesized that two mediational pathways, depressive symptoms and disclosure concerns, may mediate the association between HIV-related stigmas and adherence. A clinic-based sample of 205 people living with HIV (PLWH) completed a questionnaire battery using audio computer-assisted self-interviewing (ACASI). Contrary to previous research, there was no association between HIV-related stigmas and adherence. There was also no evidence that disclosure concerns acted as a mediational pathway, but there was evidence that depression mediated the association between internalized and enacted stigmas and intentional nonadherence since diagnosis. This lack of an association between stigma and adherence may be attributable to a different stage of the HIV epidemic, in which simplified medication regimens present fewer obstacles for PLWH. Future research should prospectively explore the interrelationships among HIV-related stigmas, mediators, and adherence outcomes in the current era of the HIV epidemic and with differing populations.

UNDERSTANDING MEDIATORS OF THE RELATIONSHIP BETWEEN HIV-RELATED STIGMA AND MEDICATION ADHERENCE AMONG PEOPLE LIVING WITH HIV (HIV)

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Understanding Mediators of the Relationship between HIV-Related Stigma and Medication Adherence among People Living with HIV (PLWH)

As of 2013, an estimated 35 million people worldwide were living with HIV, and an estimated 2.1 million people became newly infected that year (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2014). Since the introduction of antiretroviral therapies (ART), HIV-positive individuals with access to medical care are able to lead longer lives, turning a once fatal diagnosis into a more manageable chronic illness (Harrison, Song, & Zhang, 2010). Although great strides have been made, people living with HIV (PLWH) still encounter powerful and unrelenting stressors, one of which is the widespread social stigma associated with HIV. Over 30 years since the beginning of the epidemic, stigma continues to persist worldwide, representing a formidable challenge for PLWH (Mahajan et al., 2008; UNAIDS, 2013).

Stigma has been defined as negative attitudes toward an individual because of an attribute that is deemed as undesirable in a social setting (Goffman, 1963). Three types of HIV-related stigma are presumed to impact PLWH (Earnshaw & Chaudoir, 2009). Anticipated stigma involves expectations of discrimination, stereotyping, and/or prejudice from others in the future due to one's serostatus. Similarly, enacted stigma involves experiences of discrimination, stereotyping, and/or prejudice from others in the past or present due to one's serostatus. Finally, internalized stigma refers to endorsing negative feelings and beliefs about HIV and applying them to oneself. These three types of stigma are considered to be conceptually related but distinct constructs (Earnshaw & Chaudoir, 2009; Link, 1987; Meyer, 1995; Nyblade, 2006).

Research that informs our understanding of the consequences of HIV-related stigma is important, as there can be far-reaching consequences. The damaging effects of stigma may be particularly profound because of its associations with already marginalized behaviors, including

injection drug use, sexual promiscuity, and homosexual behavior (Herek & Capitanio, 1999; Reidpath & Chan, 2005). PLWH face social consequences, such as loss of social support (Logie & Gadalla, 2009). Stigma has been found to negatively influence a variety of social interactions, including those with family, friends, sexual partners, coworkers, and health professionals (Varas-Diaz, Serrano-Garcia, & Toro-Alfonso, 2005). Those who disclose their HIV status to others risk increasing stigmatizing experiences compared to those who do not disclose their status (Stutterheim et al., 2011). Stigma is also associated with poor mental health outcomes, including increased levels of anxiety, depression, and hopelessness, as well as decreases in self-esteem (Berger, Ferrans, & Lashley, 2001; Lee, Kochman, & Sikkema, 2002; Logie & Gadalla, 2009).

The experience of stigma may also be detrimental to the physical health of PLWH and interfere with their ability to manage the disease. HIV requires strict adherence to challenging medication regimens in order to decrease viral load and increase CD4 counts (Bangsberg, 2006; Paterson et al., 2000). Without near perfect adherence, PLWH risk treatment failure and possible development of resistant virus (Paterson et al., 2000). Unfortunately, poor treatment adherence continues to be common among PLWH (Cambiano et al., 2010). A recent meta-analysis found an average of 62% of participants reported $\geq$ 90% adherence to ART (Ortego et al., 2011).

Accumulated research demonstrates that HIV-related stigma is associated with medication adherence difficulties among PLWH (Sweeney & Vanable, 2016). However, studies examining this phenomenon vary considerably in their approach to conceptualizing and assessing stigma. The majority of studies have used single measures that include items assessing multiple domains of stigma, but treated the measure as a unidimensional scale (Dlamini et al., 2009; Li et al., 2011; Mo & Mak, 2009; Rao et al., 2012; Rintamaki et al., 2006; Sayles et al., 2009). A smaller subset have used single measures that include items assessing a specific domain

of stigma (DiIorio et al., 2009; Kalichman & Grebler, 2010; Peretti-Watel et al., 2006; Vanable et al., 20060. Finally, few studies to date have assessed multiple domains of stigma simultaneously (Earnshaw et al., 2013; Kingori et al., 2012; Sumari-de Boer et al., 2012; Wolitski et al., 2009). Inconsistencies in how stigma is defined and measured in the existing literature limits the ability to draw comparisons between studies and make sound conclusions regarding the extent to which specific stigma domains impact adherence.

Importantly, while many studies have examined associations between HIV-related stigma and adherence, few have sought to understand the mediators that may account for this association. Investigating the mediational pathways linking stigma to adherence is critical for illuminating key variables most relevant to use in programs designed to promote medication adherence. Three mediators have been identified, including enhanced vulnerability to mental health difficulties, reduction in self-efficacy for medication taking, and concerns about inadvertent disclosure of serostatus through pill-taking. Although the aforementioned mechanisms have often been identified in both qualitative and quantitative studies, few studies to date have sought to empirically test these pathways. One mechanism, concerns about inadvertent disclosure of serostatus through pill-taking, remains untested. Thus, the purpose of this study is to clarify unique associations between HIV-related stigma and medication adherence using more refined measures and to empirically test mediators of these associations.

Review of Association between HIV-Related Stigma and Medication Adherence

The research questions posed in the present study were informed by a critical review of research investigating the relationship between HIV-related stigma and medication adherence. A total of 16 quantitative studies have been published that examine associations between HIV-related stigma and medication adherence, which provide background for the present study. In

what follows, associations between stigma and adherence outcomes are reviewed, using the three types of stigma described previously, which include internalized, enacted, and anticipated stigmas. Next, proposed mediators of the stigma and adherence relationship are summarized, and then findings from empirical studies that have tested hypothesized mediational models are reviewed. Finally, an untested mediator and its implications for the present study are addressed.

Studies that Combined Multiple Domains of Stigma

Many studies have used a single measure that includes items assessing multiple domains of stigma, but treat the measure as a unidimensional scale. Of studies that have used combined stigma measures, nearly all have found associations between increased stigma and decreased self-reported adherence with a range of recall periods, including the past 4 days (Rintamaki et al., 2006; Mo & Mak, 2009), the past week (Li et al., 2001; Sayles et al., 2009), the past month (Dlamini et al., 2009), and a mixture of recall periods ranging from 4 days to 4 weeks (Rao et al., 2012). Of note, all but one of the studies that used combined stigma measures treated adherence as a unidimensional measure, often combining different reasons for missing doses within a single measure. However, one study attempted to differentiate between different reasons for missing doses. In this study, participants were categorized as intentional nonadherers if the reasons they endorsed included conscious decisions not to take pills and unintentional nonadherers if the reasons they endorsed were passive decisions, such as forgetfulness (Mo & Mak, 2009). Compared to all other participants, intentional nonadherers had significantly higher levels of stigma.

Only one of the studies that used a combined measure failed to find a significant association between stigma and adherence. In this study, stigma was measured using a summed score of two subscales assessing anticipated and internalized stigmas, and self-reported

adherence assessed missed doses over the past 4 days (Martinez et al., 2012). Although the authors failed to find a significant association between stigma and adherence 12 months later, this study was limited by low experiences of stigma within their sample, as well as a small sample size (N = 60). This study also sampled adolescent and young adult females, and it may be that stigma operates differently for this population.

Studies Focusing on Internalized Stigma

Two studies assessed internalized stigma, defined as self-relevant negative feelings and beliefs associated with having HIV. In one study, the authors found a significant association between higher internalized stigma and decreased self-reported adherence over the past month (DiIorio et al., 2009). In another study, higher internalized stigma was associated with unannounced telephone-based pill counts one month after baseline, but only in bivariate analyses (Kalichman & Grebler, 2010). Once covariates of drug use and poverty-related stress were included in the model, the association between stigma and adherence was attenuated, suggesting that the effects of poverty among socially disadvantaged PLWH may eclipse psychosocial factors such as stigma in impacting adherence.

Studies Focusing on Enacted Stigma

Two studies reported on findings using measures of enacted stigma, a form of stigma that is operationalized in terms of past experiences of discrimination, stereotyping, and/or prejudice from others as a result of having HIV. In one study, the authors found a significant association between the occurrence of negative behavior and mistreatment related to one's HIV status (e.g., avoidance) and decreased adherence over the past week (Vanable et al., 2006). Another study assessed perceived discrimination related to having HIV using three social relationships, which included relatives, friends, and sexual partners (Peretti-Watel et al., 2006). Only perceived

discrimination from sexual partners was significantly associated with nonadherence over the past week, suggesting that differential associations may exist for different social contexts.

Studies Focusing on Anticipated Stigma

Anticipated stigma involves expectations of discrimination, stereotyping, and/or prejudice from others in the future due to one's HIV status. None of the studies that used single measures of stigma exclusively assessed anticipated stigma.

Studies Using Multiple Measures of Stigma

Although studies using single measures of stigma yield important conclusions about the impact of stigma on adherence, studies using single measures of stigma are limited. In considering this literature, it may be that the influence of stigma on behavioral outcomes such as medication adherence may vary as a function of how stigma is operationalized. For PLWH, the awareness that they possess a socially devalued aspect of the self may be experienced in different ways (Earnshaw & Chaudoir, 2009). For example, internalizing the experience of having a stigmatized "mark" may alter how an individual thinks and feels about him/herself, whereas experiencing or anticipating prejudice, stereotyping, or discrimination may change how an individual interacts with others. Thus, different stigma measures reflect these different experiences of PLWH, and may lead to differential associations with outcomes such as adherence.

Several studies used multiple stigma measures and examined their independent effects in multivariate analyses. Two studies assessed internalized and perceived external stigmas (i.e., either anticipated or enacted stigma) simultaneously. In one study, the authors found a significant association between higher anticipated stigma and poor self-reported medication adherence over the past 2 days, but did not find significant associations between higher internalized stigma and

adherence (Wolitski et al., 2009). No associations were found using a 7-day recall period. In contrast, another study found a marginal association between higher internalized stigma and poor self-reported adherence over the past 30 days, but did not find associations between anticipated or enacted stigmas and adherence (Earnshaw et al., 2013). Together, these studies offer contradictory findings as to whether internalized or perceived external stigma exerts a stronger impact on adherence difficulties.

Two additional studies assessed multiple types of stigma simultaneously without assessing internalized stigma. One study assessed both self-reported adherence and pharmacy refill adherence, but reported results using pharmacy refill adherence due to its stronger association with viral load (Sumari-de Boer et al., 2012). The authors noted that this discrepancy in predicting virological response may have been due to social desirability, given that self-reported adherence was assessed during face-to-face interviews. Although both anticipated and enacted stigmas were associated with nonadherence over the past month in bivariate analyses, only anticipated stigma remained significantly associated in multivariate analyses. In another study, two combined measures of stigma that included items assessing anticipated, enacted, and internalized stigmas were significantly associated with self-reported adherence difficulties, but there were no associations for two measures of enacted stigma (Kingori et al., 2012). However, this study was limited by its use of combined stigma measures and lack of a recall period for adherence.

Summary of Associations between Stigma and Adherence

There is mounting evidence that HIV-related stigma interferes with medication adherence among PLWH. Nearly every study that used a single measure of stigma found an association between increased stigma and adherence difficulties, while every study that assessed multiple

indicators found an association between one type of stigma and nonadherence. However, key differences among the few studies that assessed multiple domains of stigma included variability in types of stigma assessed and range of recall periods used. These differences limit direct comparisons and make it difficult to provide firm conclusions about unique associations between types of stigma and adherence difficulties. Of note, across all but one of these studies, adherence has been considered as a unidimensional construct, which is problematic given evidence that there are two types of nonadherence: intentional and unintentional nonadherence (Wroe, 2002). Whereas intentional nonadherence is attributed to an active decision to skip or delay doses, unintentional nonadherence is attributed to forgetting, misunderstanding, or unanticipated obstacles.

The present study sought to address these limitations by assessing all three domains of stigma simultaneously and using optimal recall periods, helping to clarify unique associations between stigma domains and adherence difficulties. In addition, the present study also treated nonadherence as a multidimensional construct, using both a global measure of adherence and a measure of intentional nonadherence. In doing so, the present study has the potential to clarify whether the association of HIV-related stigma to adherence varies as a function of the type of non-adherence difficulties being reported. It may be that the experience of stigma causes PLWH to intentionally skip or delay doses, rather than simply forget to take a dose. However, many fundamental questions remain unanswered, including what pathways link stigma to adherence difficulties.

Proposed Mediators of the Stigma and Adherence Relationship

The extant literature suffers from a lack of theoretical frameworks guiding research design, with few studies employing health behavior theory in developing study hypotheses

(DiIorio et al., 2012; Dlamini et al., 2009; Earnshaw et al., 2013; Li et al., 2011; Sayles, Wong, Kinsler, Martins, & Cunningham, 2009). However, there are commonalities in the explanations offered in each study regarding potential reasons for a linkage of stigma to adherence difficulties. Many authors did not identify one particular mechanism through which stigma may impact adherence and instead suggested multiple explanations. The following section reviews three commonly suggested mechanisms.

Concerns about inadvertent disclosure of HIV status. As described below, one hypothesis is that concerns about inadvertent disclosure of HIV status may help explain the relationship between stigma and adherence difficulties. Qualitative research has found that PLWH report skipping doses when they cannot take prescribed medication without being observed doing so. PLWH who have experienced discrimination, stereotyping, or prejudice from others (i.e., enacted stigma), or who anticipate these experiences (i.e., anticipated stigma), may fear disclosing their HIV status. The complexity of medication regimens can interfere with PLWH's ability to conceal HIV status because it can require consumption at inopportune times and in public settings (Rintamaki et al., 2006). Anticipated or enacted stigma may produce concerns about potentially revealing one's HIV status when accessing or consuming medications. In these situations, PLWH may skip doses rather than risk a potential "outing" as having HIV (Ware, Wyatt, & Tugenberg, 2006).

Vulnerability to mental health difficulties. A second hypothesis is that mental health difficulties may link stigma to adherence. Qualitative research has found associations between stigma and depressive symptoms, as well as depressive symptoms and adherence. PLWH may have internalized negative beliefs or feelings about having HIV (i.e., internalized stigma) (Earnshaw et al., 2013). Internalized stigma may enhance vulnerability to mental health

difficulties, in particular depressive symptoms, which may cause lapses in adherence. Understanding the specific types of depressive symptoms associated with stigma is particularly important, as one study has found that cognitive symptoms affect adherence more than vegetative symptoms (Wagner et al., 2011). Internalized stigma may have a stronger link to cognitive depressive symptoms, such as depressed mood, loss of interest, worthlessness, and poor concentration. In contrast, vegetative depressive symptoms, such as fatigue, loss of appetite, sleep disturbance, and psychomotor agitation, may be more likely to overlap with HIV-related symptoms.

Reduction in self-efficacy for medication taking. A third hypothesis is that the association between stigma and adherence may be accounted for by a reduction in self-efficacy for medication taking. Previous research supports the relationship between self-efficacy and adherence. Self-efficacy is a judgment of one's ability to organize and execute given types of behaviors (Bandura, 1977). Self-efficacious people may be more successful in performing specific behaviors because they are more likely to persevere under difficult situations. High levels of stigma may deflate a PLWH's self-efficacy for taking medications, which may cause lapses in adherence (DiIorio et al., 2009).

Summary. Three mediators linking stigma to adherence difficulties have been proposed as potential explanations, including concerns about inadvertent disclosure of HIV status, enhanced vulnerability to mental health difficulties, and reduction in self-efficacy for medication taking. Investigating the mediational pathways linking stigma to adherence is critical for advancing a stronger theoretical framework for this literature and illuminating key variables most relevant to use in future programs and interventions. While many studies have suggested mediational pathways, few have incorporated relevant constructs to empirically test for

hypothesized mechanisms. To date, only three studies have tested mediational hypotheses that may clarify the association between stigma and adherence difficulties. These studies are discussed in the following section.

Empirical Tests of Mediators

Two studies have tested whether enhanced vulnerability to mental health difficulties mediates the relationship between stigma and adherence difficulties. In the first study, the authors hypothesized that PLWH who are experiencing high levels of stigma may be more likely to experience adherence difficulties because of increased vulnerability to mental health difficulties (Sayles et al., 2009). Mental health difficulties were assessed using a composite score from the Medical Outcomes Study Short Form (SF-12), which screens for both anxiety and depressive symptoms (Ware, Kosinski, & Keller, 1996). Results from logistic regression analyses confirmed that lower mental health status mediated the relationship between stigma and nonadherence over the past week. The second study also examined mental health as a mediator between stigma and adherence, but specifically examined depressive symptoms, as measured by the Patient Health Questionnaire (PHQ-9) (Rao et al., 2012). The authors hypothesized that stigma would be associated with depressive symptoms including fatigue, diminished concentration, and feelings of worthlessness, which are all factors that may interfere with adherence. As hypothesized, results from SEM confirmed that depressive symptoms partially mediated the relationship between increased stigma and worse adherence.

These studies are the first to provide evidence that stigma may enhance vulnerability to mental health difficulties, which in turn may interfere with self-care related activities such as adherence. However, both studies failed to control for important covariates, including social support and self-efficacy (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000; Edwards, 2006).

Controlling for self-efficacy may be particularly important, as the perception of increased barriers to adherence that results from mental illness may be the proximal determinant of adherence difficulties. The mental health measures used in both studies are also problematic. The mental health composite score used by Sayles et al. (2009) represents a global measure of mental health and lacks specificity in targeting depressive symptoms. Although Rao et al. (2012) specifically targeted depressive symptoms using the PHQ-9, this too could be improved. Research has demonstrated that there is considerable overlap between the vegetative symptom items on depressive inventories such as the PHQ-9 and HIV-related symptoms, which may inaccurately represent depressive symptomatology (Kalichman, Sikkema, & Somlai, 1995).

One study has examined the role of depressive symptoms as a mechanism between stigma and adherence while addressing these concerns. The authors tested a psychosocial model of adherence, which included depressive symptoms, self-efficacy, and social support (DiIorio et al., 2009). Depressive symptoms were measured using four cognitive depressive symptom items from the Center for Epidemiologic Studies Depression Scale (CES-D). Although the authors hypothesized that the relationship between stigma and adherence would be mediated by both self-efficacy and depressive symptoms, results from SEM suggested that only self-efficacy mediated this relationship. This finding suggests that high levels of stigma may deflate one's confidence in ability to take medications, which in turn may worsen adherence. Unlike other studies (Rao et al., 2012; Sayles et al., 2009), depressive symptoms were not found to mediate the relationship between stigma and adherence. Instead, the authors found that participants reporting decreased social support tended to have more depressive symptoms, which interfered with adherence.

These findings elucidate an exciting direction for research, as mediational pathways had previously been untested. However, lack of consistency in the measurement of stigma makes it difficult to generalize and draw comparisons across these three studies. Two of the studies used combined measures of stigma (Rao et al., 2012; Sayles et al., 2009), while one used a measure of internalized stigma (DiIorio et al., 2009). Although all three studies used self-reported measures of medication adherence, the recall periods and response formats varied. Finally, all three studies treated nonadherence as a unidimensional construct, making it difficult to understand the patients' motivation for not taking pills. In particular, the measure used by DiIorio et al. (2009) addressed unintentional nonadherence, including logistical problems with remembering to take medication, such as being away from home, forgetting, and falling asleep. However, this approach fails to clarify the relationship between stigma and intentional nonadherence, or occasions where patients make conscious decisions not to take pills.

Summary. To date, three studies have empirically tested potential mediators of the stigma and adherence relationship and identified enhanced vulnerability to mental health difficulties and reduction in self-efficacy for medication taking as possible pathways. However, inconsistencies in the measurement of stigma and adherence make it difficult to draw comparisons between these studies. The present study seeks to test mediators of the relationship between HIV-related stigma and adherence while addressing these limitations, including assessing multiple domains of stigma simultaneously, using optimal recall periods, and treating nonadherence as a multidimensional construct. The present study will fill an important gap in our understanding of unique associations between different domains of stigma to nonadherence, help to identify mechanisms linking stigma to poor adherence, and help to advance a stronger theoretical framework for this literature.

Untested Mediator

To date, enhanced vulnerability to mental health difficulties and reduction in self-efficacy for medication taking have been identified as possible mediators of the stigma and adherence relationship. Concerns about inadvertent disclosure of serostatus has also been proposed as a potential mechanism, but no empirical studies have addressed this hypothesis. Qualitative research demonstrates that PLWH may go to great lengths to avoid inadvertent disclosure through pill taking, including delaying or skipping doses, hiding medications, adopting dosing schedules or routines that conceal serostatus, lying about medications or misrepresenting the reasons for taking medications, and disguising medications in alternate containers or bottles (Golin et al., 2002; Klitzman et al., 2004; Konkle-Parker et al., 2008; Rao et al., 2007; Ware et al., 2006). In this way, PLWH may face conflicting interests between attempts to safeguard health and attempts to avoid negative consequences of inadvertent disclosure within a relationship (Ware et al., 2006). It is hypothesized that past experiences of stigma (i.e., enacted stigma) and the anticipation of future experiences of stigma (i.e., anticipated stigma) heighten concerns about disclosure, resulting in lapses in adherence. The present study seeks to address this compelling, unanswered question of *how* stigma impacts adherence, opening up previously unexplored areas for psychological research on HIV-related stigma and helping to advance a stronger theoretical framework for this literature.

Summary and Limitations of the Reviewed Literature

The present study sought to examine *how* HIV-related stigma impacts HIV medication adherence. Past research indicates that there is substantial evidence to indicate that stigma contributes to adherence difficulties among PLWH. This pervasive finding is particularly convincing given such a range of variability in stigma measurement, which included measures

combining multiple domains, measures assessing individual domains, and measures assessing multiple domains simultaneously. The few studies in the present review that assessed multiple domains of stigma simultaneously suggest there may be unique associations between individual domains of stigma and adherence, but key differences limit direct comparisons. Several studies tested mediational models that identify enhanced vulnerability to mental health difficulties and reduction in self-efficacy as possible mediators. Another mediator, concerns about inadvertent disclosure of serostatus, has been characterized in qualitative research but remains untested in empirical studies. Four methodological and conceptual limitations were identified in this review:

(a) **Absence of research on mediation**. Although three mediators have often been suggested in both the qualitative and quantitative literature, few studies have empirically tested mediational models. The present study sought to address this gap by not only clarifying the unique effects of each stigma domain on adherence, but understanding what implications this has for different mediators linking each stigma domain to adherence. A major innovation in this study is empirically testing concerns about inadvertent disclosure of HIV status as a mediator linking perceived external stigmas (i.e., anticipated and enacted stigmas) to adherence difficulties.

(b) **Need for a consistent and reliable approach to assessing HIV-related stigma.** Measurement limitations within the extant literature include the widespread use of single measures that combined different types of stigma, failure to assess all three types of stigma simultaneously, and the lack of time-sensitive language concerning past experiences of discrimination, which makes it difficult to capture current trends in the relationship between stigma and adherence. The present study strives to address these

limitations by carefully assessing all three types of stigma simultaneously and making sure to include time-sensitive language that matches adherence recall periods.

(c) **Need for standardized self-report measures of adherence.** The absence of standardized self-report measures has been identified as an obstacle within the adherence literature (Simoni et al., 2006). One study has compared multiple recall periods and response formats for self-report adherence measures with electronic monitoring device (EMD) data (Lu et al., 2008). The authors found less overestimation with a 30-day recall period than either 3- or 7-day recall periods. Lu et al. (2008) also found that items that asked patients to rate their adherence over the past 30 days were more accurate than frequencies or percents. Given this evidence (Lu et al., 2008; Simoni et al., 2006), the present study will use estimation recall for longer periods, which may be more accurate in assessing adherence, as well as represent a more clinically relevant time interval.

(d) **Need to treat nonadherence as a multidimensional construct.** Another major limitation of the current literature is their treatment of nonadherence as a unidimensional construct, given evidence that there are different types of nonadherence (Wroe, 2002). Intentional nonadherence includes a patient undertaking an active, reasoned decision-making process to disregard professional advice, such as selectively altering one's treatment regimen or choosing to discontinue, defer, or refuse treatment (Lehane & McCarthy, 2007; Littlewood & Vanable, 2014; Wroe, 2002; Wroe & Thomas, 2003). The present study will treat nonadherence as a multidimensional construct, using both a global measure of adherence, as well as a specific measure of intentional nonadherence. The hypothesis that HIV-related stigma may be associated with intentional nonadherence will be tested.

Overview of Research Aims and Hypotheses

Understanding how the experience of HIV-related stigma among PLWH undermines disease management behaviors, such as mediation adherence, is an important public health concern. At present, there is a paucity of research that adequately investigates mediators that could account for the association between HIV-related stigma and HIV medication adherence. The present study seeks to understand and clarify these mediational pathways, helping to inform both future research studies and subsequent interventions designed to improve adherence. A clinic-based sample of PLWH will be recruited to complete measures designed to address the following aims:

Aim 1: *Clarify the association between HIV-related stigma and HIV medication adherence*. The first objective is to clarify the association between HIV-related stigma and adherence using more refined measures. All three types of HIV-related stigma (i.e., internalized, anticipated, and enacted stigmas) will be included simultaneously in analyses. Data for both a global measure of adherence and intentional nonadherence will be reported, in order to identify trends that may suggest differences in the pattern of findings for these two measures. First, the the hypothesis that HIV-related stigma of any kind will be associated with a global measure of adherence will be tested. A secondary hypothesis will also be tested. For conceptual reasons, it was anticipated that HIV-related stigma of any kind will be associated with intentional nonadherence.

Aim 2: *Determine whether the association between internalized stigma and intentional medication adherence is mediated by depressive symptoms*. It is hypothesized that internalized stigma will be associated with depressive symptoms, which in turn will be associated with a global measure of adherence. Once depressive symptoms are included in the model, internalized

stigma will no longer be associated with adherence, providing evidence full mediation. As with Aim 1, data for both a global measure of adherence and intentional nonadherence will be reported, in order to identify trends that may suggest differences in the pattern of findings for these two measures.

A secondary hypothesis will also be tested. For conceptual reasons, it was anticipated that depressive symptoms may mediate the relationship between internalized stigma and intentional nonadherence. It may be that depression reduces motivation to maintain optimal health through pill-taking, resulting in an intentional decision to skip or delay doses.

Aim 3: *Determine whether the association between perceived external stigmas (i.e., anticipated and enacted stigmas) and medication adherence are mediated by concerns about inadvertent disclosure of HIV status*. It is hypothesized that both past experiences of stigma (enacted stigma) and the anticipation of future experiences of stigma (anticipated stigma) will be associated with concerns about inadvertent disclosure of serostatus through pill-taking, which in turn would increase adherence difficulties. PLWH may need to balance conflicting concerns between achieving positive outcomes (i.e., taking meds on time) and avoiding negative consequences (i.e., experience of stigma). As with our first two aims, data for both a global measure of adherence and intentional nonadherence were reported on, in order to identify trends that may suggest differences in the pattern of findings for these two measures.

A secondary hypothesis will also be tested. For conceptual reasons, it was anticipated that concerns about inadvertent disclosure of serostatus through pill-taking will mediate the relationship between perceived external stigmas and intentional nonadherence. When faced with conflicting concerns, PLWH may make a decision to intentionally disregard professional advice and choose to skip or delay doses, rather than simply forgetting to take medications.

Method

Participants

A total of 205 HIV+ participants (37.6 % female, 62% male, <1% transgender) were recruited during outpatient medical visits at a university-based infectious disease (ID) clinic to participate in the study. The mean age of participants was 46 years old (*SD* = 11, range 20-74). Forty-three percent self-identified as African-American, 42% as Caucasian, and 15% as another race or multi-racial. Nine percent of these participants identified as Hispanic/Latina/Latino. Most participants reported that they were unemployed (67%). Participants who were employed reported an average monthly income of $1132 (*SD* = $952). Twenty-six percent of participants had less than a high school diploma, 31% graduated from high school, 22% completed some college, and 20% had completed an advanced degree. The average time elapsed since HIV diagnosis was 15 years (*SD* = 9), and the average time elapsed since starting ART medication was 12 years (*SD* = 9) Participants reported currently taking an average of 3.3 pills for their HIV per day (*SD* = 2.75, range = 1-13), with approximately half the sample taking 1-2 pills per day for their HIV. With respect to current health status, 67% of the sample reported that their viral load was "undetectable" as of their most recent clinic visit, and 70% of the sample reported that they had never experienced an AIDS-defining illness. Thus, it is a fairly healthy sample and, for many, the pill burden isn't too intensive.

Procedures

Participant recruitment. The PI and a research assistant (RA) worked in collaboration with staff at the ID clinic to recruit HIV+ patients during routine visits. A designated healthcare provider (i.e., triage nurse) informed patients about the opportunity to participate in the study and

obtained verbal consent from patients regarding their willingness to be introduced to the PI or designated RA. All volunteers completed a written, informed consent form (see Appendix) prior to data collection. Eligibility for the study was limited to those who are HIV+, at least 18 years of age, English-speaking, and physical and psychologically capable of providing informed consent. Eligible patients who provided consent completed a battery of self-report assessments (see Appendix) and were compensated $20 for their time. The study was approved by institutional review boards at participating institutions.

Clinic staff approached a total of 346 patients. Of the 346 patients approached by clinic staff, 220 patients consented to be introduced to the study team and hear a description of the study. Seventy-eight patients said they were not interested in completing the study, and another 48 patients said they were not interested in completing the study on the day of their clinic appointment, but were open to being asked again in the future. Out of the 220 patients who agreed to come over to our laboratory and take the study, 214 successfully completed the study. Six participants started the study, but did not complete it due to outside factors (for example, not having enough time to complete or deciding to withdraw halfway through). Out of the 214 patients who successfully completed the study, 205 patients were currently prescribed ART medication for their HIV, making this our final sample size for the present analyses.

Survey administration and data entry. The questionnaire battery was completed using audio computer-assisted self-interviewing (ACASI), which affords greater privacy over traditional paper-and-pencil questionnaires and interviewer-administered questionnaires, thus enhancing participants' willingness to disclose sensitive information (Schroder, Carey, & Vanable, 2003). Completion of the survey occurred in a private assessment area and took a

majority of participants approximately one hour. Survey data from ACASI were exported to SPSS. All statistical analyses were conducted using SPSS version 20.0 (SPSS Inc., Chicago, IL).

Measures

What follows is a description of constructs measured and assessments employed, as well as a description of how these constructs pertain to study hypotheses. The complete questionnaire battery is available in the Appendix.

Demographic characteristics and health history. Demographic variables were obtained by self-report for descriptive purposes, including age, gender, education, employment, ethnicity, income, and sexual orientation. Health-status variables were also obtained by self-report for descriptive purposes, including years since HIV diagnosis, viral load at most recent clinic visit, previous diagnosis of AIDS, and HIV transmission route. Finally, HIV treatment variables were also obtained, including duration of HIV medication use and number of HIV pills per day.

ART adherence. ART adherence was assessed using recommended self-report measures (Simoni et al., 2006). First, ART adherence was assessed for the past month using a visual analog scale (VAS) (Simoni et al., 2006). Participants were presented with a VAS on paper, with 0% on the left end, 100% on the right end, and hash marks with the corresponding number at each increment of 10. Participants were asked to "Put a mark on the line below at the point that shows your best guess about how much of your prescribed HIV medication you have taken in the last month. We would be surprised if this were 100% for most people." Second, ART adherence was also assessed over the past week using count-based recall (Simoni et al., 2006). To estimate adherence for the past week, participants completed a timeline follow back for the past seven days in which they reported the number of pills they were prescribed to take for each day and how many they actually took. These data were used to calculate a rate of adherence for the past

week (# prescribed doses - # missed doses)/prescribed doses X 100. The advantages of assessing adherence over the past week (as compared to 2- or 4-day intervals) are that it will always include a weekend, during which adherence is often problematic. In addition, having more data points will allow for greater differentiation among patients whose good adherence is consistent, and those who have good adherence over a shorter period of time, but in general are less adherent (Simoni et al., 2006).

Intentional nonadherence to ART, since HIV diagnosis. A series of questions developed in previous research (Littlewood & Vanable, 2013) were used to examine the occurrence of *intentional nonadherence* across four domains: (a) treatment uptake – declined to begin taking ART when recommended by a medical provider; (b) treatment interruption – stopped taking one or more ART medications without telling a medical provider; (c) medication vacation – took a break of one or more days from at least one ART medication; and (d) medication changes – made changes to ART regimens. For the first three indicators, patients were asked to indicate how many times they have engaged in that specific intentional nonadherence behavior since being diagnosed or since starting ART (e.g., "[Since starting ART], how many separate times have you taken a break from your HIV meds for one or more days?"). For the "medication changes" indicator, participants were asked to report whether they have made a conscious decision to (a) take less of a medication than prescribed, (b) take a dose significantly later than scheduled, (c) take two doses at the same time to make up for a missed dose, and (d) skip the special instructions for a medication, like "with meals" or "on an empty stomach." Participants who endorsed "yes" for any of the four behaviors were counted as a positive for the medication changes indicator. A score of 1 was assigned for each domain of

intentional nonadherence (Range = 0 – 4), in order to reflect both the occurrence and extent of intentional nonadherence since being diagnosed with HIV.

Internalized stigma. The internalized stigma scale assessed self-relevant negative feelings and beliefs associated with having HIV. An internalized HIV stigma scale developed by Earnshaw et al. (2013) was used to assess internalized stigma. This internalized HIV stigma scale adapted six items from previously validated scales (Berger et al., 2001; Visser et al., 2008), according to criteria specified by Earnshaw and Chaudoir (2009) (i.e., internalized stigma items needed to measure application of shame and/or negative beliefs associated with HIV/AIDS to the self). For each item, participants were asked, "How do you feel about being HIV-positive?" Sample items included: "Having HIV makes me feel like I'm a bad person," "I feel ashamed of having HIV," and "Having HIV is disgusting to me." Items were rated on 5-point Likert-type scales with response options including: "strongly disagree" (1), "disagree" (2), "neither disagree nor agree" (3), "agree" (4), and "strongly agree" (5). Items were averaged to create a composite internalized stigma score ($\alpha = 0.91$), with higher scores indicating greater internalized stigma. All items are included in the Appendix.

Anticipated stigma. The anticipated stigma scale addressed the perceived consequences of other people knowing that the respondent has HIV. Thus, these items assessed an individual's expectations of discrimination, stereotyping, and/or prejudice from others *in the future* due to one's HIV. Items were adapted from a previously validated scale (Earnshaw et al., 2013) assessing anticipated stigma. The items were reworded to more explicitly focus on the consequences that may occur within a respondent's global social network. For each item, participants were asked, "How likely is it that people will treat you in the following ways in the future because of your HIV status?" Sample items include: "People will avoid me," "People will

look down on me," and "People will feel uncomfortable around me." Items were rated on 5-point Likert-type scales with response options including: "very unlikely" (1), "unlikely" (2), "neither unlikely nor likely" (3), "likely" (4), and "very likely" (5). Items were averaged to create a composite anticipated stigma score ($\alpha = 0.95$), with higher scores indicating greater anticipated stigma. All items are included in the Appendix.

Enacted stigma. The enacted stigma scale addressed the perceived past consequences of other people knowing that the respondent HIV. Thus, these items assessed the respondent's past experiences of discrimination, stereotyping, and/or prejudice from others due to one's HIV. Items were adapted from a previously validated scale (Earnshaw et al., 2013) assessing enacted stigma. The items were reworded to more explicitly focus on the perceived consequences that have already occurred within a respondent's global social network. For each item, participants were asked, "How often have people treated you this way in the past because of your HIV status?" Sample items include: "People have avoided me," "People have looked down on me," and "People have felt uncomfortable around me." Items were rated on 5-point Likert-type scale with response options including: "never" (1), "not often" (2), "somewhat often" (3), "often" (4), and "very often" (5). Items were averaged to create a composite enacted stigma score ($\alpha = 0.96$), with higher scores indicating greater enacted stigma. All items are included in the Appendix.

Concerns about disclosure of HIV status. A 9-item scale was developed to measure the extent to which PLWH feel the need to keep their HIV a secret. This scale was adapted from prior research (Berger et al., 2001) to measure disclosure concerns. Items chosen reflect a respondent's desire to keep his/her HIV status a secret. Sample items include: "I am often concerned about the possibility that others will find out I'm HIV+," "I worry a lot about others finding out I'm HIV+," and "I work hard to keep my HIV a secret." For each item, participants

indicated the extent to which they agree or disagree using a 5-point Likert-type scale with response options including: "strongly disagree" (1), "disagree" (2), "neither disagree nor agree" (3), "agree" (4), and "strongly agree" (5). Items were averaged to create a composite disclosure concerns score, with higher scores indicating greater desire to keep one's HIV status a secret. One item performed poorly within the scale and was dropped, leaving a high internal consistency ($\alpha = 0.92$).

Depressive symptoms. Depressive symptoms were measured using the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). The CES-D has been used in prior research with HIV-positive men and women (e.g., Ickovics et al., 2001; Moskowitz & Wrubel, 2005). The CES-D consists of 20 items such as "I felt that everything I did was an effort" or "People were unfriendly." Participants were able to answer how often they have felt this way on a 4-point Likert scale ranging from 0 = 'rarely or none of the time' to 3 = 'Most or all of the time.' A composite score on the CES-D was computed by averaging the values across the 20 items[1] ($\alpha = 0.92$).

Data Analysis

Preliminary Data Analysis

Preliminary data screening was conducted prior to data analysis. Steps included examination of missing data, outliers, normality, and psychometric properties of scales.

Missing data. There was no missing data on hypothesized predictors (i.e., HIV-related stigmas), hypothesized mediators (depression, disclosure concerns), or adherence outcomes of interest. There was missing data for one case on income due to a participant declining to answer

[1] It was previously discussed removing somatic items on the CES-D, in case those items overlapped with HIV symptoms. All analyses described below we also ran using a 13-item composite of the CES-D, which did not include somatic items. Given that there was no difference in analyses between the two composites, we kept the full 20-item CES-D in the analyses that follow.

and missing data for one case on years since HIV diagnosis due to a participant's inability to recall year of diagnosis. Missing data were not imputed for these two cases.

Outliers and normality. Histograms and stem-and-leaf plots for all study variables were examined for the presence of outliers, which are indicated by a z-score of greater than 3.29 or less than -3.29 (Tabachnick & Fidell, 2001). To ensure that the normality assumption would not be violated in the present regression analyses, outliers were truncated by giving them a value that is one unit larger than the most extreme score in the distribution (Tabachnick & Fidell, 2001). If the variable remained significantly skewed, data transformations were conducted. Summary statistics presented for adjusted variables reflect the adjusted distribution rather than the original skewed distribution.

There were no outliers in the distributions of hypothesized predictors (i.e., HIV-related stigmas) or hypothesized mechanisms (i.e., depression, disclosure concerns). However, a few of the distributions for covariates were skewed with outliers, including income, years since HIV diagnosis, duration of HIV medication use, and number of HIV pills per day. For income, six outliers were truncated and a square-root transformation was conducted to reduce positive skew (pre-skew: 3.08, post-skew: .40). One outlier was truncated for years since HIV diagnosis (pre-skew: .11, post-skew = -.04) and duration of HIV medication use (pre-skew: .36, post-skew: .24). Finally, for number of HIV pills per day, one outlier was truncated and a square-root transformation was conducted to reduce positive skew (pre-skew: 2.14, post-skew: .79).

Data transformations, including reflected log10 transformations, were not effective in reducing highly negatively skewed distributions for global adherence variables (i.e., general adherence past month, general adherence past week). Thus, outcome analyses involving global adherence variables (both past week and past month) were conducted using dichotomous

variables (95-100% of prescribed pills taken versus <95% of prescribed pills taken). Use of this cut point was selected to be consistent with the standards reported in the scientific literature (Paterson et al., 2000). Seventy-eight percent of participants were coded as adherent in the past week, while 61% of participants were coded as adherent in the past month. Our intentional nonadherence variable did not have outliers and was not inappropriately skewed, thus it remained untransformed.

Psychometric properties of scales. The psychometric properties of composite scales were examined. Cronbach's alpha (standardized) was calculated to assess internal consistency. Alphas ranged from .91 - .96 for stigma and .92 for depression and disclosure concerns (see Table 1). HIV-related stigmas and hypothesized mediators, including depression and disclosure concerns, were related in expected fashion (see Table 2). There were significant positive correlations among all three types of stigmas, *rs* .47 - .58, *ps*<.0001. There were also significant positive correlations between all three types of stigmas and depression, *rs* .42 - .47, *ps*<.0001, as well as all three types of stigmas and disclosure concerns, *rs* .28 - .59, *ps*<.0001.

Data Analyses

To identify correlates of the outcome variables, Pearson chi-square and bivariate logistic regression analyses were used for the dichotomous outcomes (i.e., global adherence in the past month and past week). Analysis of variance (ANOVA) and bivariate linear regressions were used for the continuous lifetime intentional nonadherence outcome. Multivariate logistic regression was conducted to examine the relative contribution of each predictor variable in analyses involving the dichotomous global adherence outcomes. Multivariate linear regression was used to examine the relative contribution of each predictor variable in analyses involving the

continuous lifetime intentional nonadherence outcome. Parallel mediation analyses were used to characterize potential mediators of the relationship between predictors and outcome variables.

Recommended guidelines for researchers conducting mediational analyses with .8 statistical power were used to determine an appropriate sample size for the primary study hypotheses (Fritz & MacKinnon, 2007). First, we considered our hypothesis that depression mediates the relationship between internalized stigma and adherence. A study testing depressive symptoms as a mediator of the relationship between HIV-related stigma and medication adherence reported a medium-large effect of HIV-related stigma on depressive symptoms (r = .51) and a small-medium effect of depressive symptoms on adherence (r = .21), after controlling for HIV-related stigma (Rao et al., 2012). Research by Fritz & MacKinnon (2007) allows for parameter values that correspond to small, small-medium, medium, and large effect sizes. Thus, we utilized a conservative medium estimate of HIV-related stigma on depressive symptoms and a small-medium estimate of depressive symptoms on adherence, after controlling for HIV-related stigma. An a priori sample size calculation for bias-corrected bootstrapping, which is considered to be the most powerful test of mediation, suggests a total sample size of 116 (Fritz & MacKinnon, 2007).

Second, we considered our hypothesis that concerns about inadvertent disclosure of serostatus mediate the relationship between perceived external stigmas and adherence. As this construct has been untested as a mediator, we could not utilize effect sizes from previous research in our estimates. We anticipate that these relationship may be comparable to the relationship between stigma, depression, and adherence. However, we utilized a more conservative small-medium estimate of HIV-related stigma on disclosure concerns and a small-medium estimate of disclosure concerns on adherence, after controlling for HIV-related stigma.

An a priori sample size calculation for bias-corrected bootstrapping suggests a total sample size of 148 (Fritz & MacKinnon, 2007). Based on the information above and practical considerations associated with recruitment, we aim to recruit at least 150 participants.

Results

Describing HIV-Related Stigma

As seen in Table 1, average scores for internalized stigma (M = 2.49, SD = 1.11) indicated that participants "disagreed" or "neither disagreed nor agreed" that they had internalized stigma. Averages scores for anticipated stigma (M = 3.10, SD = 1.08) indicated that participants thought future experiences of stigma were "neither unlikely nor likely," while average scores for enacted stigma (M = 2.45, SD = 1.16) indicated that participants had "not often" or "somewhat often" experienced past instances of stigma. Overall, average scores on HIV-related stigmas suggested relatively low to moderate levels of stigma, which was comparable to Earnshaw and colleagues (2013) rates of stigma using these same measures. Table 3 provides a breakdown of demographic, health status, and health treatment variables and their associations with internalized, anticipated, and enacted stigmas. Internalized stigma was negatively associated with years since HIV diagnosis, anticipated stigma was negatively associated with age, and enacted stigma was associated with greater likelihood of being unemployed.

HIV-related stigmas and ART Adherence

To evaluate the impact of HIV-related stigmas on adherence measures, the bivariate relationships between all three types of stigma (i.e., internalized, anticipated, and enacted stigmas) were characterized. A correlation matrix with all hypothesized predictors (see Table 2) was inspected for evidence of multicollinearity (Tabachnick & Fidell, 2001). Bivariate analyses

demonstrated that internalized stigma was positively correlated with anticipated stigma (r = .56, $p < .0001$) and enacted stigma (r = .47, $p < .0001$), and that anticipated stigma was positively correlated with enacted stigma (r = .58, $p < .0001$). These three scales were judged to be sufficiently distinct, allowing us to enter all three simultaneously in regression analyses to characterize their independent contributions in predicting adherence outcomes. Evidence of multicollinearity was also assessed during regression analyses by examining collinearity statistics, including tolerance and variance inflation factor (VIF). There was no evidence of tolerance < .10 or VIF > 10, indicating an absence of multicollinearity (Tabachnick & Fidell, 2001).

The first aim of the study was to clarify the association between HIV-related stigmas and adherence outcomes by examining specific types of adherence behaviors, which we characterized as global adherence and intentional nonadherence. To examine hypothesized associations between HIV-related stigmas and adherence outcomes, a series of logistic and linear regression analyses were conducted with specified indices of global adherence (past month or past week) or intentional nonadherence (since diagnosis) as the dependent variable and the three types of HIV-related stigmas as the predictor variables. Table 4 shows the results of logistic and linear regression analyses examining the relationship of HIV-related stigmas to global adherence and intentional nonadherence.

HIV-related stigmas and global adherence. As shown in Table 5, 22% of participants reported global adherence rates of less than 95% in the past week. Participants with sub-optimal global adherence (past week) were more likely to be younger, of a race/ethnicity other than Caucasian, and have lower income. As shown in Table 5, 39% of participants reported global adherence rates of less than 95% in the past month. Participants with sub-optimal global

adherence (past month) were more likely to have a lower education level and lower income. Contrary to study hypotheses, internalized, anticipated, and enacted stigmas were not associated with global adherence in the past week or global adherence in the past month (Table 4).

HIV-related stigmas and intentional nonadherence. In the domain of intentional nonadherence, a majority of participants (86%) endorsed at least one of the four types of intentional nonadherence behaviors since starting HIV treatment. As shown in Table 5, making small adjustments was the most frequently endorsed type of nonadherence (74%), followed by stopping use of one or more medications without doctor approval (48%), medication vacations (38%), and delay of treatment uptake when recommended (31%). Positive responses across each of the four intentional nonadherence domains were summed to form an index score. A score of one was assigned for each category of intentional nonadherence behavior, and the sum of these scores yielded a summary intentional nonadherence score (range = 0 – 4) reflecting both the occurrence and extent of intentional nonadherence behaviors since being diagnosed with HIV.

Participants with intentional nonadherence differed by race/ethnicity, years since diagnosis, years taking medications, and number of HIV pills per day. It was hypothesized that HIV-related stigmas would be associated with a greater degree of intentional nonadherence. Contrary to study hypotheses, internalized, anticipated, and enacted stigmas were not associated with intentional nonadherence since being diagnosed with HIV (see Table 4).

Mediators of Stigma-Adherence Relationship

Another aim of our study was to examine two hypothesized potential mediators of the relationship between HIV-related stigmas and adherence outcomes, depressive symptoms and disclosure concerns. It was hypothesized that depression would mediate the association between internalized stigma and adherence outcomes, in the presence of disclosure concerns. It was also

hypothesized that disclosure concerns would mediate the association between perceived external stigmas (i.e., anticipated and enacted stigmas) and adherence outcomes, in the presence of depressive symptoms.

Although our previous regression analyses indicated a lack of significant total effects (i.e., no significant associations between HIV-related stigmas and adherence outcomes), mediational analyses were pursued. As discussed by Hayes (2013), contrary to the historically significant and popular causal steps strategy, it is possible for a predictor to exert an effect on an outcome indirectly through a mediator even if one cannot establish a significant total effect. Thus, a significant total effect is not a prerequisite to searching for evidence of indirect effects.

Parallel mediation models with an SPSS Macro designed to examine mediator models using bootstrapping statistical methods were used (Hayes, 2013). Parallel mediation is an estimation of indirect effects in a parallel multiple mediator model with two or more mediators that allows for a simultaneous test of each mechanism while accounting for the shared association between them (Hayes, 2013). Using this design allowed for a test of the hypothesis that depression mediates the relationship between internalized stigma and adherence, in the presence of disclosure concerns. Likewise, this design allowed for a test of the hypothesis that disclosure concerns mediates the relationship between perceived external stigmas and adherence, in the presence of depression. As recommended by Hayes (2013), bias-corrected bootstrapping was used because it provides the most powerful and reasonable method of obtaining confidence limits for specific indirect effects.

One condition of the parallel mediation model is that no mediator causally influences another mediator, as would be the case in a serial mediation model. Parallel mediation was deemed appropriate given that the partial correlation between depression and disclosure concerns

after controlling for all three types of stigmas was not significant (r = -.12, p = .10). Finally, covariates for the parallel mediation models were selected based on whether they had a significant bivariate relationship with either mediator (i.e., depression or disclosure concerns) or the outcome of interest (i.e., global adherence in the past week, global adherence in the past month, or intentional nonadherence) (Hayes, 2013).

HIV-related stigmas, mediators, and global adherence. Two parallel mediation analyses using ordinary least squares path analysis with global adherence (past month) and global adherence (past week) as the outcome variables of interest were used.

Internalized stigma. As can be seen in Figure 1 and Table 6, participants who endorsed higher internalized stigma also endorsed more depressive symptoms (a_{11} = 0.129), but there was not a significant association between depressive symptoms and global adherence in the past month (b_1 = -0.463). A bias-corrected bootstrap confidence interval for the specific indirect effect ($a_{11}b_1$ = -0.06) based on 10,000 bootstrap samples included zero (-0.178 to 0.006). Participants who endorsed higher internalized stigma also endorsed more disclosure concerns (a_{12} = 0.477), but there was not a significant association between disclosure concerns and global adherence in the past month (b_2 = 0.106). A bias-corrected bootstrap confidence interval for the specific indirect effect ($a_{12}b_2$ = 0.051) based on 10,000 bootstrap samples included zero (-0.128 to 0.219). Thus, neither specific indirect effect for internalized stigma, either through depressive symptoms or disclosure concerns, was significant. There was no evidence that internalized stigma influenced global adherence in the past month independent of its effect on hypothesized mediators (c'_1 = -0.016, p = .933). As can be seen in Figure 2 and Table 7, this pattern of results was the same for global adherence in the past week. There was no evidence of specific indirect effects with this outcome.

Anticipated stigma. As can be seen in Figure 1 and Table 6, there was not a significant association between anticipated stigma and depressive symptoms (a_{21} = 0.079) or between depressive symptoms and global adherence in the past month (b_1 = -0.463). A bias-corrected bootstrap confidence interval for the specific indirect effect ($a_{21}b_1$ = -0.037) based on 10,000 bootstrap samples included zero (-0.136 to 0.005). Participants who endorsed higher anticipated stigma also endorsed more disclosure concerns (a_{22} = 0.213), but there was not a significant association between participants who endorsed more disclosure concerns and global adherence in the past month (b_2 = 0.106). A bias-corrected bootstrap confidence interval for the specific indirect effect ($a_{22}b_2$ = 0.023) based on 10,000 bootstrap samples included zero (-0.053 to 0.122). Thus, neither specific indirect effect for anticipated stigma, either through depressive symptoms or disclosure concerns, was significant. There was no evidence that anticipated stigma influenced global adherence in the past month independent of its effect on hypothesized mediators (c'_2 = 0.059, p = .748). As can be seen in Figure 2 and Table 7, this pattern of results was the same for global adherence in the past week. There was no evidence of specific indirect effects with this outcome.

Enacted stigma. As can be seen in Figure 1 and Table 6, participants who endorsed higher enacted stigma endorsed more depressive symptoms (a_{31} = 0.162), but there was not a significant association between depressive symptoms and global adherence in the past month (b_1 = -0.463). A bias-corrected bootstrap confidence interval for the specific indirect effect ($a_{31}b_1$ = -0.076) based on 10,000 bootstrap samples included zero (-0.196 to 0.009). There was not a significant association between enacted stigma and disclosure concerns (a_{32} = -0.081) or between disclosure concerns and global adherence in the past month (b_2 = 0.106). A bias-corrected bootstrap confidence interval for the specific indirect effect ($a_{32}b_2$ = -0.009) based on 10,000

bootstrap samples included zero (-0.069 to 0.017). Thus, neither specific indirect effect for enacted stigma, either through depressive symptoms or disclosure concerns, was significant. There was no evidence that enacted stigma influenced global adherence in the past month independent of its effect on hypothesized mediators ($c'_3 = -0.015$, $p = .927$). As can be seen in Figure 2 and Table 7, this pattern of results was the same for global adherence in the past week. There was no evidence of specific indirect effects with this outcome.

HIV-related stigmas, mediators, and intentional nonadherence. A parallel mediation analysis using ordinary least squares path analysis with intentional nonadherence as the outcome variable of interest was conducted.

Internalized stigma. As can be seen in Figure 3 and Table 8, participants who endorsed higher internalized stigma also endorsed more depressive symptoms ($a_{11} = 0.129$), and participants who endorsed more depressive symptoms reported greater intentional nonadherence ($b_1 = 0.323$). A bias-corrected bootstrap confidence interval for the specific indirect effect ($a_{11}b_1 = 0.042$) based on 10,000 bootstrap samples was entirely above zero (0.004 to 0.113). Participants who endorsed higher internalized stigma also endorsed more disclosure concerns ($a_{12} = 0.477$), but there was not a significant association between participants who endorsed more disclosure concerns and intentional nonadherence ($b_2 = 0.055$). A bias-corrected bootstrap confidence interval for the specific indirect effect ($a_{12}b_2 = 0.026$) based on 10,000 bootstrap samples was not entirely above zero (-0.073 to 0.137). Thus, for internalized stigma, only the specific indirect effect through depressive symptoms was significant. Finally, there was no evidence that internalized stigma influenced intentional nonadherence independent of its effect on hypothesized mediators ($c'_1 = -0.072$, $p = .528$).

Anticipated stigma. As can be seen in Figure 3 and Table 8, there was not a significant association between participants who endorsed higher anticipated stigma and depressive symptoms (a_{21} = 0.079), but participants who endorsed more depressive symptoms reported greater intentional nonadherence (b_1 = 0.323). A bias-corrected bootstrap confidence interval for the specific indirect effect ($a_{21}b_1$ = 0.026) based on 10,000 bootstrap samples included zero (-0.002 to 0.088). Participants who endorsed higher anticipated stigma also endorsed more disclosure concerns (a_{22} = 0.213), but there was not a significant association between participants who endorsed more disclosure concerns and intentional nonadherence (b_2 = 0.055). A bias-corrected bootstrap confidence interval for the specific indirect effect ($a_{22}b_2$ = 0.012) based on 10,000 bootstrap samples included zero (-0.033 to 0.072). Thus, neither specific indirect effect for anticipated stigma, either through depressive symptoms or disclosure concerns, was significant. Finally, there was no evidence that anticipated stigma influenced intentional nonadherence independent of its effect on hypothesized mediators (c'_2 = 0.005, p = .963).

Enacted stigma. As can be seen in Figure 3 and Table 8, participants who endorsed higher enacted stigma endorsed more depressive symptoms (a_{31} = 0.164), and participants who endorsed more depressive symptoms reported greater intentional nonadherence (b_1 = 0.323). A bias-corrected bootstrap confidence interval for the specific indirect effect ($a_{31}b_1$ = 0.053) based on 10,000 bootstrap samples was entirely above zero (0.005 to 0.128). There was not a significant association between enacted stigma and disclosure concerns (a_{32} = -0.081) or between disclosure concerns and intentional nonadherence (b_2 = 0.055). A bias-corrected bootstrap confidence interval for the specific indirect effect ($a_{32}b_2$ = 0.053) based on 10,000 bootstrap samples was not entirely above zero (-0.049 to 0.01). Thus, for enacted stigma, only the specific indirect effect through depressive symptoms was significant. Finally, there was no evidence that

enacted stigma influenced intentional nonadherence independent of its effect on hypothesized mediators ($c'_3 = 0.027$, $p = .785$).

Covariates. Given significant indirect effects in Figure 3, an additional analysis including covariates was conducted. The following were included as covariates when intentional nonadherence was the outcome variable: education, employment, race/ethnicity, income, years since diagnosis, years taking medications, and average number of HIV pills per day. As can be seen in Table 9 and Figure 4, these results were the same as Figure 3. A bias-corrected bootstrap confidence interval for the specific indirect effect for internalized stigma through depressive symptoms ($a_{31}b_1 = 0.054$) based on 10,000 bootstrap samples was still above zero (0.01 to 0.135). Additionally, a bias-corrected bootstrap confidence interval for the specific indirect effect for enacted stigma through depressive symptoms ($a_{31}b_1 = 0.061$) based on 10,000 bootstrap samples was also still above zero (0.012 to 0.149).

Discussion

The purpose of this study was to clarify the association between HIV-related stigmas and HIV medication adherence among PLWH using more refined measures. Current measurement limitations of the existing literature include inconsistencies in the conceptualization and assessment of stigma domains and types of adherence. Given the paucity of research that adequately investigates mediators of the stigma-adherence relationship, the present study also sought to understand and clarify two potential mediational pathways, depressive symptoms and disclosure concerns, in an effort to inform both future research studies and subsequent interventions designed to improve adherence. A clinic-based sample of PLWH was recruited to complete measures designed to address these aims. Our findings are summarized in the following sections.

Association between HIV-Related Stigmas and Adherence

Past research points to fairly consistent evidence of an association between HIV-related stigmas and medication adherence difficulties among PLWH (Sweeney & Vanable, 2016). However, studies examining this phenomenon vary considerably in their approach to conceptualizing and assessing both stigma and adherence. The present study sought a more nuanced examination of the relationship between HIV-related stigmas and adherence using more refined measures. Multiple domains of HIV-related stigma (i.e., internalized, anticipated, and enacted stigmas) were assessed and all three domains were included simultaneously in analyses. By assessing two unique forms of nonadherence, global and intentional, the relationship between these multiple domains of stigma and nonadherence could be characterized. It was hypothesized that HIV-related stigmas would be associated with two global measures of nonadherence, which assessed missed doses over the past week and past month. It was further hypothesized that HIV-related stigmas would be associated with an intentional measure of nonadherence since diagnosis, which involves the patient selectively altering one's treatment regimen or choosing to discontinue, defer, or refuse treatment.

To the contrary, it was found that none of our HIV-related stigma domains (i.e., internalized, anticipated and enacted stigmas) were associated with either of our two measures of global nonadherence, as defined as <95% of prescribed doses taken in the past week or past month. Additionally, it was found that none of our HIV-related stigma domains were associated with intentional nonadherence since diagnosis, as assessed across the domains of declining to begin medication when recommended, stopping medication without doctor approval, taking medication vacations, and making small adjustments to one's regimen. Although HIV-related stigma domains were assessed simultaneously to characterize unique contributions associated

with adherence, the same results were found when stigmas were entered separately in analyses. Thus, there were no associations between any stigma domain and any adherence outcome in our analyses.

Mediators of Stigma-Adherence Relationship

While many studies have examined associations between HIV-related stigma and adherence, few have sought to understand the mediators that may account for this association. The present study also sought to address this gap by clarifying two potential mediators that may link stigma to adherence, depressive symptoms and disclosure concerns. It was hypothesized that internalized stigma would be associated with depressive symptoms, which in turn would be associated with our two global measures of adherence. It was further hypothesized that both anticipated and enacted stigmas would be associated with concerns about inadvertent disclosure of serostatus through pill-taking, which in turn would be associated with our two global measures of adherence. For conceptual reasons, it was anticipated that both these mediational pathways would be associated with our measure of intentional nonadherence, in addition to our global measures. Although previous results indicated a lack of association between stigmas and adherence outcomes, this is not a prerequisite for searching for indirect effects, and thus, mediational analyses were pursued. As discussed by Hayes (2013), contrary to the historically significant and popular causal steps strategy, it is possible for a predictor to exert an effect on an outcome indirectly through a mediator even if one cannot establish a significant total effect.

To the contrary, it was found that neither depressive symptoms nor disclosure concerns mediated the association between our HIV-related stigma domains and our two global measures of nonadherence in the past week and past month. There was also no evidence for disclosure concerns as a mediational pathway between stigma domains and our measure of intentional

nonadherence since diagnosis. However, results do suggest that the relationship between both internalized and enacted stigmas and intentional nonadherence since diagnosis are mediated by depressive symptoms. These mediational pathways through depressive symptoms were still significant even after participant characteristics such as demographics and health status variables were taken into account.

Implications of Findings for Future Research

In the present sample, there was no evidence to suggest that HIV-related stigmas directly interfere with medication adherence for PLWH, contrary to a recent review of the stigma-adherence literature (Sweeney & Vanable, 2016), including our own previous work (Vanable et al., 2006). This difference in findings could be representative of our current sample, which was a fairly healthy sample of patients from a single clinic in Upstate New York. The majority of our sample currently had an undetectable viral load, had never experienced an AIDS-defining illness, and self-reported their overall health as ranging from "good" to "excellent." Additionally, the majority of our sample self-reported that they believed they could successfully manage their medication regimen, and overall, appeared to be successfully doing so, as evidenced by high rates of recent adherence and good health status indicators. Thus, our sample may not be representative of PLWH currently experiencing adherence difficulties. A targeted sample of patients who are experiencing varying degrees of adherence difficulties may have provided a better opportunity to test study hypotheses.

The lack of an association between HIV-related stigmas and medication adherence in our present study may also be attributable to a different stage of the HIV epidemic. That is, in the early ART era, PLWH dealt with regimens characterized by a large number of pills, complex dosing schedules, and significant food and drug interactions. With rapid advances in the area of

medicine, newer ART medications are now more potent, allowing for less complicated dosing schedules and fewer number of pills, helping to improve adherence through a reduction in pill burden. A once-a-day, single pill which combines three different medicines has even since been launched, allowing for a convenient, easy to take medication option with fewer side effects. In our present study, patients reported an average of three HIV pills per day, which was lower than our previous work at the same recruitment site (Littlewood & Vanable, 2013). What is more, approximately half of our sample reported only taking one or two pills per day to treat their HIV. This indicates that medication regimens may no longer present the same obstacles to managing HIV as they did earlier in the epidemic, thus improving adherence, lowering viral failure rates, and enhancing quality of life. More research is needed to clarify the nature of adherence difficulties since the advent of newer ART medications, and whether previously associated psychosocial factors such as stigma continue to influence adherence now that medication regimens have changed.

Finally, although there was no evidence for disclosure concerns as a mediational pathway linking HIV-related stigma to medication in the present study, there was support for depressive symptoms as a mediational pathway linking internalized and enacted stigmas to intentional nonadherence since diagnosis. It was hypothesized that disclosure concerns may act as a mediational pathway based on previous qualitative research, in which patients often reported that the complexity of medication regimens interfered with their ability to conceal serostatus when pill-taking required consumption at inopportune times and in public settings. However, less challenging medication regimens, as discussed previously, may no longer present the same obstacles as before, thus possibly explaining the null finding for this mediational pathway. Indeed, it is noteworthy that while disclosure concerns were associated with internalized and

anticipated stigmas, there were not any direct pathways linking disclosure concerns to either global or intentional nonadherence outcomes.

On the other hand, there was some support for depressive symptoms as a mediational pathway linking internalized and enacted stigmas and intentional nonadherence, which is consistent with previous empirical tests of this pathway (Rao et al., 2012; Sayles et al., 2009). Both the internalization of stigma and past experiences of stigma may result in depressive symptoms, including depressed mood, loss of interest, and feelings of worthlessness, which may in turn cause one to deliberately change one's regimen or discontinue, defer, or refuse treatment. Future research should continue to clarify the differing impact of this mediational pathway on both global and intentional nonadherence outcomes, as well as clarify how these relationships may vary among PLWH with differing sociodemographic characteristics. For example, future research could examine how people who possess other socially devalued characteristics (for e.g., female gender, African-American race) may shape people's experience of HIV-related stigma and how this may impact vulnerability to depressive symptoms and subsequent medication adherence (Earnshaw & Kalichman, 2013).

As noted, there was an absence of support for disclosure concerns as a mediational pathway and limited support for depressive symptoms as a mediational pathway. Another variable often identified in the existing literature as important to both HIV-related stigma and medication adherence is social support. Although social support had significant inverse relationships with internalized and anticipated stigmas in our sample (i.e., as stigma increased, social support decreased), there was also no evidence for social support as a mediational pathway linking HIV-related stigmas to global adherence or intentional nonadherence. Thus, it appears

that social support also does not serve as a mechanism through which stigma influences adherence.

Clinical Implications

The finding that depressive symptoms play a mediational role for internalized and enacted stigmas and intentional nonadherence also has important clinical implications. Targeting depressive symptoms, including depressed mood, loss of interest in previously enjoyable activities, and feelings of worthlessness, may be useful in helping increase patients' motivation to maintain optimal health through medication taking. As such, programs and interventions designed to increase medication adherence may benefit from incorporating components designed to focus on the internalization of stigma, experiences of stigma, and depressive symptoms, and how these may cause one to intentionally alter or discontinue their medication regimen. Cognitive-behavioral approaches may be particularly useful in identifying negative thinking related to having HIV or negative thinking related to experiences of discrimination and how these thoughts link to emotion regulation and behavior.

Strengths and Limitations of the Present Study

There are several significant innovations in the present study that serve to extend our understanding of the relationship between HIV-related stigmas and ART adherence. First, current measurement limitations within the existing literature were addressed, including the widespread use of single measures that combined different types of stigma and failure to assess all three types of stigma simultaneously. As such, the present study assessed all three types of stigma and included these multiple domains of stigma in analyses simultaneously in an effort to capture current trends in the relationship between stigma and adherence. Second, another major limitation of the current literature, the treatment of nonadherence as a unidimensional construct,

was addressed. Instead, previous qualitative research (Wroe, 2002; Wroe & Thomas, 2003) and our own past quantitative research (Littlewood & Vanable, 2013) were used to conceptualize nonadherence as a multidimensional construct in which intentionality plays a role. The measures of intentional nonadherence used in this study served to capture past occurrences of intentional nonadherence since diagnosis. To further the development of this construct, future research should characterize more recent instances of intentional nonadherence, such as stopping medication without doctor approval, taking medication vacations, and altering one's regimen within the past week or month.

Another important innovation of this research is the empirical test of mediational pathways that may link HIV-related stigmas to medication adherence. To date, few studies had tested mediational models, and of those that had, enhanced vulnerability to mental health difficulties and reduction in self-efficacy had been identified as possible mediators. Another mediator, concerns about inadvertent disclosure of serostatus, had been characterized in qualitative research but remained untested in empirical studies. The present study sought to address this gap in the literature by empirically testing depressive symptoms and disclosure concerns as two possible mediational pathways linking stigma to ART adherence. Future research should continue to examine potential mediational pathways, particularly depressive symptoms, and the role they may play in linking HIV-related stigma to intentional nonadherence.

The study also had several methodological limitations that warrant consideration. First, the generalizability of study findings is limited by having a sample of participants living in Upstate New York from a single recruitment source. This sample may not be representative of all PLWH. For example, many patients of the clinic were of a lower socioeconomic status, had been living with HIV for many years, and were fairly healthy at the time of recruitment. Future

research should examine the generalizability of these findings by testing whether they replicate among samples representing other populations of PLWH, including those who have a wider range of sociodemographic backgrounds, who have poorer health status, and who have been more recently diagnosed with HIV.

Second, the cross-sectional design of the study makes it difficult to establish the causal direction of the observed relationships among study variables. The observed associations between HIV-related stigmas, depressive symptoms, and intentional nonadherence since diagnosis reflect a snapshot at one particular moment in time. Additionally, as Earnshaw and colleagues (2013) note, a cross-sectional design may be particularly limiting for studying relationships between anticipated stigma and health behaviors. Given that anticipated stigma assess people's thoughts about what will happen to them *in the future,* it may have weaker associations with people's health behaviors, such as medication adherence, *in the past.* Future research should examine the prospective associations between all HIV-related stigmas, hypothesized mediators, and adherence outcomes using longitudinal designs, and better examine whether anticipated stigma is prospectively associated with medication adherence.

Finally, there are limitations associated with the use of self-report measures. Memory biases, social desirability, and both intentional and accidental distortion of responses may influence the accuracy of self-report (Schroder et al., 2003). As such, it is possible that our assessment of ART adherence may have been vulnerable to self-report biases or inaccurate responding (Simoni et al., 2006). However, special care was taken in how questions were worded to reduce the potential for self-report biases and inaccurate responding in the present study. Although relying solely on patient self-report has drawbacks in terms of the reliability, a concerted effort was made to assure patients that their self-reports would remain confidential

(i.e., explicitly stating that the information they reported would not be given to clinic providers or impact their care at the clinic) and to emphasize the importance of truthful responding (i.e., emphasizing that the information they provided would aid future research and treatment programs designed to help PLWH, such as themselves).

Conclusion

This study represents an important step in understanding the impact of HIV-related stigmas on medication adherence for PLWH, including the mediational pathways that may play a role in this relationship. In a fairly healthy clinic-based sample of PLWH, internalized, anticipated, and enacted stigmas did not directly interfere with global or intentional nonadherence, which may be attributable to a later stage of the HIV epidemic, in which medication regimens no longer present the same obstacles as before. Although there was no support for disclosure concerns as a mediational pathway, there was support for depression as a mediational pathway linking internalized and enacted stigmas to intentional nonadherence since diagnosis. This is consistent with previous findings and indicates a potential avenue for future research and treatment programs. To better understand the interrelationships among HIV-related stigma, hypothesized mediators, and global and intentional adherence outcomes in the current stage of the HIV epidemic, prospective research with differing populations is needed. Determining causal links would help guide future research and inform the development of treatment programs designed to improve adherence for PLWH.

Appendix A: Recruitment Script for Clinic Staff

SYRACUSE UNIVERSITY
DEPARTMENT OF PSYCHOLOGY

Point of Contact Recruitment Script for "Health Practices Research Project"
To be used by Infectious Disease Clinic staff

A research team from Syracuse University is conducting a research study on the experiences and health practices of individuals who are coping with chronic illness. The study is being conducted by Dr. Peter Vanable, a professor of psychology at Syracuse University and adjunct professor at SUNY Upstate Medical University. Your participation would be unrelated to your treatment here. This study would require that you come to do the survey, which will take approximately one hour of your time. You can earn up to $20 for participating in the survey. Would you be interested in hearing more about the research study and learning what you would need to do to participate from a study team member?

IF NO: That's okay [continue with typical visit business].

IF YES: Great, a study team member will meet you at some point during your appointment today to discuss the research with you.

Appendix B: Recruitment Script for On-Site Research Assistants

SYRACUSE UNIVERSITY
DEPARTMENT OF PSYCHOLOGY

Point of Contact Recruitment Script for "Health Practices"
To be used by on-site research assistants

We are conducting a research study on the experiences and health practices of individuals who are coping with chronic illness. The study is being conducted by Dr. Peter Vanable, a professor of psychology at Syracuse University and adjunct professor at SUNY Upstate Medical University. This study would require that you come to do the survey, which will take approximately one hour of your time. You can earn up to $20 for participating in the survey. Would you be interested and willing to participate in the study?

IF NO: That's okay. [continue with typical visit business].

IF PATIENT IS INELIGIBLE: Thank you for your time and interest in our research, but at this time, we do not have a study that you would be eligible to participate in. However, we will be conducting more research soon, and you may be eligible for one of our future projects. (Give business card with Dr. Peter Vanable's name and phone number and tell participant to check the website or contact us in the future to hear more).

IF YES: Great! Then we would love to schedule a time for you to come to our lab, which is located at 739 Irving Ave, Suite 340. Are you able to schedule now?

> IF YES: (Schedule) (Give business card with Dr. Peter Vanable's name and phone number for participant to contact if they would like further information in the meantime.)
>
> IF NO: (Give business card with Dr. Peter Vanable's name and phone number and tell participant to contact us when they are able to, or, if they prefer, take down their contact information so that we can contact them to schedule in a couple of days).

Appendix C: Consent Form

SYRACUSE UNIVERSITY
DEPARTMENT OF PSYCHOLOGY

Consent/Authorization Form
Title of Study: Health Practices Research Project

Background/Purpose:

You are invited to participate in a research study designed to learn more about the experiences and health practices of those coping with chronic illness. Our goal is to gain a better understanding of how individuals experience and manage their illness, and the obstacles they may encounter while living with a chronic illness. By focusing on these experiences and health practices, we will collect information that will enable us to develop strategies to improve the lives of individuals who are coping with chronic illness. The director of this study is Dr. Peter Vanable, a Professor of Psychology at Syracuse University and an Adjunct Professor of Medicine at SUNY Upstate Medical University. Other trained research staff will also be involved, and will be supervised by Dr. Peter Vanable of Syracuse University. We are asking approximately 200 individuals to participate in the study. You are being asked to participate in this research study because you have indicated that you are coping with a chronic illness.

Study Procedures:

If you decide to take part in this study, you will read and respond to information that is presented individually to you on a computer. You will answer questions presented on the computer screen regarding your experiences, including your feelings and opinions about yourself. You will then respond to questions about your health behaviors and experiences, including questions about your use of medicine, sexual behaviors, and challenges that you may have experienced. The study takes approximately one hour to complete, and your participation is completely voluntary.

Risks:

There are two risks associated with this study. First, you may feel uncomfortable answering questions that ask about personal or sensitive aspects of your behavior, including sexual practices and drug use. If this occurs, you may choose not to answer any question. A second risk involves the risk of disclosing private information to our research team. All information that you share with members of our team is considered strictly confidential, and we are obligated to protect your privacy. Research staff will not share the information you provide during discussion or on the survey with your doctor or nurse at the clinic where you receive treatment. 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 will have access to the key that indicates which number belongs to which participant. Your name or other identifying information will not be kept with your survey responses.

There are limits to confidentiality, however. We will keep your study data as confidential as possible, with the exception of certain information that we must report for legal or ethical reasons, as would be the case if we learn about your intent to harm yourself or others. Additionally, the researcher is not immune from legal subpoena about illegal activities. Although it is very unlikely, if law enforcement officials ask to see my data, we would have to give it to them.

Benefits:

The potential benefits are that you may learn more about your experiences and become aware of how these experiences can affect you. In addition, because the information you provide assists in the development of strategies to improve the lives of individuals who are coping with chronic illness, your participation could benefit others living with chronic illness.

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. Regardless of completion, all participants will also be offered a parking voucher that covers the cost of parking in the CNY medical building main parking garage.

Questions:

If you have any questions about the research, please contact Dr. Peter Vanable at (315) 443-1210. 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.

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 am at least 18 years of age and hereby give my consent to participate in this research study. I 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

_____
Name of subject

_____ _____
Signature of Person Obtaining Consent/Authorization Date

_____
Name of Person Obtaining Consent/Authorization

Appendix D: Consent Form Talking Points

SYRACUSE UNIVERSITY
DEPARTMENT OF PSYCHOLOGY

Consent Form Talking Points (on-site research assistant)

- Who: Dr. Peter Vanable at Syracuse University
- **Purpose**
  - to learn more about the experiences and health practices of those coping with chronic illness
  - better understanding of how individuals experience and manage their illness, and the obstacles they may encounter while living with a chronic illness
  - enable us to develop strategies to improve the lives of individuals who are coping with chronic illness
- **Procedures**
  - One-time survey on a private laptop computer
  - It will take approximately 1 hour to complete
  - The survey will ask questions regarding your experiences, including your feelings and opinions about yourself
  - The survey will include questions about a range of health behaviors and experiences, including use of medicine, sexual behaviors, and challenges you may have experienced
  - Participation is completely voluntary

- **Risks**
  - There are some risks with the study
  - First risk: Some people may feel uncomfortable answering questions that ask about personal or sensitive aspects of behaviors, including sexual behaviors and drug use
  - Second risk: Disclosing private information to research team
  - We will minimize these risks but they will not be completely eliminated

- **Confidentiality**
  - We take participant confidentiality very seriously
  - All the information you provide on the survey will be kept confidential
  - Research staff will not share the information you provide (either verbally or on survey) with anyone, including clinic where you receive treatment
  - Your names are NOT kept with your survey responses
  - Because this is research study, our findings may be presented to other health professionals to help others. However, individual responses will NEVER be identifiable in those reports.
  - Participants in this study will not have access to research records or data
  - Limits to confidentiality: (1) intent to harm yourself or others or (2) law enforcement officials ask to see data

- **Benefits**
  - You may learn more about your experiences and become aware of how these experiences affect you
  - Information you provide could assist in helping develop strategies to improves the lives of individuals who are coping with chronic illness

- **Refusal**
  - Your participation is completely voluntary. You may withdraw from the study at any time.
  - If you don't participate, you will continue to receive usual care.

- **Payment**
  - Upon completion of the survey, you will be paid $20
  - If you decide to stop before completing the survey, you will be paid $10 for each half hour of time spent doing the study.

- **Questions or Concerns**

- **Permission to Recontact**

Appendix E: Central New York Resource List

SYRACUSE UNIVERSITY
DEPARTMENT OF PSYCHOLOGY

The following document will be provided to participants by the research assistant. They will say: "Thank you for participating in our research study today. Sometimes, participating in research studies like this can make people realize that there are areas of their lives in which they could use some help. If that's the case for you, we would like to give you some information about where you can go."

Health Practices Research Project

Central New York Resource List

Infectious Disease Clinic: Upstate

Designated AIDS Center
(Infectious Disease Division of SUNY Upstate Medical University Hospital in Syracuse)
Crouse Physicians Office Building
725 Irving Avenue, Suite 211 (Clinic), Syracuse, NY 13210
Phone: (315)-464-5533
Toll-free: (877) 464-5540 ext. 5533

Case Management

AIDS Community Resources
672 W. Genesee Street, Syracuse, NY 13204
Phone: (315) 475-2430
Hotline: (800) 475-2430
Website: *www.aidscommunityresources.com*
Email: information@aidscommunityresources.com

Additional locations:

Auburn: 17 E. Genesee Street; (315) 253-7924, Ext. 34
Canton: 9 Miner Street; (315) 386-4493
Oswego: 10 George Street; (315) 343-7778
Utica: 401 Columbia Street. (315) 793-0661
Watertown: 230 Franklin Street; (315) 785-8222

Central New York Services, Inc.
518 James Street, Suite 240 Syracuse NY 13203
Phone: (315) 478-2453
Website: www.cnyservices.org
Focus: Case Management & Supportive Services

Arnot Ogden Medical Center
HIV Clinic/Tompkins County DOH
401 Harris B Dates Dr, Ithaca, NY 14850
Phone: (607) 274-6718
Website: www.aomc.org

SUNY Upstate Medical University
(Research Foundation of SUNY)
750 East Adams St., Syracuse, NY 13210
Phone: (315) 464-7353

Syracuse Model Neighborhood Facility, Inc.
401 South Ave., Syracuse, NY 13204
Phone: (315) 474-6823
Website: www.swccsyr.org

Dental Care

Alvin Holmes, D.D.S.
1939 E. Genesee Street, Syracuse, NY 13210
Phone: 479-7019

Cicero Dental Associates PLLC
7770 Frontage Rd, Cicero, NY 13039
Phone: (315) 458-3088

Mattydale Center for Dentistry
2412 Brewerton Rd, Mattydale, NY 13211
Phone: 454-4400

St. Joseph's Hospital Dental Clinic
101 Union Avenue, Syracuse, NY 13203
Phone: (315) 448-5477

Charles T. Sitrin Nursing Home Dental Clinic
2050 Tilden Avenue, New Hartford, NY 13413
Phone: (866) 274-8746

Syracuse Community Health Center Dental Clinic
819 S. Salina Street, Syracuse, NY 13202
Phone: (315) 476-7921

United Cerebral Palsy Dental Clinic
4 Commerce Lane, Canton, NY 13617
Phone: (315) 386-8191

SUNY Upstate Medical University Outpatient Dental Clinic
90 Presidential Plaza - 4130 UHCC Suite 4141, Syracuse, NY 13210
Phone: (315) 464-5256
Toll-free: (800) 464-8668

Westside Dental Services
1116 Arsenal Street Suite 202, Watertown, NY 13601
Phone: (315) 779-2222

Housing

AIDS Community Resources Rental Assistance Program (HOPWA)
627 W. Genesee Street, Syracuse, NY 13204
Phone: (315) 475-2430

Abraham House
1203 Kemble Street, Utica, New York 13501
Phone: (315) 733-8210

Website: www.theabrahamhouse.org

CNYHSA Rental Assistance Program (HOPWA & AIDS Institute)
5700 Commons Park Drive, E. Syracuse, NY 13057
Phone: (315) 472-8099
Website: www.cnyhsa.com

DePalmer House

-Operated by Liberty resources, Inc.
Syracuse, New York 13202
Phone: (315) 475-1544
Website: www.liberty-resources.org

Friends of Dorothy House.
212 Wayne Street, Syracuse, NY 13203
Phone: (315) 471-6853
Website: www.friendsofdorothysyracuse.com
Focus: Renovated Victorian house operated by a dedicated couple who rent a one-bedroom apartment for independent living & provide family support for one hospice bed for a PWA in end-stage care.

Mesa Commons

-Operated by Liberty Resources, Inc.
Syracuse, NY 13208
Phone: (315) 701-0293, ext 14
Website: www.liberty-resources.org

Welch Terrace
P.O. Box 37197, Syracuse, NY 13235
1047 E. Fayette St. #209, Syracuse, NY 13210
Phone: (315) 422-5611
Focus: One-bedroom apartments in Syracuse for HIV-positive individuals/couples.

YMCA of Greater Syracuse
340 Montgomery Street, Syracuse, NY 13202
Phone: (315) 474-6851
Website: www.ymcaofgreatersyracuse.org
Focus: 13 units with private bath reserved for HIV/AIDS residents; other rooms available without private baths.

Legal Services

AIDS Law Project
472 S. Salina Street, Suite 300, Syracuse, NY 13202 (located at Legal Services of Central New York in Syracuse)
Phone: (315) 475-3127
Toll-free: (866) 475-9967
Website: www.lscny.org

Legal Services of Central New York
472 S. Salina Street, Suite 300, Syracuse, NY 13202
Phone: (315) 475-3127
Website: www.lscny.org
Focus: Legal services for people living with HIV/AIDS and their children.

Mental Health Services

AIDS Community Resources: Mental Health Counseling & Support
627 W. Genesee Street, Syracuse, NY 13204
Phone: (315) 475-2430
Website: www.aidscommunityresources.com

ARISE, Inc.
635 James Street, Syracuse, NY 13203
Phone: (315) 472-3171
Website: www.ariseinc.org
Focus: Disability services; Mental Health Counseling (including HIV/AIDS)

Cayuga Counseling Services
17 Genesee Street Suite 1, Auburn, NY 13021
Phone: (315) 253-9795
Focus: Outpatient Mental Health Clinic

Center for Living with Loss (Hospice of CNY)
990 7th North Street, Liverpool, NY 13088
Phone: (315) 634-1100
Website: www.hospicecny.org

Central New York Services
518 James Street Suite 240, Syracuse, NY 13203
Phone: (315) 478-2453
Website: www.cnyservices.org

Commonwealth Place
6010 E. Molloy Road, DeWitt, NY 13211
Phone: (315) 434-2470
Main Intake Phone: (315) 470-8304 or Toll-free: (800) 727-6873

Forensic Consultants Ltd. Center for Human Services
319 E. Water Street, Syracuse Suite 1, NY 13202
Phone: (315) 472-1212

Hutchings Psychiatric Center
620 Madison Street, Syracuse, NY 13210
Phone: (315) 426-3600

Liberty Resources HCP (HIV Counseling Program)
1065 James St. Suite 200, Syracuse, NY 13203
Phone: (315) 425-1004

Mohawk Valley Psychiatric Center
1400 Noyes St., Utica, NY 13502
Phone: (315) 738-4405

Onondaga Case Management
220 Herald Place, Syracuse, NY 13202
Phone: (315) 472-7363

Onondaga Pastoral Counseling Services
324 University Avenue, Syracuse, NY 13210
Phone: (315) 472-4471

St. Joseph's Hospital: CPEP (Comprehensive Psychiatric Emergency Program)
201 Prospect Avenue, Syracuse, NY 13203
Phone: (315) 448-6555

St. Joseph's Outpatient Mental Health Services
724 James Street, Syracuse, NY 13203
Phone: (315) 703-2700

Syracuse Community Health Counseling Addictions Psychological Program
819 S. Salina Street, Syracuse, NY 13202
Phone: (315) 234-5918

Transitional Living Services
420 E. Genesee Street Suite 100, Syracuse, NY 13202
Phone: (315) 474-2117

Domestic Violence

Vera House, Inc. (Domestic Violence Shelter)
Administrative Office, 2122 Erie Blvd. East, Syracuse, NY 13224
6181 Thompson Road, Suite 100, Syracuse, NY 13206
Phone: (315) 425-0818
Shelter/24-hour Crisis Line: (315) 468-3260

Rape & Sexual Assault Line: (315) 422-7273
Focus: Crisis relocation for victims of domestic violence

Nutrition

The Living Room (a program of Liberty Resources)

326 Montgomery Street, Syracuse, NY 13203
Phone: (315) 478-0367 extension 4
Focus: Congregate meal program; Heart's Content-Home delivered meals; Pantry service (members only)

Substance Abuse Services

Addictions Crisis Center

210 Lansing St., Utica, NY 13501
Phone: (315) 735-1149

Alcohol Services, Inc

247 W. Fayette St. Suite 201, Syracuse, NY 13202
Phone: (315) 471-2885

Center for Community Alternatives

115 E. Jefferson Street, Suite 300, Syracuse, NY 13202
Phone: (315) 422-5638

Central New York Services

518 James Street, Syracuse, NY 13203
Phone: (315) 478-2453

Commonwealth Place

6010 E. Molloy Road, Syracuse, NY 13211
Phone: (315) 434-2470

Crouse Chemical Dependency Treatment Services

410 S. Crouse Avenue, Syracuse, NY 13210
Phone: (315) 470-7314

Insight House

500 Whitesboro Street, Utica, NY 13502
Phone: (315) 724-5168
Toll-free: (800)530-2741
Website: www.insighthouse.com

Liberty Resources HCP (HIV Counseling Program) Services

316 Catherine Street, Syracuse, NY 13203
Phone: (315) 701-0293

MATS (Managed Addictions Treatment Services) Program

--Located at Onondaga County Mental Health Department.

421 Montgomery Street, 10th Floor, Syracuse, NY 13202
Phone: (315) 425-1695 or (315) 435-3355

Prevention Network/OCAA

1050 W. Genesee Street, Syracuse, NY 13204
Phone: (315) 471-1359

Recovery Counseling Services

109 S. Warren St., Syracuse, NY 13202
Phone: (315) 475-1771

SBH (Syracuse Behavioral Healthcare)
847 James Street, Syracuse, NY 13206
Phone: (315) 471-1564

Needle Exchange Program

Southern Tier AIDS Program, Inc.
Syringe Exchange Site
501 South Meadow St., Ithaca, NY 14850
Phone: (607) 272-4098

Transportation Services

STAR Transportation (ACR)
627 W. Genesee Street, Syracuse, NY 13204
Phone: (315) 475-2430

Treatment Adherence

AIDS Community Resources

627 W. Genesee Street, Syracuse, NY 13204
Phone: (315) 475-2430

Multiple Service Agencies

American Indian Community House
120 E. Washington Street, Suite 400, Syracuse, NY 13202
Phone: (315) 470-0200
Website: *www.aich.org*
Focus: Multiple Service Agency (MSA) offering Prevention Education in Syracuse/Onondaga County for Native Americans

Central New York Health Systems Agency, Inc.
5700 Commons Park Drive, East Syracuse, NY 13057
Phone: (315) 472-8099
Website: www.cnyhsa.com

Focus: Community-based Health Planning, HIV/AIDS Nework, HIV/AIDS Rental Assistance, HIV/AIDS Capacity-building & Technical Assistance for Minority-Serving Programs

Central New York HIV CARE Network (A Program of CNYHSA, Inc., East Syracuse)
(Ryan White/AIDS Institute-funded Network for 14-county Central New York region)
5700 Commons Park Drive, East Syracuse, NY 13057
Phone: (315) 472-8099
Website: www.cnyhsa.com
Focus: Coordination of community response to HIV/AIDS; needs assessment & priority-setting; community awareness and advocacy in 14-county CNY region

F.A.C.E.S. Program/Syracuse Model Neighborhood Facility (at Southwest Community Center)
401 South Avenue, Syracuse, NY 13204
Phone: (315) 474-6823
Focus: Multiple Services Agency (MSA) offering Prevention Education & supportive services in Syracuse/Onondaga County for minorities

Liberty Resources, Inc.
(main HIV/AIDS site at The Living Room)
1065 James St. Suite 200, Syracuse, NY 13203
Phone: (315) 425-1004
Website: www.liberty-resources.org
Focus: HIV Counseling for Mental Health & Substance Abuse; Housing referrals; congregate & independent housing unites; Nutrition services; Return to Work counseling

HIV/AIDS Prevention & Education

Black Leadership Commission on AIDS/Syracuse
Pastor Chauncey Brown, True Vine Baptist Church, P.O. Box 6, Syracuse, NY 13207
Phone: (315) 478-0429
Contact Name: Audrey Otis, Coordinator, 403 Liberty Street, Syracuse, NY 13204
Phone: (315) 478-0012
Focus: Promoting HIV/AIDS awareness and response among African-American congregations and communities

Covenant Fellowship of Churches
Rev Leslie J. Johnson, Tucker Missionary Baptist Church, 515 Oakwood Avenue, Syracuse, NY 13205
Phone: (315) 475-8175
Rev. Collette Matthews, New Covenant Baptist Church, 107 E. Beard Avenue, Syracuse, NY 13205
Phone: (315) 440-6564
Focus: HIV/AIDS Prevention Education for African-American congregations and communities

Leadership Training Institute (LTI)
c/o Cicatelli Associates, Inc., 505 8th Avenue, Suite 1601, New York, NY 10018-6505
Phone: (212) 594-7741
Focus: AIDS Institute-funded training and skills-building resource for Persons Living with HIV/AIDS to increase quality and outcomes of clinical provider/patient partnerships

REACH CNY
1010 James Street, Syracuse, NY 13203
Phone: (315) 424-0009

Appendix F: Full Questionnaire

Introduction, Demographics, & Health History

We want to gain a better understanding of your experiences coping with a chronic illness. You'll be asked to express your feelings and opinions about yourself and your health. We will use the information we obtain from the study to develop programs to help people live healthier lives and inform HIV care providers about the needs and preferences of people living with HIV.
To help us learn from your experiences, please tell us what you really think, not just what you think we'd want to hear. All your responses are kept private. If you find a question that you don't understand, please ask for assistance. Thank you for participating!

1. What is your gender? 1❑Female 2❑Male 3❑Transgender [DEMO1]

2. How old are you? _____ years old [DEMO2]

3a. In what year were you born? _____ [DEMO3Y]

3b. In what month were you born? _____ [DEMO3M]

3c. On what day of the month were you born?_____ [DEMO3D]

4. What is the highest level of education that you have completed? [DEMO4]
1❑Less than high-school
2❑High-school diploma or GED
3❑Some college
4❑Associates degree or Technical Certification
5❑Bachelors degree
6❑Masters degree
7❑Doctoral degree

5. Which of the following BEST describes your racial/ethnic background? Is it... [DEMO5]
1❑Native Hawaiian or Other Pacific Islander
2❑Black or African-American
3❑White/Caucasian
4❑Asian
5❑American Indian or Alaska Native
6❑Mixed or Multi-racial
7❑Other _____ [DEMO5A]

6. Do you consider yourself to be Hispanic/Latina/Latino? [DEMO6]
0❑No 1❑Yes

7. Which of the following statements applies best to you? [DEMO7]
1❑I am sexually attracted to men.
2❑I am sexually attracted to men and women.

3❑I am sexually attracted to women.

8. Which best describes your current relationship status? [DEMO8]
1❑In a committed relationship
2❑Single and dating one or more people
3❑Single and interested in dating but not currently dating
4❑Single and not interested in a relationship at all

9. Are you married? [DEMO9]
0❑No 1❑Yes

10. Is English your first language? [DEMO10]
0❑No 1❑Yes

11. Are you currently employed? [DEMO11]
0❑No (skip to 12) 1❑Yes (go to 11a)

11a. On average, how many hours per week do you work? [DEMO11A]
1❑Less than 10 hours
2❑10 – 20 hours
3❑21 – 39 hours
4❑40+ hours

12. 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. [DEMO12]

Monthly income: $ _____

13. From which of the following sources do you regularly receive income? (Check all that apply)
1 ❑ Wages or salary from job [DEMO13A]
2 ❑ Unemployment [DEMO13B]
3 ❑ Welfare [DEMO13C]
4 ❑ Disability [DEMO13D]
5 ❑ Spouse/Partner [DEMO13E]
6 ❑ Family [DEMO13F]
7 ❑ Friends [DEMO13G]

14. In what year were you diagnosed with HIV? [DEMO14] _____

15. Are you currently prescribed medication to treat your HIV? [DEMO15]
0❑No (Skip to 16) 1❑Yes (Go to 15a)

15a. In what year did you begin taking medication to treat your HIV? [DEMO15A] _____

16. What was your most recent viral load result? [DEMO16]
1 ❑ Undetectable

2 ❑ Detectable
3 ❑ Don't Know

17. How many clinic appointments have you missed in the past year? [DEMO17] _____

18. Have you ever experienced an AIDS-defining illness? [DEMO18]
0❑No 1❑Yes

19. What is the most likely way that you became infected with HIV? [DEMO19]
1❑Sex with a man who was HIV+
2❑Sex with a woman who was HIV+
3❑Shared needles with a person who was HIV+
4❑Blood transfusion or other medical procedure
5❑Don't know
6❑Other _____ [DEMO19A]

20. *Have you ever* received therapy for any emotional or mental health problems? [DEMO20]
0❑No (Skip to 22) 1❑Yes

If Yes:
20a. Check all that apply. [DEMO20A]
❑Depression or depression-related disorders? [DEMO20AA]
❑Anxiety or anxiety-related disorders? [DEMO20AB]
❑Posttraumatic stress disorder or other trauma-related disorders? [DEMO20AC]
❑Eating disorders? [DEMO20AD]
❑Insomnia or other sleep-related disorders? [DEMO20AE]
❑Substance-related or addictive disorders? [DEMO20AF]
❑Personality disorders? [DEMO20AG]
❑Bipolar or bipolar-related disorders? [DEMO20AH]
❑Schizophrenia or other psychotic disorders? [DEMO20AI]
❑Obsessive-compulsive or related disorders? [DEMO20AJ]

21. Are you *currently* receiving therapy for any emotional or mental health problems? [DEMO21]
0❑No (Skip to 22) 1❑Yes

If Yes:
21a. Check all that apply. [DEMO21A]
❑Depression or depression-related disorders? [DEMO21AA]
❑Anxiety or anxiety-related disorders? [DEMO21AB]
❑Posttraumatic stress disorder or other trauma-related disorders? [DEMO21AC]
❑Eating disorders? [DEMO21AD]
❑Insomnia or other sleep-related disorders? [DEMO21AE]
❑Substance-related or addictive disorders? [DEMO21AF]
❑Personality disorders? [DEMO21AG]

❑Bipolar or bipolar-related disorders? [DEMO21AH]
❑Schizophrenia or other psychotic disorders? [DEMO21AI]
❑Obsessive-compulsive or related disorders? [DEMO21AJ]

22. *Have you ever* been prescribed medication for any emotional or mental health problems? [DEMO22]

0❑No (Skip to next section) 1❑Yes

If Yes:

22a. Check all that apply. [DEMO22A]

❑Depression or depression-related disorders? [DEMO22AA]
❑Anxiety or anxiety-related disorders? [DEMO22AB]
❑Posttraumatic stress disorder or other trauma-related disorders? [DEMO22AC]
❑Eating disorders? [DEMO22AD]
❑Insomnia or other sleep-related disorders? [DEMO22AE]
❑Substance-related or addictive disorders? [DEMO22AF]
❑Personality disorders? [DEMO22AG]
❑Bipolar or bipolar-related disorders? [DEMO22AH]
❑Schizophrenia or other psychotic disorders? [DEMO22AI]
❑Obsessive-compulsive or related disorders? [DEMO22AJ]

23. Are you *currently* prescribed medication for any emotional or mental health problems? [DEMO23]

0❑No (Skip to next section) 1❑Yes

If Yes:

23a. Check all that apply. [DEMO23A]

❑Depression or depression-related disorders? [DEMO23AA]
❑Anxiety or anxiety-related disorders? [DEMO23AB]
❑Posttraumatic stress disorder or other trauma-related disorders? [DEMO23AC]
❑Eating disorders? [DEMO23AD]
❑Insomnia or other sleep-related disorders? [DEMO23AE]
❑Substance-related or addictive disorders? [DEMO23AF]
❑Personality disorders? [DEMO23AG]
❑Bipolar or bipolar-related disorders? [DEMO23AH]
❑Schizophrenia or other psychotic disorders? [DEMO23AI]
❑Obsessive-compulsive or related disorders? [DEMO23AJ]

Center for Epidemiologic Studies Depression Scale (CES-D)
(Radloff, 1977)

Instructions. Below is a list of ways you might have felt or behaved. Please tell us how often you have felt this way during the past week.

0❑ Rarely or none of the time
1❑ Some or a little of the time
2❑ Occasionally or a moderate amount of the time
3❑ Most or all of the time

1. I was bothered by things that usually don't bother me. [DEP1]
2. I did not feel like eating; my appetite was poor. [DEP2]
3. I felt that I could not shake off the blues even with help from my family or friends. [DEP3]
4. I felt I was just as good as other people. [DEP4]
5. I had trouble keeping my mind on what I was doing. [DEP5]
6. I felt depressed. [DEP6]
7. I felt that everything I did was an effort. [DEP7]
8. I felt hopeful about the future. [DEP8]
9. I thought my life had been a failure. [DEP9]
10. I felt fearful. [DEP10]
11. My sleep was restless. [DEP11]
12. I was happy. [DEP12]
13. I talked less than usual. [DEP13]
14. I felt lonely. [DEP14]
15. People were unfriendly. [DEP15]
16. I enjoyed life. [DEP16]
17. I had crying spells. [DEP17]
18. I felt sad. [DEP18]
19. I felt that people dislike me. [DEP19]
20. I could not get "going." [DEP20]

Social Rejection Scale
(Ewart, Elder, & Smyth, 2014)

People often feel stressed at work, in the neighborhood, or out in the community, because they don't know how other people really feel about them. By using the following scale, please show how often you wonder what others think or feel about you.

How often do you wonder if someone…

	Rarely			**Sometimes**			**Often**
Likes you? [SOCREJ1]	1	2	3	4	5	6	7
Respects you? [SOCREJ2]	1	2	3	4	5	6	7
Is interested in what you have to say? [SOCREJ3]	1	2	3	4	5	6	7
Wants you in their group? [SOCREJ4]	1	2	3	4	5	6	7
Thinks they're better than you? [SOCREJ5]	1	2	3	4	5	6	7
Believes untrue stories they heard about you? [SOCREJ6]	1	2	3	4	5	6	7
Thinks you can be pushed around? [SOCREJ7]	1	2	3	4	5	6	7
Doesn't want you around? [SOCREJ8]	1	2	3	4	5	6	7
Says mean things about you behind your back? [SOCREJ9]	1	2	3	4	5	6	7
Doesn't like the way you look, or the way you dress? [SOCREJ10]	1	2	3	4	5	6	7

City Stress Inventory
(Ewart & Suchday, 2002)

Listed below are stressful things that people living in cities have experienced in their neighborhoods. For each event listed, please indicate if this event, or something like it, happened in the neighborhood(s) where you lived during the PAST YEAR. Indicate if the event happened, and how often, by checking the appropriate box.

1. I saw people dealing drugs near my home. [CITY1]
   1❒ Never 2❒ Once 3❒ A few times 4❒ Often

2. I saw strangers who were drunk or high hanging out near my home. [CITY2]
   1❒ Never 2❒ Once 3❒ A few times 4❒ Often

3. I heard adults arguing loudly on my street. [CITY3]
   1❒ Never 2❒ Once 3❒ A few times 4❒ Often

4. There was a gang fight near my home. [CITY4]
   1❒ Never 2❒ Once 3❒ A few times 4❒ Often

Perceived Stress Scale (PSS)

(Cohen, Kamarck, & Mermelstein, 1983; Cohen & Williamson, 1988)

Instructions: The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate how often you felt or thought a certain way.

0 = Never
1 = Almost never
2 = Sometimes
3 = Fairly often
4 = Very often

1. In the last 30 days, how often have you felt that you were unable to control the important things in your life? [PSS1]
2. In the last 30 days, how often have you felt confident about your ability to handle your personal problems? [PSS2]
3. In the last 30 days, how often have you felt that things were going your way? [PSS3]
4. In the last 30 days, how often have you felt difficulties were piling up so high that you could not overcome them? [PSS4]

HIV-Related Social and Health Stressors
(Adapted from Kalichman & Grebler, 2010)

Instructions. Listed below are stressful life events that people living with HIV have experienced. For each event listed, please indicate if you have experienced this event in the past three months.

Note: The following questions will be asked for each of the 16 experiences listed below:

1. Friend was seriously ill [HVSTR1]
2. Tried to meet new people [HVSTR2]
3. Experienced discrimination [HVSTR3]
4. Disclosed HIV to family [HVSTR4]
5. Disclosed HIV to friend [HVSTR5]
6. Disclosed HIV to sex partner [HVSTR6]
7. Started new relationship [HVSTR7]
8. Ended a relationship [HVSTR8]
9. Change in viral load [HVSTR9]
10. Change in CD4 count [HVSTR10]
11. Started new medication [HVSTR11]
12. Had a serious illness [HVSTR12]
13. Hospitalized [HVSTR13]
14. Change in health [HVSTR14]
15. Changed doctor [HVSTR15]
16. Change in appearance [HVSTR16]

1. Have you experienced this event (_____) in the past 3 months? [HVSTR1]
   0□ No (Skip to 2) 1□ Yes (Go to 1a)

1a. How much stress did this event (_____) cause you in the past 3 months? [HVSTR1A]
   0□ No stress
   1□ A little stress
   2□ Some stress
   3□ A lot of stress

Shift and Persist Questionnaire
(Chen, Lee, Cavey, & Ho, 2013)

(Adapted from Connor-Smith, Compas, Wadsworth, Thomsen, and Saltzman, 2000)

Below you will see a list of things that people sometimes do, think, or feel when something stressful happens. Everybody deals with problems in their own way. Please rate how much you do each of the following things when something stressful happens in your life:

1 = Never
2 = Sometimes
3 = Usually
4 = Always

1. I tell myself that I can get through it, or that I will do better next time. [SHIFT1]
2. I tell myself that everything will be all right. [SHIFT2]
3. I think of ways to laugh about it so it doesn't seem so bad. [SHIFT3]

(Adapted from Scheier, Carver, and Bridges, 1994)

Next, please rate how strongly you agree with each of the following statements:

1 = Strongly disagree
2 = Disagree
3 = Neither agree or disagree
4 = Agree
5 = Strongly agree

4. In uncertain times, I usually expect the best. [SHIFT4]
5. If something can go wrong for me, it will. [SHIFT5]
6. I'm always optimistic about my future. [SHIFT6]
7. I hardly ever expect things to go my way. [SHIFT7]
8. I rarely count on good things happening to me. [SHIFT8]
9. Overall, I expect more good things to happen to me than bad. [SHIFT9]

HIV-related Stigma Experiences
(Adapted from Earnshaw et al., 2013)

Instructions. We are interested in your perspective on the stigma associated with having HIV. Please tell us how much you AGREE or DISAGREE with each statement by checking the response that best fits for you. There is no right or wrong answer. We are interested in your personal experiences.

1❑ Strongly disagree
2❑ Disagree
3❑ Neither disagree nor agree
4❑ Agree
5❑ Strongly agree

1. Having HIV makes me feel like I'm a bad person. [INTSTIG1]
2. I feel I'm not as good as others because I have HIV. [INTSTIG2]
3. I feel ashamed of having HIV. [INTSTIG3]
4. I think less of myself because I have HIV. [INTSTIG4]
5. Having HIV makes me feel unclean. [INTSTIG5]
6. Having HIV is disgusting to me. [INTSTIG6]

Instructions. Now we'd like to know how likely you think it is that people you know will treat you certain ways **in the future** because of your HIV status.

1❑ Very unlikely
2❑ Unlikely
3❑ Neither unlikely nor likely
4❑ Likely
5❑ Very likely

1. People will avoid me. [ANTSTIG1]
2. People will look down on me. [ANTSTIG2]
3. People will treat me differently. [ANTSTIG3]
4. People won't take my needs seriously. [ANTSTIG4]
5. People will discriminate against me. [ANTSTIG5]
6. People will not listen to me. [ANTSTIG6]
7. People will feel uncomfortable around me. [ANTSTIG7]
8. People will treat me with less respect. [ANTSTIG8]
9. People will reject me. [ANTSTIG9]

Instructions. Now we'd like to know how often people have treated you certain ways **in the past** because of your HIV status. This means experiences that have already happened to you.

1❑ Never
2❑ Not often
3❑ Somewhat often

4❑ Often
5❑ Very often

1. People have avoided me. [ENSTIG1]
2. People have looked down on me. [ENSTIG2]
3. People have treated me differently. [ENSTIG3]
4. People haven't taken my needs seriously. [ENSTIG4]
5. People have discriminated against me. [ENSTIG5]
6. People have not listened to me. [ENSTIG6]
7. People have felt uncomfortable around me. [ENSTIG7]
8. People have treated me with less respect. [ENSTIG8]
9. People have rejected me. [ENSTIG9]

Beliefs about Viral Load and Infectiousness
(Kalichman et al., 2010; Vanable et al., 2003)

Instructions. Please indicate to what extent you agree with the following statements.

1 ❑Strongly disagree
2 ❑Disagree
3 ❑Somewhat disagree
4 ❑Somewhat agree
5 ❑Agree
6 ❑Strongly agree

1. People with HIV who take HIV medications are less likely to infect their sex partners during unsafe sex. [INFECT1]
2. It is safe to have sex without a condom with an undetectable viral load. [INFECT2]
3. An HIV+ person with an undetectable viral load is unlikely to transmit HIV to a sex partner. [INFECT3]
4. HIV treatments make it easier to relax about unsafe sex. [INFECT4]

Talking about your Health

To what extent have you told the following people about your HIV status?

	Disclosed HIV status to:	0 Told **none** of them	1 Told **some** of them	2 Told **all** of them	3 Does not apply
1.	Parent(s) [DISC1]	☐	☐	☐	☐
2.	Brothers or sisters(s) [DISC2]	☐	☐	☐	☐
3.	Primary partner or spouse [DISC3]	☐	☐	☐	☐
4.	Other sexual partner(s) [DISC4]	☐	☐	☐	☐
5.	Children [DISC5]	☐	☐	☐	☐
6.	Extended family (e.g., cousins, Aunts and uncles) [DISC6]	☐	☐	☐	☐
7.	Closest friend(s) [DISC7]	☐	☐	☐	☐
8.	Other friends [DISC8]	☐	☐	☐	☐
9.	People at work [DISC9]	☐	☐	☐	☐
10.	Landlord [DISC10]	☐	☐	☐	☐
11.	Sexual partners who are HIV-negative [DISC11]	☐	☐	☐	☐
12.	Sexual partners who are HIV-positive [DISC12]	☐	☐	☐	☐
13.	Health care provider(s) [DISC13]	☐	☐	☐	☐
14.	Neighbors [DISC14]	☐	☐	☐	☐

Concerns about Inadvertent Disclosure of HIV Status

Instructions. Next, you will read statements that other people living with HIV have felt about being HIV+. Please tell us how much you AGREE or DISAGREE with each statement by checking the response that best fits for you. There are no right or wrong answers. Please tell us how you really feel about your HIV status.

1❑ Strongly disagree
2❑ Disagree
3❑ Neither disagree nor agree
4❑ Agree
5❑ Strongly agree

1. I am often concerned about the possibility that others will find out I'm HIV+. [DISCCON1]
2. I work hard to keep my HIV a secret. [DISCCON2]
3. I worry a lot about others finding out I'm HIV+. [DISCCON3]
4. I never feel I need to hide the fact that I have HIV. [DISCCON4]
5. I am very careful whom I tell that I have HIV. [DISCCON5]
6. I worry people who know I have HIV/AIDS will tell others. [DISCCON6]
7. I told people close to me to keep my HIV/AIDS a secret. [DISCCON7]
8. In many areas of my life, no one knows that I have HIV/AIDS. [DISCCON8]
9. Telling someone I have HIV/AIDS is risky. [DISCCON9]

Medical Outcomes Study Social Support Survey (MOS-SSS)
(Hayes, Sherbourne, & Mazel, 1995; Moser et al., 2012)

People sometimes look to others for companionship, assistance, or other types of support. Please indicate how often each of the following kinds of support is available to you if you need it.

1 = None of the time
2 = A little of the time
3 = Some of the time
4 = Most of the time
5 = All of the time

1. Someone to help you if you were confined to bed. [SOCSUP1]
2. Someone to take you to the doctor if you needed it. [SOCSUP2]
3. Someone to prepare your meals if you were unable to do it yourself. [SOCSUP3]
4. Someone to help with daily chores if you were sick. [SOCSUP4]
5. Someone to have a good time with. [SOCSUP5]
6. Someone to turn to for suggestions about how to deal with a personal problem. [SOCSUP6]
7. Someone who understands your problems. [SOCSUP7]
8. Someone to love and make you feel wanted. [SOCSUP8]

Beliefs about Medicines Questionnaire (BMQ)
(Horne, 1999; Horne et al., 2004; Horne et al., 2007)

(CURRENT HAART USERS)

Instructions. Next, you will hear statements that other people living with HIV have made about HIV meds. Please tell us how much you AGREE or DISAGREE with each statement by checking the response that best fits for you.

1 ❑Strongly Disagree
2 ❑Disagree
3 ❑Somewhat disagree
4 ❑Somewhat agree
5 ❑Agree
6 ❑Strongly Agree

1. My health depends on HIV medications. [BMQ1]
2. Without HIV meds, I would become very ill. [BMQ2]
3. My health in the future will depend on HIV medications. [BMQ3]
4. HIV medications are a mystery to me. [BMQ4]
5. Having to take HIV meds worries me. [BMQ5]
6. I sometimes worry about the long-term effects of HIV medications. [BMQ6]
7. HIV medications disrupt my life. [BMQ7]
8. I sometimes worry about becoming too dependent on HIV medications. [BMQ8]
9. My life would be impossible without HIV meds. [BMQ9]
10. HIV meds protect me from becoming worse. [BMQ10]

(NO MEDS CURRENTLY)

Instructions. Next, you will hear statements that other people living with HIV have made about HIV meds. Please tell us how much you AGREE or DISAGREE with each statement by checking the response that best fits for you. Even if you have never taken HIV medications, we want to know about your personal views of HIV meds and how you believe they would affect you if you were taking them.

1 ❑Strongly Disagree
2 ❑Disagree
3 ❑Somewhat disagree
4 ❑Somewhat agree
5 ❑Agree
6 ❑Strongly Agree

1a. My health depends on HIV medications. [BMQ1A]
2a. Without HIV meds, I would become very ill. [BMQ2A]
3a. My health in the future will depend on HIV medications. [BMQ3A]
4a. HIV medications are a mystery to me. [BMQ4A]
5a. Having to take HIV meds worries me. [BMQ5A]
6a. I sometimes worry about the long-term effects of HIV medications. [BMQ6A]

7a. Taking HIV medications would disrupt my life. [BMQ7A]
8a. I sometimes worry that I will become too dependent on HIV medications. [BMQ8A]
9a. My life would be impossible without HIV meds. [BMQ9A]
10a. HIV meds would protect me from becoming worse. [BMQ10A]

HIV Adherence Self-Efficacy Scale (ASES)

Instructions. We are going to ask you about situations that could occur during your treatment for HIV. In these questions, we are only talking about medications that you might be taking for HIV. We will ask you to tell us in **the past 30 days, including today,** how confident you have been that you can do the following things. Use this response scale ranging from 0 ("cannot do at all") to 10 ("completely certain can do").

Cannot do at all	0
	1
	2
	3
	4
Moderately certain can do	5
	6
	7
	8
	9
Completely certain can do	10

In the past 30 days, how confident have you been that you can:

1. Stick to your medication regimen even when side effects begin to interfere with daily activities? [EFFIC1]
2. Integrate your medication regimen into your daily routine? [EFFIC2]
3. Integrate your medication regimen into your daily routine even if it means taking medication or doing other things in front of people who don't know you are HIV-infected? [EFFIC3]
4. Stick to your medication schedule even when your daily routine is disrupted? [EFFIC4]
5. Stick to your medication schedule when you aren't feeling well? [EFFIC5]
6. Stick to your medication schedule when it means changing your eating habits? [EFFIC6]
7. Continue with your medication regimen even if doing so interferes with daily activities? [EFFIC7]
8. Continue with the medication plan your physician prescribed even if your T-cells drop significantly in the next three months? [EFFIC8]
9. Continue with your medication plan even when you are feeling discouraged about your health? [EFFIC9]
10. Continue with your medication plan even when getting to your clinic appointments is a major hassle? [EFFIC10]
11. Continue with your medication plan even when people close to you tell you that they don't think that it is doing any good? [EFFIC11]
12. Get something positive out of your participation in treatment, even if the medication you are taking does not improve your health? [EFFIC12]

Experiences with HIV medications

Instructions. People have a variety of experiences taking HIV medications. Please answer each of the following related to your experiences.

1. I disguise my HIV medications, so that others won't see them. [MEDEXP1]
   1❑Never 2❑Not often 3❑Somewhat often 4❑Often 5❑Very often

2. I tell a white lie about what type of medication I am taking if someone asks. [MEDEXP2]
   1❑Never 2❑Not often 3❑Somewhat often 4❑Often 5❑Very often

3. I hide my HIV medications, so that others won't see them. [MEDEXP3]
   1❑Never 2❑Not often 3❑Somewhat often 4❑Often 5❑Very often

4. I remove myself from social situations to take medications. [MEDEXP4]
   1❑Never 2❑Not often 3❑Somewhat often 4❑Often 5❑Very often

5. I plan the events in my day around when I have to take medications. [MEDEXP5]
   1❑Never 2❑Not often 3❑Somewhat often 4❑Often 5❑Very often

HIV Medication Adherence

Instructions. The next questions will ask about your HIV medications. We understand that there are many challenges to taking HIV medications, and that many people struggle to take their pills as prescribed. Telling us about your actual experiences with HIV medications will help us to get a better understanding of what is needed to improve HIV care. Please answer honestly and do not worry about telling us that you don't take your pills perfectly. Your answers are confidential.

1. *Since you were diagnosed*, has your doctor or nurse practitioner ever recommended that you start taking HIV meds and you decided that it was not the right time for you? [MED1]
❑0 No (skip to **#2**) ❑1Yes

1a. On how many separate occasions has your doctor or nurse practitioner discussed the need for you to begin HIV meds and you decided not to? [MED1A]
#_____

2. *Since you first started taking HIV meds*, have you ever **stopped** taking one or more of your meds for any reason? ❑0 No (skip to **#3**) ❑1Yes [MED2]

2a. On how many separate occasions have you stopped taking one or more of your HIV meds for more than a day? [MED2A] #_____

2b. On how many of these occasions was your decision to stop based on a recommendation from your HIV doctor? [MED2B] #_____

3. Some people we have talked to say that they sometimes take "medication vacations" – meaning that they deliberately decide to take a break from taking some or all of their medication for a period of time. *Since you first started taking HIV meds*, have you ever deliberately taken a break from your meds, even for just one day? [MED3] ❑0 No (Skip to #4a) ❑1 Yes

3a. How many separate times have you deliberately taken a break from your HIV meds for one or more days? [MED3A] #_____

Instructions. Some people we have talked to say that sometimes they deliberately make small adjustments to how they take their HIV medications for a variety of reasons.

4a. *Since you started taking HIV medications, have you ever...* ...taken less of a medication than was prescribed? [MED4A] ❑0 No ❑1 Yes

4b. *Since you started taking HIV medications, have you ever...* ...taken a medication dose significantly later than you had scheduled? [MED4B] ❑0 No ❑1 Yes

4c. *Since you started taking HIV medications, have you ever...* ...taken two doses at the same time to make up for a previous missed dose? [MED4C] ❑0 No ❑1 Yes

4d. *Since you started taking HIV medications, have you ever...* ...skipped the special

instructions for your medication, like “with meals”, “on an empty stomach”, “every 8 hours”, or “with plenty of fluids” [MED4D] ❑0 No ❑1 Yes

(Global Adherence Question) Instructions

Please think about your medication over the past seven days.

5a. How many pills are you supposed to take on DAY 1 (yesterday)? [MED5A]
5b. Day 2 (day before yesterday) [MED5B]
5c. Day 3 [MED5C]
5d. Day 4 [MED5D]
5e. Day 5 [MED5E]
5f. Day 6 [MED5F]
5g. Day 7 [MED5G]

Now, remember that you just filled in the number of pills that you are supposed to take for your HIV for each day in the past week.

6a. How many of your pills did you forget to take OR decide to skip on DAY 1 (yesterday)? [MED6A]
6b. Day 2 (day before yesterday) [MED6B]
6c. Day 3 [MED6C]
6d. Day 4 [MED6D]
6e. Day 5 [MED6E]
6f. Day 6 [MED6F]
6g. Day 7 [MED6G]

Instructions. For the next question, please look at **HANDOUT A**. [MED7]

Put a mark on the line below at the point that shows your best guess about how much of your prescribed HIV medication you have taken **in the last month**. We would be surprised if this were 100% for most people.

For example: 0% means you have taken no medication
50% means you have taken half your medication
100% means you have taken every single dose of your medication

Instructions. For this question, please look at **HANDOUT B**. Again, there is a scale marked 0 to 100. [MED8]

Put a mark on the line below at the point that shows your best guess about **how often you have deliberately made small adjustments** in how you take your HIV meds over the **past month**. Making small adjustments could include taking more or less of a medication than prescribed, taking a medication at a different time than scheduled, taking two doses at the same time to make up for a missed dose, or skipping the special instructions for your medication. We would be surprised if this were 0% for most people.

For example: 0% means you never make small adjustments to your regimen
50% means you make small adjustments about half the time
100% means that you always make small adjustments to your regimen

Instructions. For this question, please look at the scale on **HANDOUT C**. [MED9]

Some people we have talked to say that they sometimes deliberately skip a dose of their HIV medication for personal reasons.

In the past month, HOW OFTEN have you deliberately skipped a dose of your HIV meds for personal reasons?

For example: 100% means you skipped every dose of your meds.
50% means that you skipped about half of your doses
0% means that you never skipped a dose in the past month

Instructions: For this question, please look at the scale on **HANDOUT D.** [MED10]

Some people we have talked to say that they sometimes forget a dose of their HIV medication.

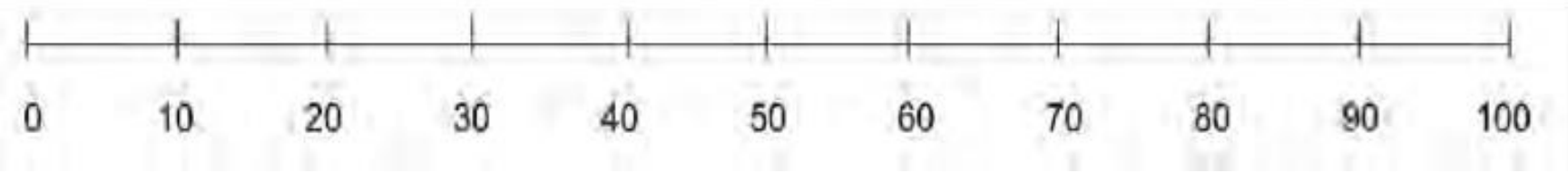
In the past month, HOW OFTEN have you forgotten a dose of your HIV meds?

For example: 100% means you forgot every dose of your meds.
50% means you forgot about half of your doses.
0% means that you never forgot a dose in the past month

HANDOUT A

Put a mark on the line below at the point that shows your best guess about how much of your prescribed HIV medication you have taken **in the last month**. We would be surprised if this were 100% for most people.

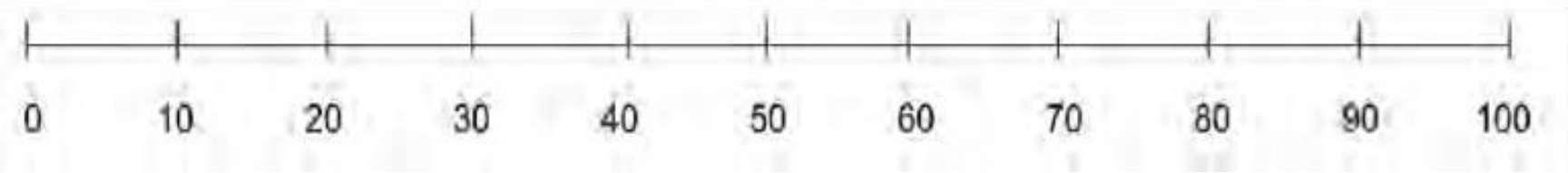
Examples: 0% means you have taken no medication
50% means you have taken half your medication
100% means you have taken every single dose of your medication



HANDOUT B

Put a mark on the line below at the point that shows your best guess about **how often you made small adjustments** in how you take your HIV meds **over the past month**. We would be surprised if this were 0% for most people.

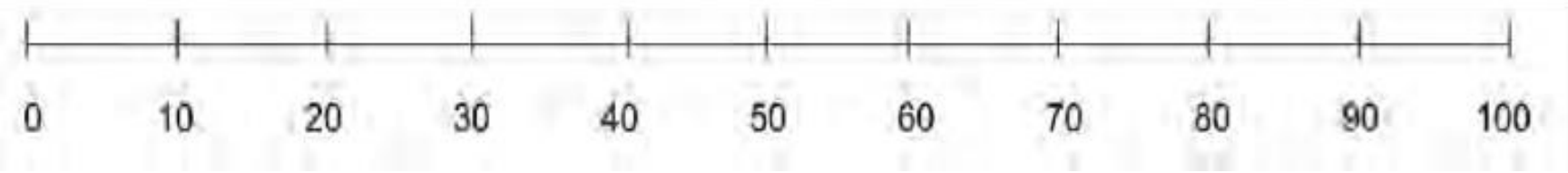
Examples: 0% means you never make small adjustments to your regimen
50% means you make small adjustments about half the time
100% means that you always make small adjustments to your regimen



HANDOUT C

Put a mark on the line below at the point that shows your BEST GUESS about **how often** in the **past month** you skipped a dose of your HIV meds because you were having side effects, had a change in your plans, or for some other reason. We would be surprised if this were 0% for most people.

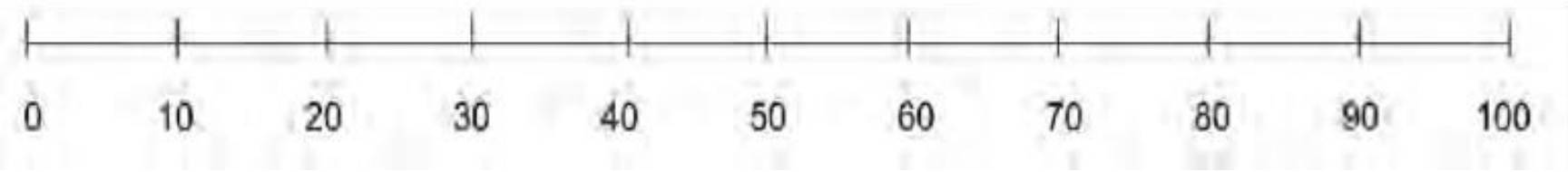
Examples: 100% means you skipped every dose of your meds.
50% means that you skipped about half of your doses
0% means that you never skipped a dose in the past month



HANDOUT D

Put a mark on the line below at the point that shows your BEST GUESS about **how often** in the **past month** you forgot to take a dose of your HIV meds. We would be surprised if this were 0% for most people.

Examples: 100% means you skipped every dose of your meds.
50% means that you skipped about half of your doses
0% means that you never skipped a dose in the past month



HANDOUT E [SES1]

Think of this ladder as representing where people stand in their communities.

People define community in different ways; please define it in whatever way is most meaningful to you. At the **top** of the ladder are the people who have the highest standing in their community. At the **bottom** are the people who have the lowest standing in their community.

Where would you place yourself on this ladder?

Please place a large **"X"** on the rung where you think you stand at this time in your life, relative to other people in your community.

HANDOUT F [SES2]

Think of this ladder as representing where people stand in the United States.

At the **top** of the ladder are the people who are the best off – those who have the most money, the most education and the most respected jobs. At the **bottom** are the people who are the worst off – who have the least money, least education, and the least respected jobs or no job. The higher up you are on this ladder, the closer you are to the people at the very top; the lower you are, the closer you are to the people at the very bottom.

Where would you place yourself on this ladder?

Please place a large **"X"** on the rung where you think you stand at this time in your life, relative to other people in the United States.

Tobacco, Alcohol, and Drug Use

Instructions. You will answer some questions about your experiences with smoking, alcohol, and other drugs. By **alcoholic beverages**, we mean beer, wine, or hard liquor. When we say **a drink**, we mean 12 oz. of beer, 6 oz. of malt liquor, 4 to 5 oz. of wine (a glass), or 1 to 1.5 oz. of hard liquor (a shot).

1. During the **past 30 days**, on how many days did you smoke cigarettes? [TAD1] _____ days
☐ If 0 days, skip to #2

1a. During the **past 30 days**, on the days you smoked, how many cigarettes did you smoke? [TAD1A] _____ cigarettes per day

1b. For how many years have you been smoking? [TAD1B]
_____years [TAD1BY] _____months [TAD1BM]

1c. How soon after you wake up do you smoke your first cigarette? [TAD1C]
1☐Within 5 minutes 2☐6-30 minutes 3☐31-60 minutes 4☐After 60 minutes

1d. Are you currently trying to quit smoking or using any treatments to help you quit smoking? By treatment, we mean seeing a counselor or therapist, attending a quit smoking program, or using a smoke cessation medication like nicotine patches, gum, bupropion, or Varenicline. Check all that may apply. [TAD1D]
☐No [TAD1DA]
☐Yes, using medication [TAD1DB] → 1e. What type of medication? [TAD1E] _____
☐Yes, seeing counselor or therapist [TAD1DC]
☐Yes, attending a smoking cessation program [TAD1DD]

2. During the **past 30 days**, on how many days did you have at least one drink of alcohol? [TAD2] _____ days ☐ If 0 days, skip to #3

2a. On days when you drank, about how many drinks did you drink on the average? [TAD2A] _____ drinks

2b. *If female:* How many times during the **past 30 days** did you have 4 or more drinks on one occasion? [TAD2B] _____ times

2c. *If male:* How many times during the **past 30 days** did you have 5 or more drinks on one occasion? [TAD2C] _____ times

3. Have you ever used cocaine or crack (ready rock, rock)? [TAD3]
0☐ No (Skip to #4) 1☐ Yes

3a. In the **past 30 days**, on how many days did you use cocaine or crack (ready rock, rock)? [TAD3A] _____ days

4. Have you ever used speed/uppers, or methamphetamine? [TAD4]
0☐ No (Skip to #5) 1☐ Yes

4a. In the **past 30 days**, on how many days did you use speed/uppers, or methamphetamine? [TAD4A] _____ days

5. Have you ever used marijuana (pot, weed, grass, herb, reefer)? [TAD5]
0☐ No (Skip to #6) 1☐ Yes

5a. In the **past 30 days**, on how many days did you use marijuana (pot, weed, grass, herb, reefer)? [TAD5A] _____ days.

6. Have you ever used inhalants such as amyl nitrate, called "poppers," "rush," or "locker room?" [TAD6] 0☐ No (Skip to #7) 1☐ Yes

6a. In the **past 30 days**, on how many days did you use such inhalants (poppers, rush, etc)? [TAD6A] _____ days.

7. Have you ever used heroin (smack, junk, dope)? [TAD7]
0☐ No (Skip to #8) 1☐ Yes

7a. In the **past 30 days**, on how many days did you use such heroin (smack, junk, dope)? [TAD7A] _____ days.

8. Have you ever shared needles to inject drugs? [TAD8]
0☐ No (Skip to next section) 1☐ Yes

8a. In the **past 30 days**, with how many people did you share needles? [TAD8A]
_____ people

Alcohol Use Disorders Identification Test (AUDIT)

Instructions. You will now answer more questions about your use of alcoholic beverages **during the past year**. In the last year..

1. How often do you have a drink containing alcohol? [AUDIT1]
0☐ Never (Skip to next section)
1☐ Monthly or less
2☐ 2-4 times per month
3☐ 2-3 times per week
4☐ >4 times per week

2. How many drinks containing alcohol do you have on a typical day when you are drinking? [AUDIT2]
0☐ 1 or 2
1☐ 3 or 4

2☐ 5 or 6
3☐ 7 to 9
4☐ >10

3. How often do you have 6 or more drinks on one occasion? [AUDIT3]
0☐ Never
1☐ Less than monthly
2☐ Monthly
3☐ Weekly
4☐ Daily or almost daily

4. How often during the last year have you found that you were not able to stop drinking once you had started? [AUDIT4]
0☐ Never
1☐ Less than monthly
2☐ Monthly
3☐ Weekly
4☐ Daily or almost daily

5. How often during the last year have you failed to do what was normally expected of you due to drinking? [AUDIT5]
0☐ Never
1☐ Less than monthly
2☐ Monthly
3☐ Weekly
4☐ Daily or almost daily

6. How often during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session? [AUDIT6]
0☐ Never
1☐ Less than monthly
2☐ Monthly
3☐ Weekly
4☐ Daily or almost daily

7. How often during the last year have you had a feeling of guilt or remorse after drinking? [AUDIT7]
0☐ Never
1☐ Less than monthly
2☐ Monthly
3☐ Weekly
4☐ Daily or almost daily

8. How often during the last year have you been unable to remember what happened the night before because you had been drinking? [AUDIT8]
0☐ Never

1☐ Less than monthly
2☐ Monthly
3☐ Weekly
4☐ Daily or almost daily

9. Have you or someone else been injured as a result of your drinking? [AUDIT9]
0☐ No
1☐ Yes, but not in the past year
2☐ Yes, in the past year

10. Has a relative, friend, doctor, or other health worker been concerned about your drinking or suggested you cut down? [AUDIT10]
0☐ No
1☐ Yes, but not in the past year
2☐ Yes, in the past year

Drug Abuse Screening Test (DAST)

Instructions. In these next few questions, when we talk about "drugs" and "drug use", we mean the use of any street drugs or the use of prescribed or over the counter drugs in excess of the directions or for any non-medical reasons. These questions only refer to drugs, not alcohol. For all of these questions, please think ONLY about your drug use in the LAST YEAR. Please remember that your responses will be kept confidential and will NOT be seen by your doctor or other clinic staff. In the last year…

1. Have you used drugs other than those required for medical reasons? [DAST1]
0☐ No (skip to next section) 1☐ Yes

2. Did you abuse more than 1 drug at a time? [DAST2]
0☐ No 1☐ Yes

3. Were you always able to stop using drugs when you want to? [DAST3]
0☐ No 1☐ Yes

4. Have you had “blackouts” or “flashbacks” as a result of drug use? [DAST4]
0☐ No 1☐ Yes

5. Did you ever feel bad or guilty because of your use of drugs? [DAST5]
0☐ No 1☐ Yes

6. Did your partner or family ever complain about your involvement with drugs? [DAST6]
0☐ No 1☐ Yes

7. Have you neglected your family because of your use of drugs? [DAST7]
0☐ No 1☐ Yes

8. Have you engaged in illegal activities in order to obtain drugs? [DAST8]

0□ No 1□ Yes

9. Did you ever experience withdrawal symptoms (felt sick) when you stopped taking drugs? [DAST9]

0□ No 1□ Yes

10. Have you had medical problems as a result of your drug use (e.g., memory loss, hepatitis, convulsions, bleeding)? [DAST10]

0□ No 1□ Yes

Chronic Pain

Instructions: Next, we would like to ask you some questions about any pain you might be experiencing.

1. How much bodily pain have you had during the past 4 weeks? [PAIN1]

0□ = None
1□ = Mild
2□= Moderate
3□= Severe
4□= Very severe

2. Do you currently suffer from any type of chronic pain, that is, pain that occurs constantly or flares up frequently? Do not report aches or pains that are fleeting or minor. [PAIN2]

0□ No (Skip to next section) 1□ Yes (Continue to #2a)

2a. During the past 3 months, on average, how would you rate your pain? Indicate on the scale below, where 0 is "no pain" and 10 is "pain as bad as could be." [PAIN2A]

0 (no pain) –1—2—3—4—5—6—7—8—9—10 (pain as bad as could be)

Lifetime Sexual Behavior

Instructions. Next are some questions about sexual behavior. For the following questions, a *sexual partner* is someone you have had anal, oral, or vaginal sex with.

1. How many male sexual partners have you had in your lifetime? #_____ [LSEX1]

2. How many female sexual partners have you had in your lifetime? #_____ [LSEX2]

3. How many male sexual partners have you had in the last year? #_____ [LSEX3]

4. How many female sexual partners have you had in the last year? #_____ [LSEX4]

Since learning that you were HIV+….

5. Since learning that you were HIV+, how many partners have you had sex with? [LSEX5] # _____
   If "0 partners," SKIP questions 6-8.

6. Considering all the partners you have had sex with since learning that you were HIV+, how many of those partners did you disclose your HIV status to before having sex with them for the first time? [LSEX6] #_____

7. Since learning that you were HIV+, how many different partners have you had unprotected anal or vaginal sex with (even just one time), where you were unsure of the partner's HIV-status or the partner was HIV-negative? [LSEX7] #_____

8. Since learning that you were HIV+, how many HIV+ partners have you had unprotected vaginal or anal sex with (even just one time)? [LSEX8] #_____

Sexual Behavior with your Primary Partner, Last 3 Months

1. Have you been in a steady or primary relationship within the last 3 months? A primary relationship involves someone you are emotionally close to and have sex with regularly. [STPART1]

0☐ no.... **skip to the next section**

1☐ yes ⟶ 2. What is the gender of your partner? [STPART2]
1☐female 2☐ male 3☐transgender

3. How long have you been seeing this person? [STPART3]
___ years [STPART3Y] ___ months [STPART3M]

With your steady partner, how many times did you engage in each of the following behaviors in the last 3 months? **NOTE: these questions refer to the last 3 months.**

4. How many times did you give or receive oral sex without a condom: [STPART4] #_____

5. How many times did you give or receive oral sex with a condom: [STPART5] #_____

6. How many times did you have receptive anal sex (you were the bottom) without a condom**:** [STPART6] #_____

7. How many times did you have receptive anal sex (you were the bottom) with a condom: [STPART7] #_____

8. How many times did you have insertive anal sex (you were the "top") without a condom: [STPART8] #_____

9. How many times did you have insertive anal sex (you were the "top") with a condom: [STPART9] #_____

10. How many times did you have vaginal sex without a condom: [STPART10] #_____

11. How many times did you have vaginal sex with a condom: [STPART11] #_____

12. Have you disclosed your HIV status to your steady partner? [STPART12]
0 ☐ No 1☐ Yes

13. What is your primary partner's HIV status? [STPART13]
1☐ I'm not sure 2☐ HIV-negative 3☐ HIV-positive

Sexual Behavior with Non-steady Partners, Last 3 Months

1. How many men other than a steady partner have you had oral or anal sex with in the past 3 months? [NSPART1] #_____**men**

2. How many women other than a steady partner have you had oral or anal sex with in the past 3 months? [NSPART2] #_____**women**

If 0 for both #1 and #2 → Skip to "Most Recent Sexual Experience" section

3. Have any of your NON-STEADY partners in the LAST THREE MONTHS been HIV-negative or of unknown HIV status? [NSPART3]

0 ☐No (skip to question #13)
1 ☐Yes

Thinking only of these non-steady partners who were of unknown HIV status or HIV-negative…

4. How many times did you give or receive oral sex without a condom: [NSPART4] #_____

5. How many times did you give or receive oral sex with a condom: [NSPART5] #_____

6. How many times did you have receptive anal sex (you were the bottom) without a condom: [NSPART6] #_____

7. How many times did you have receptive anal sex (you were the bottom) with a condom: [NSPART7] #_____

8. How many times did you have insertive anal sex (you were the "top") without a condom: [NSPART8] #_____

9. How many times did you have insertive anal sex (you were the "top") with a condom: [NSPART9] #_____

10. How many times did you have vaginal sex without a condom: [NSPART10] #_____

11. How many times did you have vaginal sex with a condom: [NSPART11] #_____

12. How many of these non-steady partners have you disclosed your HIV status to? [NSPART12] _____ partners.

13. Have any of your NON-STEADY partners in the last three months been **HIV+?** [NSPART13]

0☐No (skip to "Most Recent Sexual Experience" section)

1☐Yes

Thinking only of these non-steady partners who were HIV+ in the last three months …

14. How many times did you give or receive oral sex without a condom: [NSPART14] #_____

15. How many times did you give or receive oral sex with a condom: [NSPART15] #_____

16. How many times did you have receptive anal sex (you were the bottom) without a condom: [NSPART16] #_____

17. How many times did you have receptive anal sex (you were the bottom) with a condom: [NSPART17] #_____

18. How many times did you have insertive anal sex (you were the "top") without a condom: [NSPART18] #_____

19. How many times did you have insertive anal sex (you were the "top") with a condom: [NSPART19] #_____

20. How many times did you have vaginal sex without a condom: [NSPART20] #_____

21. How many times did you have vaginal sex with a condom: [NSPART21] #_____

22. How many of these non-steady partners have you disclosed your HIV status to? [NSPART22] _____ partners

Most Recent Sexual Experience

For questions on this page, please think of **the most recent time** you had a sexual experience with a man or woman.

1. Was your partner a… [RSEX1]
   1 ☐ Primary or "steady" partner
   2 ☐ someone you knew well but not a steady partner
   3 ☐ a casual acquaintance or anonymous partner
   4 ☐ other

2. Approximately when did this sexual experience occur? [RSEX2]
   _____years [RSEXY] _____month [RSEX2M]

3. What was the gender of this partner? [RSEX3]
   1 ☐ Female 2 ☐ Male 3 ☐ Transgender

4. At the time, did you....

   4a1. Have insertive anal sex (you were the "top")? [RSEX4A1]
   0 ☐ No 1 ☐ Yes

   4a2. Use a condom from the beginning until the end of anal sex? [RSEX4A2]
   0 ☐ No 1 ☐ Yes

   4b1. Have receptive anal sex (you were the "bottom")? [RSEX4B1]
   0 ☐ No 1 ☐ Yes

   4b2. Use a condom from the beginning until the end of anal sex? [RSEX4B2]
   0 ☐ No 1 ☐ Yes

   4c1. Give or receive oral sex? [RSEX4C1]
   0 ☐ No 1 ☐ Yes

   4c2. Use a condom from the beginning until the end of oral sex? [RSEX4C2]

0 ☐ No 1 ☐ Yes

4d1. Have vaginal sex? [RSEX4D1]
0 ☐ No 1 ☐ Yes

4d2. Use a condom from the beginning until the end of vaginal sex? [RSEX4D2]
0 ☐ No 1 ☐ Yes

4e1. Disclose your HIV status? [RSEX4E1]
0 ☐ No 1 ☐ Yes 2☐Partner already knew my HIV status

5. How many drinks did you have just before or during sex with this partner? [RSEX5] # _____

6. What drugs were you using? Check all that apply. [RSEX6]
☐Marjiuana [RSEX6A]
☐Cocaine [RSEX6B]
☐Poppers [RSEX6C]
☐Other drugs [RSEX6D]
☐None [RSEX6E]

7. How aroused were you feeling just before or during sex? [RSEX7]
Not at all 1 2 3 4 5 6 7 A lot

8. To what extent were you feeling depressed just before or during sex? [RSEX8]
Not at all 1 2 3 4 5 6 7 A lot

9. How loved were you feeling just before or during sex? [RSEX9]
Not at all 1 2 3 4 5 6 7 A lot

10. To what extent were you feeling disgusted or ashamed before or during sex? [RSEX10]
Not at all 1 2 3 4 5 6 7 A lot

11. How thrilled were you feeling just before or during sex? [RSEX11]
Not at all 1 2 3 4 5 6 7 A lot

12. Was your sexual partner using any alcohol before or during sex? [RSEX12]
0 ☐ No 1 ☐ Yes 2☐Not sure

13. Was your sexual partner using any drugs before or during sex? [RSEX13]
0 ☐ No 1 ☐ Yes 2☐Not sure

14. What was your partner's HIV status? [RSEX14]
1☐I'm not sure 2☐HIV-negative 3☐HIV-positive

Substance Use and Sexual Behavior

1. Have you had oral, vaginal, or anal sex in the past 3 months? [SUBSEX1]

0 ☐ No (Skip to next section) 1 ☐ Yes

0 ☐ Never
1 ☐ Rarely
2 ☐ Sometimes
3 ☐ About half
4 ☐ Most times
5 ☐ Nearly all times
6 ☐ Every time

In the last three months, how often have you…

2. …used any amount of alcohol before or during sex? [SUBSEX2]
3. …used marijuana before or during sex? [SUBSEX3]
4. …used cocaine (powder or crack) before or during sex? [SUBSEX4]
5. …injected drugs before or during sex? [SUBSEX5]
6. …used poppers before or during sex? [SUBSEX6]
7. …used other drugs not listed above before or during sex? [SUBSEX7]
8. …used a condom during sex? [SUBSEX8]
9. …discussed condom use or safer sex? [SUBSEX9]

General Health Behaviors

(Adapted from Project InSight Survey)

Instructions. We'd like to ask you some more questions about your health.

1. How would you describe your general health? [GENBEH1]

1☐ excellent 2 ☐very good 3☐ good 4☐ fair 5☐ poor

	Never	Seldom	Sometimes	Most days	Nearly every day	Every day
2. How often do you eat breakfast? [GENBEH2]	1	2	3	4	5	6
3. How often do you eat at least some vegetables? [GENBEH3]	1	2	3	4	5	6
4. How often do you eat at least some fruit? [GENBEH4]	1	2	3	4	5	6

5. How often do you do different physical activities (such as exercising, taking a walk, riding a bike, or playing a sport)? [GENBEH5]

1☐Never
2☐Seldom
3☐Sometimes
4☐Most days
5☐Nearly every day
6☐Every day

6. On an <u>average</u> day, how many hours do you watch TV or watch shows, movies or other content through Netflix or other internet-based service? [GENBEH6]

1☐ I do not watch TV on an average day
2☐ Less than 1 hour per day
3☐ 1 hour per day
4☐ 2 hours per day
5☐ 3 hours per day
6☐ 4 hours per day
7☐ 5 or more hours per day

7. On an <u>average</u> day, how many hours do you use a computer for something other than work? [GENBEH7]

1☐ I do not use a computer on an average day
2☐ Less than 1 hour per day
3☐ 1 hour per day
4☐ 2 hours per day
5☐ 3 hours per day
6☐ 4 hours per day
7☐ 5 or more hours per day

8. Do you own a smartphone? [GENBEH8]

0 ☐ No
1 ☐ Yes

9. How often do you get less sleep than you think you should? [GENBEH9]
1 ☐ Never
2 ☐ Seldom
3 ☐ Sometimes
4 ☐ Most days
5 ☐ Nearly every day
6 ☐ Every day

10. People sometimes feel tired during the daytime. During your daytime activities, how much of a problem do you have with tiredness (feeling sleepy, struggling to stay awake)? [GENBEH10]
1 ☐ No problem at all
2 ☐ A little problem
3 ☐ More than a little problem
4 ☐ A big problem
5 ☐ A very big problem

Life Expectancy and Perception of Health Risks

Instructions: Now we would like to ask you some more questions your perception of your health risks.

1. Think back to when you first received your HIV diagnosis. At that time, what did you expect your life expectancy to be compared to others in your community? [LIFE1]

1❑Much lower than average
2❑Lower than average
3❑About average
4❑Higher than average
5❑Much higher than average

2. At this current point in time, what do you expect your life expectancy to be compared to others in your community? [LIFE2]

1❑Much lower than average
2❑Lower than average
3❑About average
4❑Higher than average
5❑Much higher than average

How likely do you think your cause of death will be due to the following:

1❑Very unlikely
2❑Unlikely
3❑Neither unlikely nor likely
4❑Likely
5❑Very likely

3….*AIDS?* [LIFE3]
4….*Cardiovascular disease?* [LIFE4]
5…..*Alzheimer's disease?* [LIFE5]
6….*Diabetes-related?* [LIFE6]
7….*Cancer?* [LIFE7]

HIV Symptoms and HAART Side Effects
(*Justice et al., 2001*)

Instructions. We are interested in the types of physical problems that you have been experiencing. You will be asked to indicate whether you have had each of the problems in our list in the past 30 days and, if so, how much it has been bothering you in the past 30 days.

Note: The following questions will be asked for each of the 20 symptoms listed below:

1. Fatigue or loss of energy [SYMP1]
2. Fevers, chills, or sweats [SYMP2]
3. Feeling dizzy or lightheaded [SYMP3]
4. Pain, numbness, or tingling in the hands or feet [SYMP4]
5. Trouble remembering [SYMP5]
6. Nausea or vomiting [SYMP6]
7. Diarrhea or loose bowel movements [SYMP7]
8. Felt sad, down, or depressed [SYMP8]
9. Felt nervous or anxious [SYMP9]
10. Difficulty falling or staying asleep [SYMP10]
11. Skin problems, such as rash, dryness, or itching [SYMP11]
12. Cough or trouble catching your breath [SYMP12]
13. Headache [SYMP13]
14. Loss of appetite or a change in the taste of food [SYMP14]
15. Bloating, pain, or gas in your stomach [SYMP15]
16. Muscle aches or joint pain [SYMP16]
17. Problems with having sex, such as loss of interest or loss of satisfaction [SYMP17]
18. Changes in the way your body looks, such as fat deposits or weight gain [SYMP18]
19. Problems with weight loss or wasting [SYMP19]
20. Hair loss or changes in the way your hair looks [SYMP20]

1. Have you experienced _____ in the past 30 days? [SYMP1]
   0 No (Skip to #2) 1 Yes (Go to #1a)

1a. How much did _____ bother you in the past 30 days? [SYMP1A]
   1 It doesn't bother me
   2 It bothers me a little
   3 It bothers me a lot
   4 It bothers me terribly

Relationship Qualities

1. Do you have a primary close, romantic, or sexual partner? [RELAT1]
   0□ No (Skip to next section) 1□ Yes

Instructions. Now we'd like to know how much your partner helps with your medication. How often is each of the following kinds of support available to you from your partner if you need it?

1	2	3	4	5
Never	Seldom	Sometimes	Frequently	Always

2. Your partner reminds you to take your medications [RELAT2]
3. Your partner helps you to believe you can take my medications as prescribed [RELAT3]
4. Your partner checks in with you about your medications [RELAT4]

Attitudes toward Pre-Exposure Prophylaxis (PrEP)

1. Have you heard about pre-exposure prophylaxis, or PrEP? [PREP1]
0□ No 1□ Yes (Skip description of PrEP)

From CDC http://www.cdc.gov/hiv/prevention/research/prep/

"Pre-exposure prophylaxis, or PrEP, is a way to reduce risk for HIV infection for people who do not have HIV by taking a pill every day. The pill contains two medicines that are used in combination with other medicines to treat HIV. When someone is exposed to HIV through sex or injection drug use, these medicines can work to keep the virus from establishing a permanent infection."

(Adapted from Brooks et al., 2011)

Instructions. For the following questions, please imagine that you are in a relationship with a partner who is HIV-negative-- regardless of your current relationship status.

2. Imagine that you have an HIV-negative partner. Would you want your HIV-negative partner to take pre-exposure prophylaxis, or PrEP? [PREP2]
___0 NO ___1 YES
3. Would you trust that PrEP would work for your partner? [PREP3]
___0 NO ___1 YES
4. Would you be willing to talk to your partner about starting PrEP? [PREP4]
___0 NO ___1 YES
5. Do you think your partner would react negatively if you talked to him/her about PrEP? [PREP5]
___0 NO ___1 YES
6. Would you be willing to talk to a healthcare provider about starting your partner on PrEP? [PREP6]
___0 NO ___1 YES

Instructions. Continue to imagine that you have an HIV-negative partner. Now, imagine that your HIV-negative partner is currently taking PrEP.

7. Do you think your partner would take PrEP as often as prescribed? [PREP7]
___0 NO ___1 YES
8. Do you think your partner would experience any stigma or discrimination because he/she is taking PrEP? [PREP8]
___0 NO ___1 YES
9. Would you feel more protected from transmitting HIV to your partner? [PREP9]
___0 NO ___1 YES
10. Would you use condoms less with your partner? [PREP10]
___0 NO ___1 YES
11. Would you worry less about infecting your partner? [PREP11]
___0 NO ___1 YES

12. Would you and your partner engage in riskier sexual behavior (e.g., sex without a condom, anal sex) [PREP12]

___0 NO ___1 YES

13. Would you tell your friends that your partner was taking PrEP? [PREP13]

___0 NO ___1 YES

14. Would you be concerned about your partner's long-term health because of PrEP? [PREP14]

___0 NO ___1 YES

How often would you be willing to provide each of the following kinds of support to your HIV-negative partner on PrEP if they needed it?

1	2	3	4	5
Never	Seldom	Sometimes	Frequently	Always

15. I would remind my partner to take medications [PREP15]
16. I would help my partner to believe they can take their medications as prescribed [PREP16]
17. I would check in with my partner about their medications [PREP17]

Table 1

Descriptive Statistics for Continuous Predictors and Mediators

Predictor	*n*	Mean	*SD*	Median	Possible Range	Observed Range	Skewness	Kurtosis	Cronbach's α
Internalized stigma	205	2.49	1.11	2.33	1-5	1-5	0.43	-0.66	.91
Anticipated stigma	205	3.10	1.08	3.22	1-5	1-5	-0.18	-0.74	.95
Enacted stigma	205	2.45	1.16	2.22	1-5	1-5	0.37	-1.02	.96
Depressive symptoms	205	1.06	0.65	1.00	0-3	0-2.8	0.34	-0.66	.92
Disclosure concerns	205	3.44	1.05	3.63	1-5	1-5	-0.45	-0.52	.92

Table 2
Correlation Matrix for Predictors and Mediators (N=205)

	1	2	3	4	5
1. Internalized	1.0	.56†	.47†	.43†	.59†
2. Anticipated		1.0	.58†	.42†	.45†
3. Enacted			1.0	.47†	.28†
4. Depression				1.0	.19**
5. Disclosure concerns					1.0

*$p < .05$. **$p < .01$. †$p < .0001$.

Table 3
Relationship between Participant Characteristics and HIV Stigmas

	Internalized			Anticipated			Enacted		
	M(SD)	*r*	*F*	*M(SD)*	*r*	*F*	*M(SD)*	*r*	*F*
Demographic variables									
Age		-.08			-.15*			-.14	
Gender									
Female (n=77)	2.53 (1.13)		.28	3.03 (1.17)		.29	2.41 (1.22)		.08
Male (n=127)	2.46 (1.10)			3.14 (1.03)			2.48 (1.13)		
Transgender (n=1)	3.17 (n/a)			3.44 (n/a)			2.33 (n/a)		
Education									
< High school diploma (n=54)	2.39 (1.01)		.34	2.88 (1.07)		1.85	2.46 (1.16)		.39
Graduated high school (n=64)	2.55 (1.18)			3.27 (1.10)			2.54 (1.25)		
Some higher education (n=87)	2.51 (1.12)			3.11 (1.06)			2.37 (1.10)		
Employment									
No (n=137)	2.50 (1.10)		.02	3.11 (1.05)		.02	2.57 (1.11)		4.14*
Yes (n=68)	2.48 (1.13)			3.09 (1.16)			2.22 (1.23)		
Ethnicity									
Caucasian (n=86)	2.52 (1.17)		.09	3.13 (1.11)		.09	2.50 (1.17)		.25
Other races (n=119)	2.47 (1.07)			3.08 (1.06)			2.42 (1.16)		
Monthly Income		-.03			-.02			-.08	
Sexual Orientation									
Heterosexual (n=99)	2.59 (1.12)		1.40	3.20 (1.08)		1.58	2.47 (1.20)		.04
MSM/Bisexual/ Lesbian (n=106)	2.40 (1.10)			3.01 (1.08)			2.44 (1.13)		

	Internalized			Anticipated			Enacted		
	M(SD)	*r*	*F*	*M(SD)*	*r*	*F*	*M(SD)*	*r*	*F*
Health status variables									
Years since HIV diagnosis		-.16*			-.12			.07	
Viral load									
Undetectable (n=137)	2.50 (1.14)		.02	3.12 (1.06)		.10	2.51 (1.16)		.58
Detectable (n=31)	2.51 (1.14)			3.03 (1.02)			2.30 (1.14)		
Don't Know (n=37)	2.46 (0.10)			3.09 (1.21)			2.35 (1.19)		
Diagnosed with AIDS									
No (n=144)	2.52 (1.12)		.34	3.13 (1.07)		.38	2.43 (1.16)		.19
Yes (n=61)	2.42 (1.10)			3.03 (1.10)			2.50 (1.18)		
HIV transmission route									
Sex with a man (n=132)	2.45 (1.10)		.37	3.06 (1.11)		1.13	2.37 (1.16)		.78
Sex with a woman (n=23)	2.59 (1.22)			3.49 (0.83)			2.48 (1.22)		
Shared needles (n=18)	2.39 (1.06)			2.99 (0.99)			2.67 (1.07)		
Other/Don't Know (n=32)	2.65 (1.12)			3.05 (1.16)			2.66 (1.17)		
HIV treatment variables									
Duration of HIV medication use		-.13			-.13			.05	
# HIV pills per day		-.09			-.02			.06	

Table 4
Regression Analyses for HIV-Related Stigmas on Medication Adherence Outcomes

	Global adherence (month)			Global adherence (week)			Intentional		
	OR	95% CI	*p*	OR	95% CI	*p*	*B*	*SE*	*p*
Internalized	0.98	0.71-1.34	.89	0.90	0.62-1.31	.59	-0.004	0.10	.97
Anticipated	1.04	0.74-1.48	.82	1.32	0.88-1.97	.18	0.04	0.11	.70
Enacted	0.91	0.67-1.23	.53	0.92	0.64-1.32	.65	0.08	0.10	.43
Constant	1.89	---	.42	2.46	---	.08	1.60	0.28	<.001
	-2LL = 272.79			-2LL = 213.99			R^2 = 0.009		
	Cox & Snell R^2 = 0.003			Cox & Snell R^2 = 0.009			F (3,201) = 0.58 , p = .63		

Note. OR = Odds Ratio. *B* = Unstandardized coefficient.

Table 5
Descriptive Statistics for Global and Intentional Nonadherence Indices (N = 205)

	n	%
Global Adherence		
Past week (% of prescribed pills taken)		
95-100%	160	78
<95%	45	22
Past month (% of prescribed pills taken)		
95-100%	126	61
<95%	79	39
Intentional Nonadherence Since HIV Diagnosis		
Refuse/delay treatment uptake		
No	142	69
Yes	63	31
Stopped taking med without doctor approval		
No	107	52
Yes	98	48
One or more medication vacations		
No	126	62
Yes	79	38
Made small adjustments to regimen		
No	54	26
Yes	151	74
Summary intentional nonadherence score (0-4)		
Endorsed 0 indicators	29	14
Endorsed 1 indicator	60	29
Endorsed 2 indicators	44	22
Endorsed 3 indicators	45	22
Endorsed 4 indicators	27	13

Table 6

Regression Coefficients, Standard Errors, and Model Summary Information for Parallel Mediator Model Depicted in Figure 1

		Consequent									
		M_1 (DEP)				M_2 (DISC CONCERNS)				Y (GENADH MONTH)	
Antecedent		Coeff.	*SE*	*p*		Coeff.	*SE*	*p*		Coeff.	*SE*	*p*
X_1 (INT)	a_{11}	0.129	0.043	.003*	a_{12}	0.477	0.065	<.001*	c'_1	-0.016	0.188	.933
X_2 (ANT)	a_{21}	0.079	0.048	.098	a_{22}	0.213	0.072	.004*	c'_2	0.059	0.185	.748
X_3 (ENACT)	a_{31}	0.164	0.042	<.001*	a_{32}	-0.081	0.063	.198	c'_3	-0.015	0.163	.927
M_1 (DEP)		---	---	---		---	---	---	b_1	-0.463	0.268	.084
M_2 (DISCCON)		---	---	---		---	---	---	b_2	0.106	0.177	.547
Constant	i_{M1}	0.086	0.122	.483	i_{M2}	1.179	0.185	<.001*	i_y	0.491	0.555	.377
		$R^2 = 0.29$				$R^2 = 0.37$				-2LL = 269.12		
		F (3, 201) = 27.39, p <.0001				F (3, 201) = 39.74, p <.0001				Cox & Snell $R^2 = 0.02$		

Table 7

Regression Coefficients, Standard Errors, and Model Summary Information for Parallel Mediator Model Depicted in Figure 2

		Consequent										
		M_1 (DEP)				M_2 (DISC CONCERNS)				Y (GENADH WEEK)		
Antecedent		Coeff.	*SE*	*p*		Coeff.	*SE*	*p*		Coeff.	*SE*	*p*
X_1 (INT)	a_{11}	0.129	0.043	.003*	a_{12}	0.477	0.065	<.001*	c'_1	-0.106	0.192	.636
X_2 (ANT)	a_{21}	0.079	0.048	.098	a_{22}	0.213	0.072	.004*	c'_2	0.289	0.212	.173
X_3 (ENACT)	a_{31}	0.164	0.042	<.001*	a_{32}	-0.081	0.063	.198	c'_3	-0.019	0.192	.920
M_1 (DEP)		---	---	---		---	---	---	b_1	-0.384	0.315	.222
M_2 (DISCCON)		---	---	---		---	---	---	b_2	0.101	0.207	.624
Constant	i_{M1}	0.086	0.122	.483	i_{M2}	1.179	0.185	<.001*	i_y	0.771	0.634	.224
		$R^2 = 0.29$				$R^2 = 0.37$				-2LL = 212.11		
		F (3, 201) = 27.39, p <.0001				F (3, 201) = 39.74, p <.0001				Cox & Snell $R^2 = 0.02$		

Table 8

Regression Coefficients, Standard Errors, and Model Summary Information for Parallel Mediator Model Depicted in Figure 3

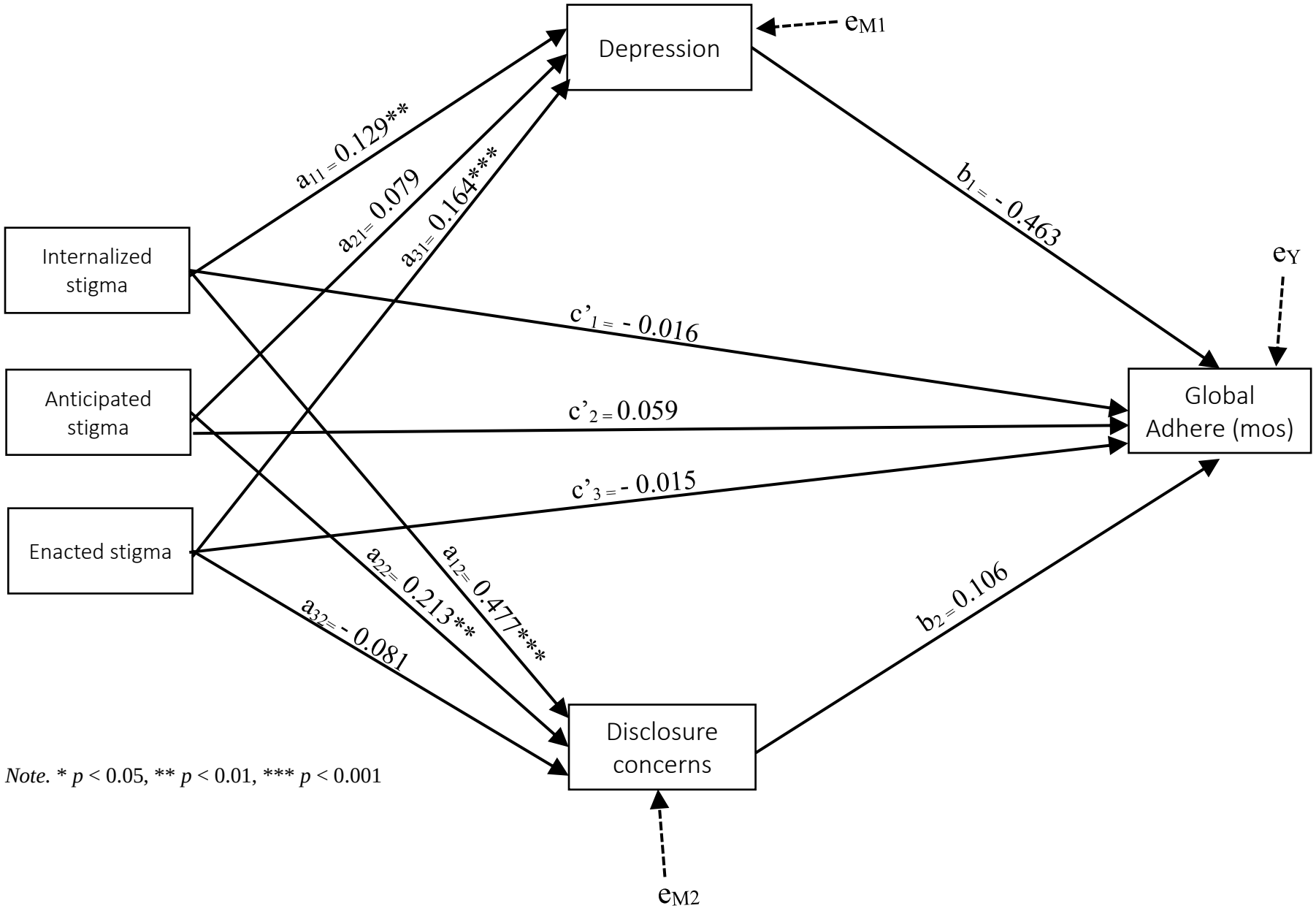
		Consequent									
		M_1 (DEP)				M_2 (DISC CONCERNS)				Y (INT NONADHERE)	
Antecedent		Coeff.	*SE*	*p*		Coeff.	*SE*	*p*		Coeff.	*SE*	*p*
X_1 (INT)	a_{11}	0.129	0.043	.003*	a_{12}	0.477	0.065	<.001*	c'_1	-0.072	0.114	.528
X_2 (ANT)	a_{21}	0.079	0.048	.098	a_{22}	0.213	0.072	.004*	c'_2	0.005	0.113	.963
X_3 (ENACT)	a_{31}	0.164	0.042	<.001*	a_{32}	-0.081	0.063	.198	c'_3	0.027	0.099	.785
M_1 (DEP)		---	---	---		---	---	---	b_1	0.323	0.163	.049*
M_2 (DISCCON)		---	---	---		---	---	---	b_2	0.055	0.108	.609
Constant	i_{M1}	0.086	0.122	.483	i_{M2}	1.179	0.185	<.001*	i_y	1.474	0.341	<.001*
		$R^2 = 0.29$				$R^2 = 0.37$				$R^2 = 0.03$		
		$F(3, 201) = 27.39$, $p < .0001$				$F(3, 201) = 39.74$, $p < .0001$				$F(5, 199) = 1.16$, $p = .331$		

Table 9. *Regression Coefficients, Standard Errors, and Model Summary Information for Parallel Mediator Model Depicted in Figure 4*

		Consequent										
		M_1 (DEP)				M_2 (DISC CONCERNS)				Y (INT NONADH)		
Antecedent		Coeff.	*SE*	*p*		Coeff.	*SE*	*p*		Coeff.	*SE*	*p*
X_1 (INT)	a_{11}	0.123	0.042	<.01*	a_{12}	0.488	0.063	<.001*	c'_1	-0.021	0.112	.852
X_2 (ANT)	a_{21}	0.09	0.046	.054	a_{22}	0.171	0.07	.015*	c'_2	0.02	0.109	.859
X_3 (ENACT)	a_{31}	0.139	0.041	<.001*	a_{32}	-0.04	0.062	.516	c'_3	-0.024	0.100	.803
M_1 (DEP)		---	---	---		---	---	---	b_1	0.434	0.167	.01*
M_2 (DISCCON)		---	---	---		---	---	---	b_2	0.038	0.111	.731
C_1 (EDUCATE)		-0.13	0.049	<.01*		0.145	0.074	.051		0.108	0.116	.357
C_2 (EMPLOY)		-0.253	0.086	<.01*		0.252	0.130	.054		0.169	0.206	.413
C_3 (RACE)		0.092	0.079	.249		-0.171	0.12	.155		-0.351	0.185	.059
C_4 (INCOME)		-0.004	0.003	.165		0.015	0.004	<.01*		0.005	0.007	.455
C_5 (YRSDIAG)		0.003	0.007	.642		0.003	0.01	.754		0.035	0.016	.029*
C_6 (YRSMED)		-0.012	0.007	.092		-0.008	0.011	.44		-0.008	0.017	.623
C_7 (PILLSDAY)		-0.021	0.058	.718		0.09	0.087	.306		0.324	0.134	.017*
Constant	i_{M1}	0.711	0.204	<.001*	i_{M2}	0.901	0.307	<.01*	i_y	0.102	0.500	.837
		Adj. $R^2 = 0.381$				Adj. $R^2 = 0.428$				Adj. $R^2 = 0.139$		
		$F(10, 192) = 11.83$, $p < .0001$				$F(10, 192) = 16.1$, $p < .0001$				$F(12, 190) = 2.56$, $p < .01$		

Figure 1

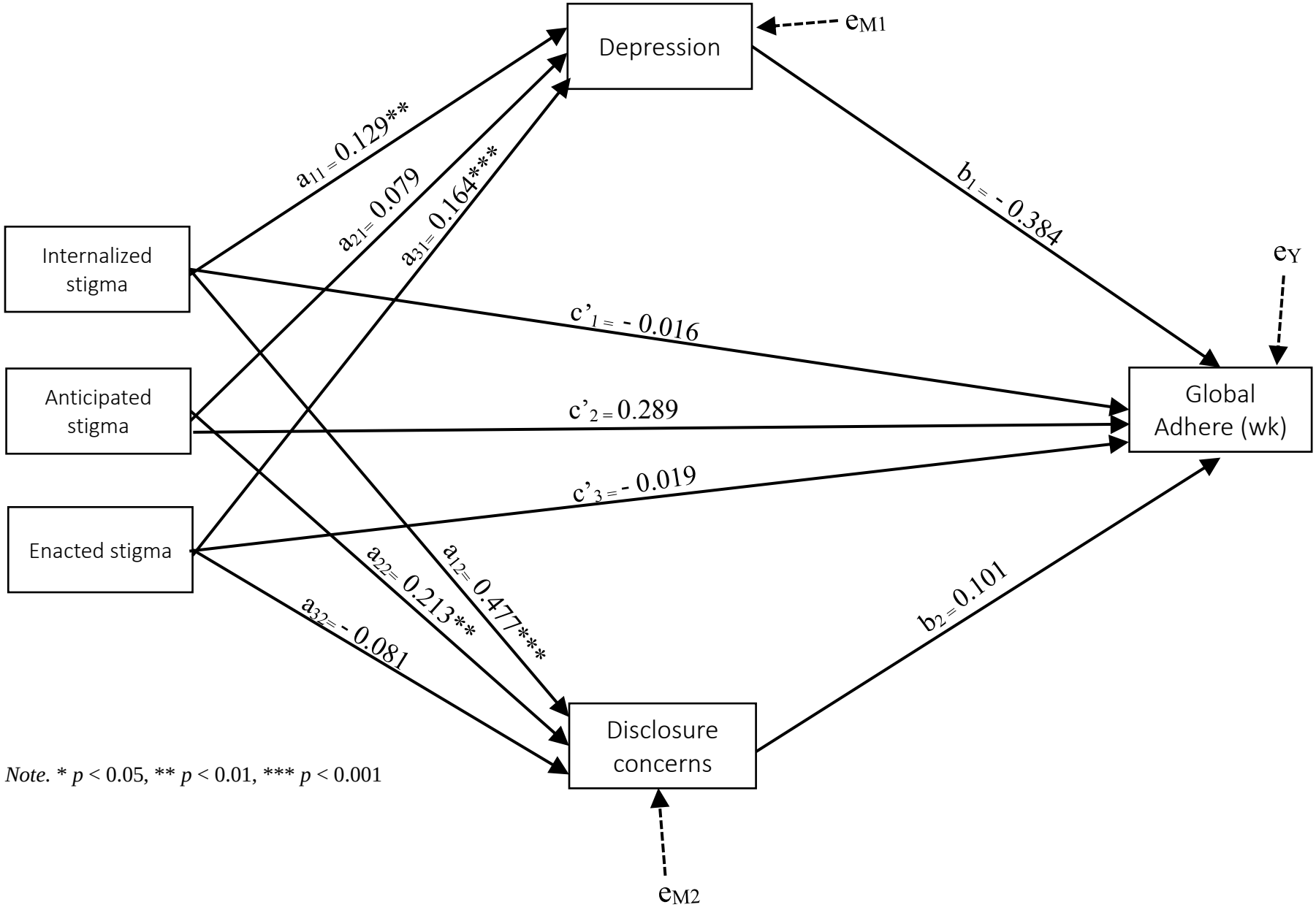
Associations for HIV-related stigmas, hypothesized mediators, and global adherence (past month)



Note. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Figure 2

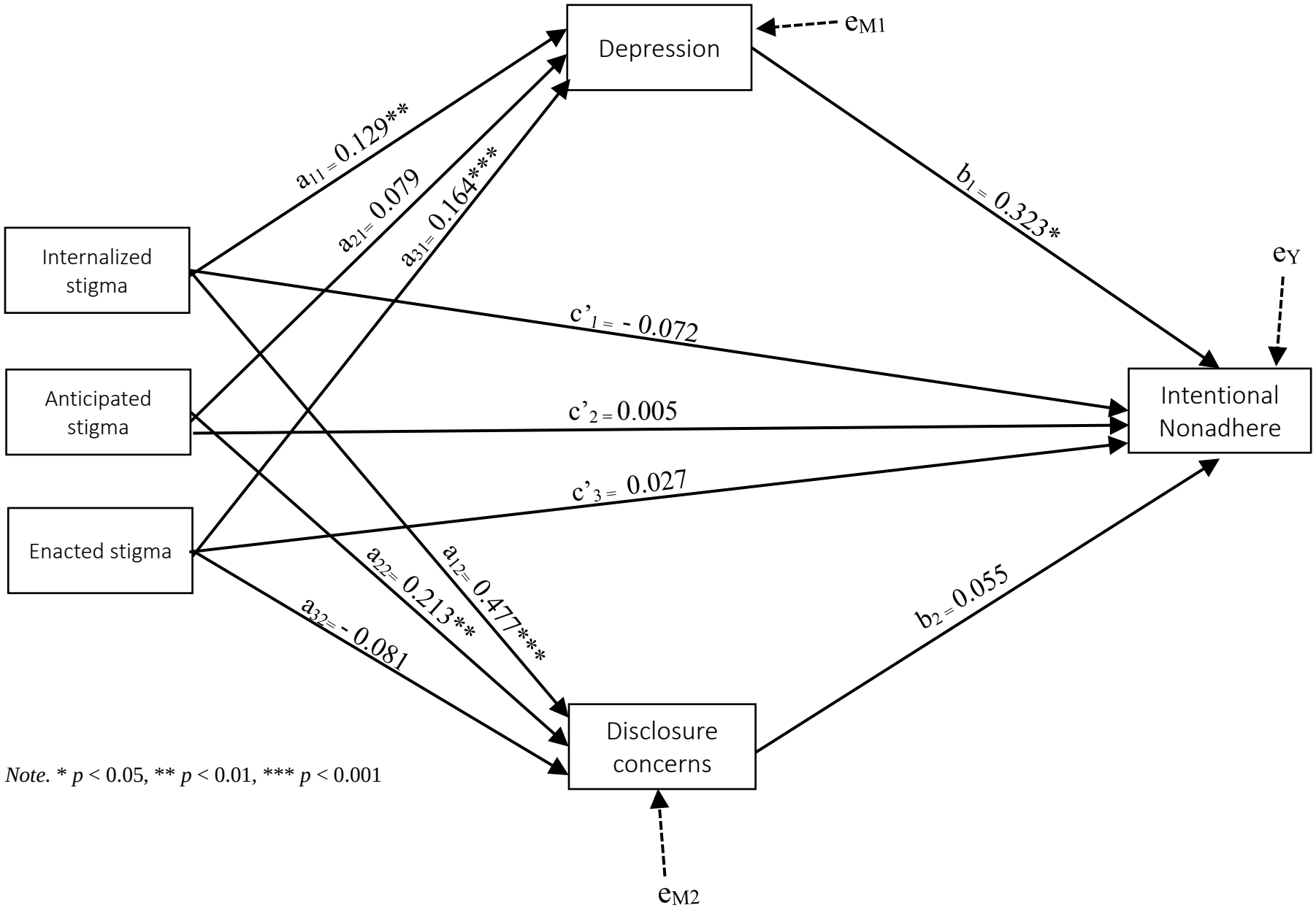
Associations for HIV-related stigmas, hypothesized mediators, and global adherence (past week)



Note. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Figure 3

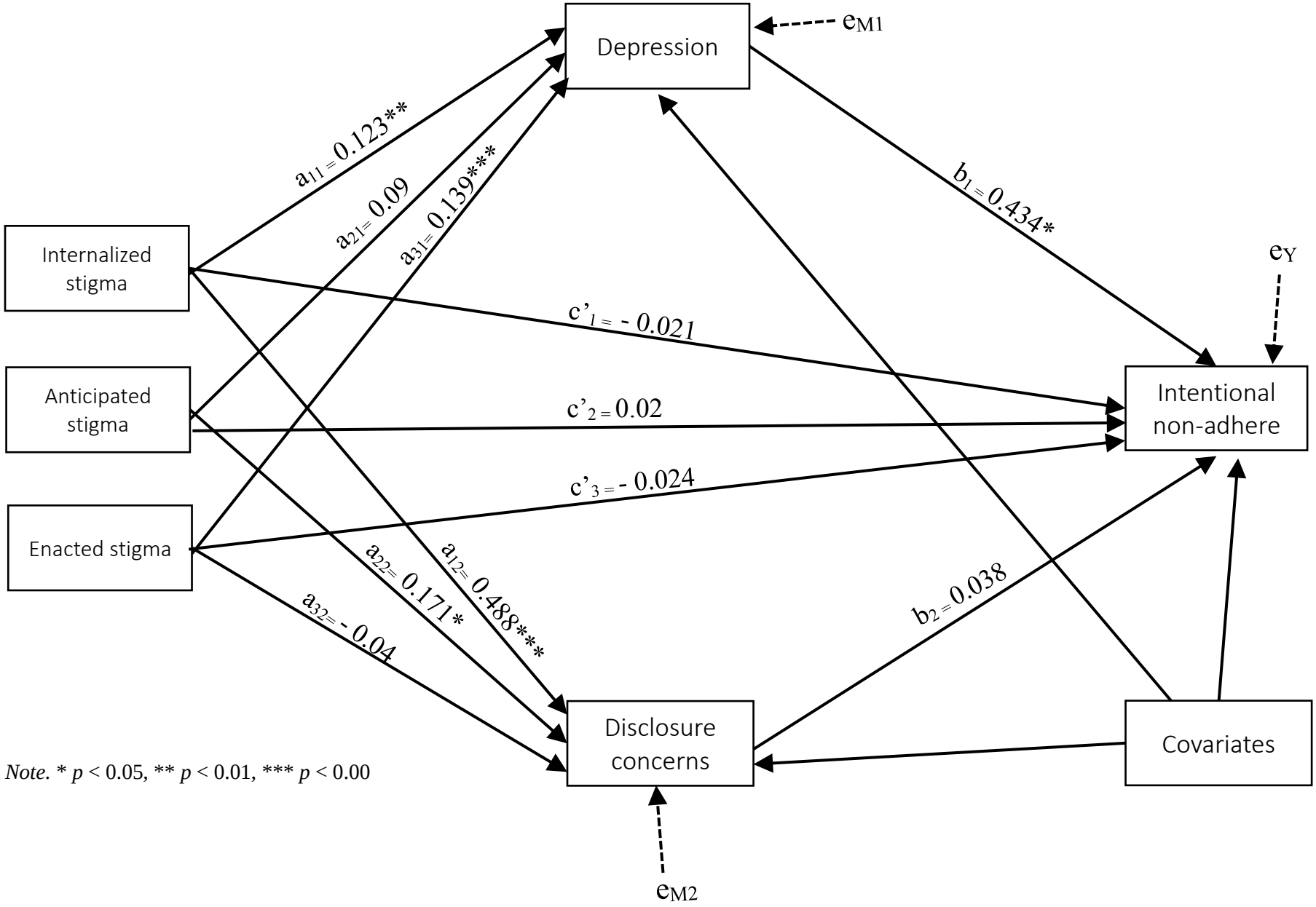
Associations for HIV-related stigmas, hypothesized mediators, and intentional nonadherence



Note. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Figure 4

Associations for HIV-related stigmas, hypothesized mediators, and intentional non-adherence, with covariates.



Note. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.00$

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