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# The Patient-Provider Relationship and HIV Medication Adherence: Indirect Effects of Medication Beliefs

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## Abstract

Research examining variables that influence medication adherence among HIV-positive individuals remains an important priority. The patient-provider relationship may influence HIV medication adherence, though findings have varied across studies and there is a paucity of research examining mechanisms that may account for patient-provider influences on adherence. One potential mechanism that may explain this relationship is patient's beliefs about medications, specifically how patients weigh the necessity of medications relative to concerns about negative side effects. Using data from a sample of 116 HIV patients recruited during outpatient care, this study aimed to (a) examine the effect of the patient-provider relationship on both adherence and intentional nonadherence; and (b) clarify whether there is an indirect effect of this relationship through medication beliefs. Primary study hypotheses were tested using bootstrapped mediation models. Results showed that the patient-provider relationship was positively associated with adherence but not intentional nonadherence. There was strong support for an indirect effect of this relationship through medication beliefs for adherence but not intentional nonadherence. This study could inform interventions to improve the patient-provider relationship as well as target potentially modifiable patient beliefs about their medications.

The Patient-Provider Relationship and HIV Medication Adherence: Indirect Effects of  
Medication Beliefs

by

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B.A., University at Buffalo, 2012

Thesis

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## The Patient-Provider Relationship and HIV Medication Adherence: Indirect Effects of Medication Beliefs

There are an estimated 1.2 million people living with HIV/AIDS (PLWHA) in the United States and more than 36 million worldwide (World Health Organization; WHO, 2016). With approximately 40,000 new infections per year in the United States and over 2 million worldwide (WHO, 2015), stemming the HIV epidemic remains an important public health priority. Over the past decade, the lifespan of those newly infected with HIV has nearly doubled (Samji et al., 2013) and HIV is now widely considered a manageable chronic condition by physicians and public health experts (Deeks, Lewin, & Havlir, 2013). However, strict adherence to highly active antiretroviral therapy (HAART) is of critical importance to avoid disease progression and prevent viral resistance (Paterson et al., 2000). Despite significant treatment advances, poor medication adherence (defined as below 90-95% of prescribed doses) remains common (Cambiano, et al., 2010). Indeed, a recent meta-analysis by Ortego & colleagues (2011) found that only 62% of those prescribed HAART adhere to recommended guidelines.

Identifying patient factors that contribute to medication adherence difficulties is of vital importance, as poor adherence is associated with lower CD4 counts and a higher viral load (Paterson et al., 2000). These factors contribute to the HIV epidemic by increasing HIV transmission risk (Attia, et al., 2009) and highlight the importance of treatment as prevention guidelines as well as test and treat strategies (WHO, 2016). Substandard adherence may lead to the development of drug-resistant HIV strains (Hatano & Deeks, 2007; Rosenbloom, Hill, Rabi, Siliciano, & Nowak, 2012), increased risk for opportunistic infections (Swindells et al., 2002), and increased risk for virologic failure (Aberg et al., 2013; Paterson et al., 2000). Further, poor adherence to one class of drugs that are commonly used in HAART regimens, Non-Nucleoside

Reverse Transcriptase Inhibitors (NNRTI's) can lead to cross-resistance of the entire NNRTI class of drugs (Li et al., 2005; Parienti, et al., 2004). Given the role of adherence in predicting treatment success, researchers have emphasized the importance of identifying potentially modifiable factors that influence adherence (Beach et al., 2006).

Research has identified a number of patient-specific factors associated with adherence among PLWHA. For example, social support and adherence self-efficacy are positively associated with adherence, while depressive symptoms, current substance use, and HIV-related stigma have been found to be negatively associated with adherence (Langebeek et al., 2014). Although patient and treatment related variables have been studied extensively among PLWHA, one risk factor that has received attention in recent years concerns the relationship between patients and their treatment teams, and more specifically the patient-provider relationship (Beach et al., 2006). The quality of the patient-provider relationship has been shown to improve adherence among chronic disease patients (Stange et al., 2010), and recent data suggests that specific components of the patient-provider relationship may play a role in HAART adherence (Langebeek et al., 2014). Interest in the role of patient-provider relationships and adherence among PLWHA is in keeping with growing recognition of the importance of patient-provider relationships across all of health care (Swick et al., 1999).

Among PLWHA, the advent of HAART and the prospect of long term survival enhanced the importance of collaborative patient-provider interactions, where patients make decisions alongside their providers (Wagner et al., 2005). Accordingly, research has focused on understanding the impact of several aspects of the patient-provider relationship on adherence, including provider trust, communication, disease-specific information, collaboration, and satisfaction (Ironson, Lucette, & McIntosh, 2015; Schneider, Kaplan, Greenfield, Li, & Wilson,

2004). While a number of studies have documented the importance of the patient-provider relationship as a determinant to medication adherence among PLWHA (Beach et al., 2006; Oetzel et al., 2015; Langebeek et al., 2014), other studies have failed to find an association between the patient-provider relationship and adherence (Moralejo, et al., 2006; Holmes et al., 2007; Kalichman, Ramachandran, & Catz, 1999), and one study found that better provider communication and interpersonal skills predicted *poorer* adherence (Ingersoll & Heckman, 2005). Further, only a few studies have sought to identify factors that may clarify mechanisms linking aspects of the patient-provider relationship to adherence.

Whereas a lack of trust, or a poor relationship with one's provider may undermine engagement in healthcare generally, the impact of the patient-provider relationship on adherence may be explained in part by the influence of the patient-provider relationship on beliefs about medications. Medication beliefs have been shown to negatively impact treatment adherence (Nozaki et al., 2013). Horne and colleagues (1999) developed an approach to explain non-adherence that emphasizes patient's beliefs about the *necessity* of medications and *concerns* related to negative effects of medications. Specifically, the extent to which patients rate their need for medication relative to their concerns about medication, operationalized as a differential score, is a strong predictor of medication adherence across chronic health conditions, including HIV (Horne et al., 2013). Preliminary findings suggest that the association between the patient-provider relationship and adherence may be partially explained by medication beliefs (Altrice et al., 2001; Gauchet et al., 2007).

The present study aimed to clarify the effect of provider trust and satisfaction on medication adherence and examine the role of patient beliefs as a potential mechanism linking the patient-provider relationship to adherence. Hypotheses were generated based on the past

findings concerning the effect of the patient-provider relationship on HAART adherence and research pointing to the role of medication beliefs as a mechanism for explaining the effect of the patient-provider relationship on adherence.

### **Patient-Provider Relationship among PLWHA**

The patient-provider relationship in HIV care first received attention during the late 1990's in a series of qualitative studies that documented how provider knowledge, interpersonal skills, and personalized-care were often described as contributing to better adherence (Bakken et al., 2000; Roberts 2000). Trust in one's providers is considered a cornerstone of modern medicine, as care is presumed to be optimized when patients trust their provider to have their best interest in mind (Hall, Dugan, Zheng, & Mishra, 2001). Trust is especially important as many PLWHA report experiencing stigma (Lowther, Selman, Harding, & Higginson, 2014), including a significant minority who report stigmatizing experiences in healthcare settings (Naughton & Vanable, 2013; Nyblade, et al., 2009). Further, medical mistrust, which includes mistrust of one's provider, is especially high among men who have sex with men (MSM) and African-American communities, two groups that are especially vulnerable to HIV infection (Halbert, Armstrong, Gandy, & Shaker, 2006; Santos et al., 2013).

Among PLWHA, *provider trust*, which includes honesty, fidelity, and confidentiality, has generally been associated with better adherence across numerous qualitative and quantitative studies (Hall et al., 2001). Indeed, one recent meta-analysis (Langebeek et al., 2014) found that both provider trust and satisfaction was associated with better adherence. However, the included studies varied considerably in their measurement of the patient-provider relationship and pooled trust and satisfaction together. Other researchers consider these distinct variables, as trust involves a level of risk in the decision to be vulnerable with another person (Blackstone et al.,

2012; Thom & Campbell, 1999). Among cross-sectional studies, low provider trust has been linked to poorer medication adherence among PLWHA in prison settings (Altice, Mostashari, & Friedland, 2001), urban HIV clinics (Blackstock et al., 2012), Southern Infectious Disease (ID) clinics (Whetten et al., 2006), and among African HIV clinics (Watt et al., 2010). In contrast, Holmes and colleagues (2007) found that among 116 HIV positive patients, provider trust was not associated with adherence over a 12-month period. Despite some mixed findings, these results suggest that provider trust may play a key role in adherence outcomes. However, there is a significant lack of empirical data on the mechanisms that may help to explain the ways in which provider trust enhance or diminish medication adherence.

Another widely studied factor is *provider satisfaction*, which refers to a patient's appraisal of the services received based on interactions with their provider (Crow, Gage, Hampson, & Hart, 2003). A number of studies have investigated the influence of provider satisfaction on adherence, with mixed results. For example, provider satisfaction has been associated with better adherence in a sample of outpatients from both the United States (Schneider et al., 2004) and Canada (Godin et al., 2005). In contrast to these findings, several studies have failed to find a direct relationship between satisfaction and adherence. For example, provider satisfaction was not associated with adherence in outpatients from Sweden (Schonnesson et al., 2006), Spain (Moralejo et al., 2006), and rural areas throughout the United States (Cosio, et al., 2010). Among studies examining provider satisfaction and adherence, only one examined potential mediators of this association. DiIorio and colleagues (2009) found a positive relationship between patient satisfaction and adherence, and their final model showed that provider satisfaction indirectly influenced adherence through self-efficacy and depression. Taken together, findings provide only mixed support for the impact of provider satisfaction on

adherence and only limited data on potential mediating variables that may explain this relationship.

Research is needed to clarify the extent to which patient-provider variables influence patient behavior, as is research that clarifies potential mechanisms to explain these relationships. One possible mechanism linking provider relationship variables to adherence is the impact that the patient-provider relationship may have on patient's medication beliefs. An understanding of the interconnection between the patient-provider relationship and patient's medication beliefs has the potential to improve adherence focused interventions (Beach et al., 2015).

### **Testing the Indirect Effect of Medication Beliefs in the Patient-Provider to Adherence Relationship**

Given the importance of patient-provider relationships in HIV care, research is needed to clarify the role of specific patient-provider relationship variables on adherence and to clarify psychological factors that may explain the ways in which provider level variables shape health behavior outcomes. It is conceivable that patient-provider relationships affect adherence by simple virtue of the fact that doctors instruct patients to take medicine as prescribed. Effective patient education leads to medication taking behaviors, and the extent to which patients follow through with instructions would depend primarily on the clarity of the patient education.

Researchers have proposed a second possibility, namely that the strength of the patient-provider relationship influences adherence levels in so far as relationship factors help to solidify patient's beliefs about the need for medication. For example, if a patient trusts their providers, they may be more likely to internalize statements made about the importance of taking medication as prescribed as a means of maintaining health. On the other hand, if a patient does not trust their

providers, they may believe their providers are attempting to minimize the actual side effects of a medication. In turn, these beliefs about medications may influence a patient's adherence.

The present study tested the hypothesis that patient's beliefs about the necessity of medication and concerns about side effects will mediate the effect of the patient-provider relationship on adherence. This perspective is in keeping with that which is proposed by the Necessity/Concerns Framework (Horne et al., 2004). Drawing from self-regulation theory, Reynolds (2003) proposed a self-regulatory model to explain the numerous factors involved in adherence behavior in patients with chronic illness. Self-regulation theory (Diefenbach & Leventhal, 1996; Leventhal et al., 1997) suggests that people develop a representation of their illness based on background experiences such as their relationship with their providers, as well as the method of treatment (e.g., medication). While complex in nature, research has demonstrated that beliefs about medications fall under two categories: perceptions related to the *necessity* of a medication and *concerns* about adverse side effects (Horne et al., 2004; Horne, Weinman, & Hankins, 1999). A key consideration in this theory is the importance of the differential between the *necessity* and *concerns* beliefs. For example, a patient who believes their medications are not important to their long-term health and report several concerns related to side effects may be less likely to take their medications as prescribed. One recent meta-analysis (Horne et al., 2013) identified these two factors as a strong predictor of adherence among PLWHA. Given that providers play a critical role in educating patients by addressing concerns and emphasizing the necessity of medications (Altice, Mostashari, & Friedland, 2001), it is possible that beliefs about medications can explain the effect of the patient-provider relationship on medication adherence.

To date, only one study has investigated the role of both necessity and concerns related to medications as a mediator of the association between patient-provider relationships and medication adherence. Gauchet, Tarquinio, and Fischer (2007) used a structural equation modeling approach to evaluate the relationship between HIV patients' confidence in their provider, beliefs about medication and adherence. Their results showed higher provider confidence predicted greater adherence, and this relationship was partially mediated by patients' beliefs in the necessity of HIV medications, but not concerns about medication side-effects. Conceptually, this suggests that patients' beliefs about the necessity of their medications are influenced by interactions with their provider. The authors tested an additional model where beliefs about medications and provider confidence were reversed. That is, beliefs about medications predicting medication adherence, mediated by provider confidence. Importantly, the fit was less optimal, suggesting that confidence in the provider is influencing patients' beliefs about their medication, and not the other way around. Results from this study are consistent with the notion that patients' medication beliefs are formed, in part, by the confidence ascribed to interactions with their health care provider.

The study by Gauchet and colleagues (2007) has several limitations. First, the study evaluated only one aspect of the patient-provider relationship (confidence). There is evidence from meta-analytic work that other aspects of the patient-provider relationship, such as trust and satisfaction are relevant to medication adherence (Langebeek et al., 2014). Second, the authors used the original 18-item Beliefs about Medicines Questionnaire (BMQ) and related four subscales (Specific-Necessity, Specific-Concerns, General Overuse, General Harm) rather than the HIV-specific BMQ-HAART. In their final model, they included three additional variables related to values which may have confounded their results. Further, previous research has found



that the interaction between necessity beliefs and concerns is a stronger predictor of adherence than either variable alone (Horne et al., 2004). Specifically, Horne and colleagues (2004) found that patients were more likely to report lower adherence if their concerns about medications were high relative to their perception of the necessity of HAART. Finally, the authors used a measure of adherence that created a total medication adherence score. This methodology fails to capture more deliberate decisions to skip or alter doses, which can be classified as *intentional nonadherence* (Wroe, 2002). Several studies in HIV-infected patients have found rates of intentional nonadherence from 11%-20% (Heath et al., 2002; Mo & Mak, 2009). Further, Norton and colleagues (2010) found that patients who reported intentionally skipping doses were more likely to report difficulty talking to their health care provider. Thus, intentional nonadherence may reflect a poor patient-provider relationship and including such a measure will allow better understanding of the mechanisms involved.

### **Current Study**

The current study aimed to clarify the association between the patient-provider relationship as measured from the patient's perception, and HAART adherence using the Necessity/Concerns Framework. First, this study examines the effect of provider *trust* and *satisfaction* on adherence and intentional nonadherence. It was hypothesized that both provider *trust* and *satisfaction* will be positively associated with overall medication adherence levels and negatively associated with engagement in intentional nonadherence. Next, this study examines the ability of the Necessity/Concerns Framework to explain the association of provider trust and satisfaction on adherence. It was hypothesized that there will be an indirect effect of the patient-provider to adherence relationship through medication beliefs, as measured by the *necessity-concerns differential*, (i.e., difference between perceived *necessity* of medications relative to

*concerns* about medications, see Figure 1). Specifically, patients who report more positive relationships with their providers will endorse more *necessity* beliefs relative to *concerns* beliefs which will in turn lead to increased medication adherence and decreased engagement in intentional nonadherence. Those patients who report poor relationships with their providers will endorse more *concerns* beliefs relative to *necessity* beliefs which will lead to decreased medication adherence and increased engagement in intentional nonadherence.

This study is the first to investigate the effect of the patient-provider relationship on both adherence and intentional nonadherence in a sample of PLWHA while examining the role of medication beliefs as defined by the Necessity/Concerns Framework. The results from this study will help to elucidate malleable factors that can be targeted by interventions aimed at providers or patients. Study hypotheses were tested using data from 116 patients participating in a study examining barriers to health and coping in the context of HIV care (see Littlewood and Venable, 2013).

## **Methods**

### **Participants**

A total of 150 participants from Upstate New York (41% female, 57% male, 2% transgender) were recruited for study participation during an outpatient HIV care visit. For the present study, participants were required to be current HAART users, bringing the final sample size to 116. The average age was 44 years old (range 19-64). 48% of participants self-identified as African-American, 41% as Caucasian, 6% as Multi-Racial, 4% as Native American, and 1% as Pacific Islander. The average time elapsed since HIV diagnosis was 11 years and 59% of our sample reported their viral load was currently “undetectable” (viral load <50). The majority of

participants were unemployed (62%), 19% of participants did not have a high school diploma, 37% had a high school degree, and 43% reported at least some college.

## **Procedures**

*Participant recruitment.* Participants were recruited during routine outpatient HIV care visits. Patients were informed about the opportunity to participate in the study by a clinic staff member. Verbal consent to be approached by the research team was obtained by a health care provider before a patient was asked about study participation. A second source of study participants was through a pool of past study participants who had previously agreed to be contacted regarding future studies opportunities. Informed consent was obtained from all participants before data collection. Eligible participants were HIV-positive, at least 18 years old, currently undergoing HAART treatment, English-speaking, and capable of providing informed consent. Participants were compensated \$20 upon study completion.

*Survey administration and data entry.* The questionnaires were administered using audio computer-assisted self-interviewing (ACASI). ACASI has been shown to increase patient's disclosure of sensitive information over traditional interviews (Schroder, Carey, & Venable, 2003). Surveys were completed in a private room and required roughly one hour to complete. Survey data was exported to SPSS and merged with medical chart data. All statistical analyses were conducted using SPSS v16.0 (Statistical Package for the Social Sciences; SPSS Inc., Chicago, IL).

## **Measures**

*Demographics.* Data obtained from self-report included age, education, income, ethnicity, employment status, duration of HIV medication usage, and sexual orientation.

*HAART adherence.* Items assessing HAART adherence were adapted based on research conducted by Simoni and colleagues (2006). Self-reported adherence was assessed for the past week and past month. For the past week, participants completed a timeline follow back (TLFB) for the past seven days. The TLFB asks participants to report the number of pills they are supposed to take every day and how many they actually took. From these data, a past-week adherence score is calculated  $(\text{prescribed doses} - \text{missed doses}) / (\text{prescribed doses}) \times 100$ . The advantage of assessing adherence for the past week compared to past several days is that a weekend will always be included, and previous research has shown adherence is often problematic on weekends (Bachhuber et al., 2010). Additionally, these data may allow us to differentiate those who are consistently adherent from those who are typically less adherent, but have better adherence over shorter periods (Simoni et al., 2006). For the past month, HAART users completed a visual analog scale (VAS) ranging from 0-100% where they estimated the amount of HIV medications they took. Past month adherence was dichotomized as  $\geq 95\%$  or  $< 95\%$ , consistent with previous research (Viswanathan et al., 2015).

*Intentional nonadherence since HIV diagnosis.* To capture the prevalence of intentional nonadherence occurring since the time of diagnosis, 16 items assessed four domains consistent with previous research (Laws et al., 2000; Littlewood & Vanable, 2013; Roberts & Mann, 2003): (1) Treatment uptake, whereby patients declined to begin taking HAART despite recommendations from their physician; (2) treatment interruption, in which patients stopped taking some or all of their medications without telling their provider; (3) medication vacation, where patients “took a break” of more than one day from some or all of their medications; and (4) medication changes, representing any intentional alterations to their HAART regimens (e.g., taking less than prescribed, taking a dose later than scheduled, doubling up on their dosage to

make up for a missed dose, or skipping any special instructions). A score of 1 was assigned for each category with a positive response, and the sum of these scores yielded an intentional nonadherence composite score (range 0-4). This measure assesses the underlying motivation of intentionally nonadherent patients as patients make decisions about treatment based on a wide range of factors (Wroe, 2002).

*Intentional nonadherence, past month.* To estimate the extent of intentional nonadherence in the past month, participants were asked how often they made changes to their prescribed HAART regimens or skipped a dose of their medication for personal reasons (e.g., feeling depressed, side effects, change in plans, or other). Participants indicated their response by placing a mark on a visual analog scale with anchors (0 = Never, 50 = About half the time, 100 = All the time). A single intentional nonadherence score for the past month was calculated by taking the average of these items. This measure was included in addition to the previous lifetime assessment of intentional nonadherence to ensure answers were based on their current provider (e.g., patients may have engaged in different behaviors with a prior provider).

*Beliefs About Medications.* To assess patients beliefs about HAART medications, the validated Beliefs about Medicines Questionnaire – HAART version (BMQ-HAART) was used (Horne et al., 1999). Two subscales were used for the present study: perceived *necessity* of HAART and *concerns* about potential adverse consequences of using HAART. Items related to the perceived *necessity* of HAART refer to participant’s beliefs that taking HAART is necessary for their health and longevity. The *necessity* subscale consists of 8 items such as “My health depends on HIV medications” and “HIV meds can keep me alive”. Items related to *concerns* about adverse consequences refer to both concerns about long term effects of HAART use and more tangible concerns such as side effects or embarrassment from medication use. The

*concerns* subscale consists of 11 items such as “My HIV meds give me unpleasant side-effects” and “Having to take HIV meds worries me”. Patients were asked to rate their agreement of 19 statements about HIV medications using a 5-point Likert scale with a range of “strongly agree” to “strongly disagree.” Internal reliability for both scales was good (alpha = .70 for necessity and .74 for concerns) and is consistent with other samples (Horne et al., 2004).

Consistent with previous methodology (Horne et al., 2004; Horne et al., 2007), a *necessity-concerns differential* was calculated by computing mean scores for both subscales and subtracting concerns scores from necessity scores (range -4: 4). This differential score reflects how patients rate the necessity of medication relative to their concerns and has been shown to be a stronger predictor of adherence than either subscale alone (Horne et al., 2007). As such, the model for the present study will test this differential score as a potential mediator of the patient-provider to adherence relationship. Higher differential scores reflect patients placing more value on the necessity of medication relative to concerns about medication.

*Patient-Provider Relationship.* The quality of the patient-provider relationship was assessed using 26 items based on previous work by Schneider and colleagues (2004). For the present study, the subscales of provider trust (3-items) and provider satisfaction (3-items) were of interest. Items related to overall satisfaction with their treatment team (e.g., Overall, how would you rate your provider’s personal manner?) were rated on a 5-point Likert scale from 1 (Poor) to 5 (Excellent). Items related to trust in their treatment team (e.g., I can tell my HIV care provider anything, even things that I might not tell anyone else) were rated on a 6-point Likert scale from 1 (Strongly Disagree) to 6 (Strongly Agree) while one item (All things considered, how much do you trust your HIV care provider?) was rated on a 5-point scale of 1 (Not at all) to 5 (Completely). Of note, this measure captures the patient’s perception of their relationship with

providers. Internal reliability for both subscales in this sample was good (alpha for satisfaction = 0.96 and for trust, alpha = 0.83) and is consistent with other studies (Schneider et al., 2004).

### **Data Analytic Plan**

Power analyses were conducted to determine if the primary hypotheses could be tested using this sample of 116 patients with at least the 0.8 minimum statistical power recommendation for mediation analyses (Fritz & Mackinnon, 2007). The only study to test the patient-provider to adherence relationship mediated by medication beliefs found a small-medium effect of the provider relationship on medication beliefs and a small-medium effect of medication beliefs on adherence (Gauchet et al., 2007). Of note, the authors used a different measure of the patient-provider relationship and medication beliefs. Nonetheless, these estimates were used to guide the current study. The effect of the patient-provider relationship on medication beliefs and the effect of medication beliefs on adherence was estimated to be small-medium. An a-priori sample size calculation suggested a total sample size of 92. The sample size of the present study exceeds this sample size; thus, this study has acceptable statistical power.

All statistical analyses were conducted using SPSS version 16 (SPSS Inc., Chicago, IL). First, descriptive statistics were conducted to characterize the sample. Next, bivariate correlations were examined for hypothesized associations of the patient-provider relationship, beliefs about medications, and both medication adherence and intentional nonadherence. Finally, mediation models (see Figure 1) tested the effect of provider *trust* on the mediator (beliefs about medications, a path), the effect of the mediator (beliefs about medications) on both outcomes (adherence and intentional nonadherence, b path), and the effects of provider *trust* on both outcomes (adherence and intentional nonadherence, c path). Next, two additional mediation models (see Figure 1) tested the effect of provider *satisfaction* on the mediator (beliefs about

medications, a path), the effect of the mediator (beliefs about medications) on both outcomes (adherence and intentional nonadherence, b path), and the effects of provider *satisfaction* on both outcomes (adherence and intentional nonadherence, c path).

To ensure the causal path represents the most viable model fit, several alternative mediation models were tested. It may be possible that beliefs about medications influence the patient-provider relationship, rather than vice versa. In these models, the *necessity-concerns differential* was entered as the independent variable, and both *provider trust* and *satisfaction* were entered as mediators in separate models with adherence and intentional nonadherence as outcomes.

Analyses were conducted using an SPSS macro designed to examine mediation models using bootstrapping methods (PROCESS; Preacher & Hayes, 2008). The macros provide path coefficients for the mediation models and bootstrapped 95% confidence intervals for the indirect effect of provider *satisfaction* and *provider trust* on both outcomes of adherence and intentional nonadherence via beliefs about medications.

## Results

### Descriptive Findings

As shown in Table 1, participants reported moderate to high levels of trust in and satisfaction with their providers (M's = 4.59 and 4.38 respectively). With regard to medication beliefs (the *necessity-concerns differential*), participants reported a lower number of concerns (M = 2.46; SD = .64) relative to necessity beliefs (M = 4.33; SD = .57). On average, participants reported taking 92% of their prescribed medications in the previous week and 90% of their prescribed medications in the past month. Approximately 90% of patients reported  $\geq 95\%$



adherence in the past month. The average rate of intentional nonadherence over the past month was 18%.

### **Association of Trust and Satisfaction to Adherence**

The first set of analyses examined the hypothesis that both provider *trust* and *satisfaction* would be positively associated with medication adherence and negatively associated with intentional nonadherence. Consistent with this hypothesis, provider trust was positively associated with past week adherence ( $r = .34, p < .05$ ; Table 2) and past month adherence ( $r = .18, p < .05$ ). Provider satisfaction was also positively associated with past week adherence ( $r = .21, p < .05$ ) and past month adherence ( $r = .23, p < .05$ ). Provider trust was negatively associated with past month intentional nonadherence ( $r = -.24, p < .05$ ) but was not associated with lifetime intentional nonadherence. Provider satisfaction was not associated with either past month intentional nonadherence or lifetime intentional nonadherence.

### **Tests of the indirect effect of medication beliefs on 7 Day and 30-Day Adherence**

Tables 3 and 4 provide comprehensive statistical information for each model. Path results common to multiple models are reported only in the first model in which they appear. For all models, covariates of age, gender, and time on HAART were included, as these factors have been linked with poorer adherence (Beer & Skarbinski, 2014).

A major goal of this study was to test the hypothesis that there would be an indirect effect of provider trust on adherence via beliefs about medications. Regression analyses established that provider trust was not associated with past 30-day adherence while beliefs about medications trended toward significance ( $b: \beta = .372; z = 1.905; p = .057$ ). Based on 10,000 bootstrap re-samples, the indirect effect of provider trust on 30-day adherence via mediation

beliefs was positive and significant (Table 4: OR = .184; SE = .990; 95% CI: .251 to 4.14). The model with 7-day adherence as the dependent variable was not significant.

The next model replaces provider trust with provider satisfaction, variables that are moderately correlated with one another ( $r = .65$ ,  $p < .001$ ). Provider satisfaction was not associated with 7-day adherence in the model but was associated with medication beliefs (a:  $\beta = 0.289$ ;  $t = 2.855$ ;  $p < .01$ ). Medication beliefs and 7-day adherence were positively associated (b:  $\beta = 3.331$ ;  $t = 2.312$ ;  $p = 0.023$ ). Based on 10,000 bootstrap re-samples, there was a significant positive indirect effect of provider satisfaction on 7-day adherence via medication beliefs (Table 4:  $\beta = .961$ ; SE = .634; 95% CI: .126 to 2.71). Given that adherence may vary on a week-to-week basis, the model was tested again with 30-day adherence as the outcome. Regression analyses established that provider satisfaction was not associated with 30-day adherence while medication beliefs was positively associated with 30-day adherence (b: OR= .442;  $z = 2.351$ ;  $p = .019$ ). Based on 10,000 bootstrap re-samples, there was a significant positive indirect effect of provider satisfaction on 30-day adherence via medication beliefs (Table 4:  $\beta = .127$ ; SE = .084; 95% CI = .021 to .344).

### **Indirect Effect of Medication Beliefs in Relation to Intentional Non-Adherence**

A second primary goal of the present study was to test whether there is an indirect of the patient-provider to adherence relationship through medication beliefs. It was hypothesized that the patient-provider to intentional nonadherence relationship would be partially influenced by medication beliefs such that better patient-provider relationships would lead to a higher necessity-concerns differential, and lower engagement in intentional nonadherence. To examine this hypothesis, the previous models were run replacing the outcome of medication adherence with intentional nonadherence. Based on 10,000 bootstrap re-samples, the indirect effects of

provider trust on both measures of intentional nonadherence through medication beliefs were not significant. Model 4 (Table 3) tests the indirect effect of provider satisfaction to intentional nonadherence through medication beliefs. There was a significant negative indirect effect of provider satisfaction on lifetime intentional nonadherence via beliefs about medications (Table 4:  $\beta = -.056$ ;  $SE = .036$ ; 95% CI:  $-.153$  to  $-.004$ ). Regression analyses established that provider satisfaction was not associated with lifetime intentional nonadherence while medication beliefs (b:  $\beta = -.195$ ;  $t = -1.977$ ;  $p = .05$ ) was associated with lifetime intentional non-adherence. Neither model with past 30-day intentional nonadherence as the outcome was significant.

### **Alternative Models**

Given the possibility that beliefs about medications influence the patient-provider relationship, rather than vice versa, several alternative models were examined (Table 4). Medication beliefs were entered as the independent variable and both provider trust and satisfaction were entered as mediators in separate models. In these models both past week and past month adherence, as well as past month and lifetime intentional nonadherence were entered as the dependent variables. All models with provider satisfaction as the mediator were not significant. However, the indirect effect of medication beliefs to past week adherence via provider trust achieved significance ( $\beta = 1.731$ ;  $SE = 1.101$ ; 95% CI:  $.232$  to  $4.86$ ).

Given the use of a difference score as a mediator, additional models were run with both necessity beliefs and concern beliefs entered in parallel. Results confirmed a significant indirect effect of provider trust to past 30-day adherence via medication beliefs ( $\beta = .194$ ;  $SE = .148$ ; 95% CI:  $.012$  to  $.604$ ). The necessity beliefs path was significant ( $\beta = -.226$ ;  $SE = .163$ ; 95% CI:  $-.012$  to  $.604$ ) but the concern beliefs path was not. Additional models were not significant.

These results confirm that the necessity-concerns difference score provided a more sensitive test of the hypotheses in this study.

### **Discussion**

The present study is the first to examine the indirect effect of the patient-provider relationship on both HIV medication adherence and intentional nonadherence through medication beliefs. Findings from this sample of 116 HIV-infected adults provide support for the importance of patients' beliefs about medications in the patient-provider to adherence relationship. In keeping with the first major hypothesis, provider trust and satisfaction showed positive associations with both adherence outcomes. Contrary to predictions, the hypothesized association of patient-provider relationship to intentional nonadherence was largely not supported. Only provider trust was negatively associated with past month intentional adherence, and not lifetime intentional nonadherence. Provider satisfaction was unrelated to both intentional nonadherence outcomes.

The primary aim of this study was to examine the role of patient's medication beliefs in the patient-provider to adherence relationship. The second major hypothesis, that there would be a significant positive indirect effect of the patient-provider relationship to adherence through medication beliefs received strong support, particularly in the context of provider satisfaction. Study findings confirmed an indirect effect of provider satisfaction and both general adherence outcomes via medication beliefs. Thus, findings provide preliminary evidence that a patient's level of satisfaction with and trust in their providers influences whether they internalize the information provided by the providers, and that information may in turn influence decisions about adherence.

With regard to provider trust, there was a significant indirect effect for past month, but not past week adherence through medication beliefs. An alternative model with provider trust as the mediator found an indirect effect of medication beliefs to past month and past week adherence via provider trust. This finding raises the possibility that patient's medication beliefs also influence a patient's perception of their providers. One possibility is that if a patient's preconceived medication beliefs are congruent with the message from their providers, the patient is more likely to adhere to their medications. When the message received by patients is at odds with their beliefs, the patient may feel dissatisfied with their care or distrustful of their providers leading to poorer adherence. Negative medication beliefs may also reflect a more general skepticism or distrust of healthcare. Longitudinal data are needed to confirm the directionality of these effects.

An important and understudied area of HIV behavioral research concerns the role of intentional nonadherence, where volitional decisions by patients are made to alter their medication regimen. These deliberate decisions are a related yet separate phenomena from adherence which has led some to hypothesize they may be a product of a poor patient-provider relationship (Norton et al., 2010). In this study, it was hypothesized that a better patient-provider relationship would lead to more positive medication beliefs, and in turn less engagement in intentional nonadherence. In this sample, only provider satisfaction to lifetime intentional nonadherence through medication beliefs was significant. Provider trust was largely unrelated to intentional nonadherence. Of note, lifetime intentional nonadherence may reflect experiences with previous providers or older classes of HIV medication which have poorer adherence rates (e.g., Heath et al., 2002). Given the relative lack of association between study variables with intentional nonadherence, a spurious finding cannot be ruled out.

For PLWHA, a variety of patient-specific factors influence medication adherence, including adherence self-efficacy, substance use, depressive symptoms, social support, and demographic factors (Langebeek et al., 2014). The present research expands beyond a focus on individual level factors to consider the influence of patient perceptions of their provider in relation to medication adherence. Future research can extend the present findings by considering the role of patient-provider influences within a broader framework of both individual, contextual, and dyadic factors related to adherence. Self-regulation models provide a unifying framework that allows for a better understanding of how multiple factors interact to influence an individual's understanding of their illness and subsequent health behaviors related to treatment (Levanthal et al., 1997). According to self-regulation theory, patient's construct schemas about their illness based on factors such as culture, previous experience, and interactions with others, including their healthcare providers. A better understanding of the interplay among these variables can aid in our understanding of how patient-provider relationships influence adherence within the broader context of the multitude of factors that have been linked with adherence and related outcomes.

Overall, while additional work is needed, this study points to the potential importance of dialogue between patients and providers. The quality of the patient-provider relationship sets the stage for patient education by building trust and shared satisfaction. With an increasingly cost-driven environment where providers face-to-face time with patients is often limited, providers are challenged to build rapport and efficiently communicate with their patients. Although more research is needed, these initial findings point to the possibility that medical training should emphasize the development of communication skills in addition to medical expertise. It may also be beneficial for healthcare organizations to assess patient's perceptions of their providers,

particularly in the context of chronic illness which require high levels of medication adherence. Such feedback, where low trust or satisfaction is evident, can help organizations and providers improve patient outcomes through interventions aimed at improving doctor-patient relationships.

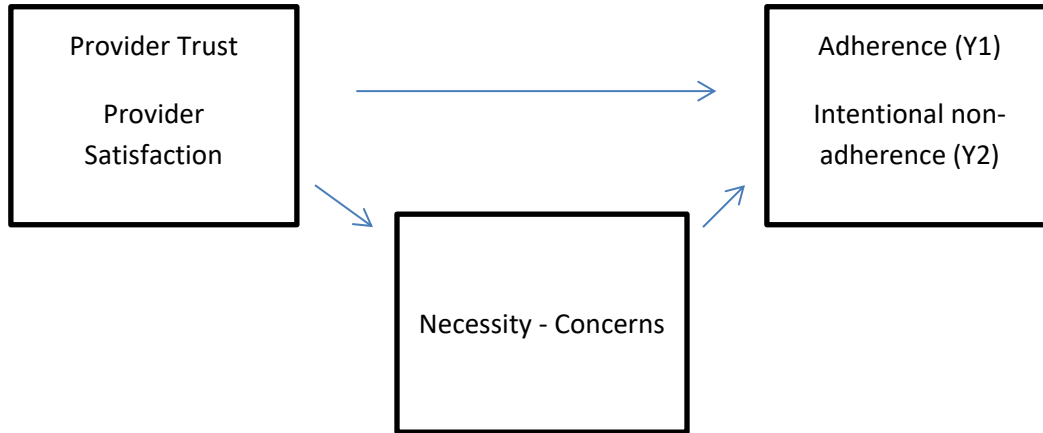
This study has several limitations, the first being the modest sample size and cross-sectional nature of these data which precludes causal inference. Although these findings point to the possibility that patient-provider relations influence beliefs rather than vice-versa, longitudinal data would help provide clearer evidence of the temporal sequencing of these effects. Our sample was recruited from an outpatient IV clinic; researchers are encouraged to examine these findings in underserved communities such as rural areas or individuals without consistent care (e.g., Stepleman, et al., 2006). Additionally, this project framed provider trust and satisfaction as separate variables. It may be that a model that includes both variables simultaneously or controls for one another is a better fit for these data. It is possible that provider trust and satisfaction reflect a more general attitude toward their providers rather than separate but related constructs. Future research should test such models to determine if they better explain the relationship between these variables.

Strengths of this study include a demographic makeup that is representative of PLWHA at large and is consistent with other samples of outpatient HIV patients (e.g., Beach et al., 2013; Cambiano et al., 2010). Methodologically, this study used a well-established measure of medication beliefs (Horne et al., 2013) and two previously developed measures of adherence and intentional nonadherence. This study's inclusion of intentional nonadherence is novel and adds to the paucity of literature on this variable.

In conclusion, the results of the present study suggest that one mechanism through which the patient-provider relationship influences medication adherence may be patients' beliefs about

their medications. These data provide preliminary evidence that the quality of a patient's perceived relationship with their providers and their beliefs about medications are relevant factors that exert an influence on HIV medication adherence and may be useful predictors of adherence. Providers are encouraged to focus attention on building strong rapport, trusting relationships and overall satisfaction to set the stage for effective patient education. Ensuring they educate patients about the necessity of taking medication and alleviating any concerns may improve patient outcomes and health.





**Figure 1.** Conceptual model. The effect of provider trust and provider satisfaction on Adherence (Y1) and Intentional nonadherence (Y2) with beliefs about medications (Necessity/Concerns differential) as a mediator.

**Table 1.** Demographic and Summary Statistics

Variable	(n)	(%)	M	SD
Age (years)			45.35	8.60
Less than High School	22	19		
High School diploma	41	35.3		
Some College or Degree	53	20.5		
Gender				
Male	67	57.8		
Female	47	40.5		
Transgender	2	1.7		
Race				
African American	50	43.1		
White	54	46.6		
Multiracial or Other	12	10.3		
Currently Employed	44	37.9		
Provider Trust			4.59	.86
Provider Satisfaction			4.38	1.01
Necessity/Concerns			2.24	1.13
Necessity			4.33	.57
Concerns			2.46	.64
Past Week Adherence		92.48		
Past Month Adherence		89.70		
Lifetime Intentional Nonadherence*			2.04	1.16
Past Month Intentional Nonadherence		17.69		

*Note:* n = 116.

**Table 2.** Bivariate Correlations Between Primary Variables

Variable	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1.Trust	-									
2.Satisfaction	<b>.65*</b>	-								
3.Necessity/Concerns	<b>.39*</b>	<b>.26*</b>	-							
4.Necessity	<b>.35*</b>	.04	<b>.74*</b>	-						
5.Concerns	<b>-.26*</b>	<b>-.34*</b>	<b>-.80*</b>	<b>-.19*</b>	-					
6.Past week adherence	<b>.34*</b>	<b>.21*</b>	<b>.26*</b>	.18	<b>-.22*</b>	-				
7.Past month adherence	<b>.18*</b>	<b>.23*</b>	<b>.23*</b>	<b>.25*</b>	-.12	<b>.36*</b>	-			
8.Intentional – Lifetime	-.08	-.05	<b>-.19*</b>	-.13	.16	-.14	<b>-.41*</b>	-		
9.Intentional – past 30-day	<b>-.24*</b>	-.13	-.17	<b>-.20*</b>	.08	<b>-.53*</b>	<b>-.46*</b>	<b>.25*</b>	-	

*Note:* Correlations represent Pearson's r, \* p < .05, Past month adherence: 0 = ≤ 95%, 1 = ≥ 95%.

**Table 3.** Path Results for Simple Mediation Models.

<b>Model 1.</b> Trust → BMQ → Adherence	<i>B</i>	<i>SE</i>	<i>T</i>	<i>P value</i>
(a) Trust → BMQ	0.610	0.108	5.655	<.001**
(b) BMQ → Adherence past week	1.690	1.528	1.106	0.271
(c') Trust → Adherence past week	6.309	1.991	3.168	.002**
(b) BMQ → Adherence past month	.372	.195	Z: 1.905	.057
(c') Trust → Adherence past month	.266	.253	Z: 1.052	.293
<b>Model 2.</b> Satisfaction → BMQ → Adherence	<i>B</i>	<i>SE</i>	<i>T</i>	<i>P value</i>
(a) Satisfaction → BMQ	0.289	0.101	2.854	0.005**
(b) BMQ → Past week	3.331	1.441	2.312	0.023*
(c') Satisfaction → Past week	2.707	1.610	1.681	0.095
(b) BMQ → Past month	.442	.188	Z: 2.351	.019*
(c') Satisfaction → Past month	.014	.198	Z: .069	.945
<b>Model 3.</b> Trust → BMQ → Intentional Nonadherence	<i>B</i>	<i>SE</i>	<i>T</i>	<i>P value</i>
(b) BMQ → Past month	-1.855	2.067	-.897	.372
(c') Trust → Past month	-4.534	2.691	-1.685	.095
(b) BMQ → Lifetime	-.183	.108	-.1701	.092
(c') Trust → Lifetime	-.030	.140	-.217	.829
<b>Model 4.</b> Satisfaction → BMQ → Intentional Nonadherence	<i>B</i>	<i>SE</i>	<i>T</i>	<i>P value</i>
(b) BMQ → Past month	-3.023	1.912	-1.581	.117
(c') Satisfaction → Past month	-1.936	2.128	-.910	.365
(b) BMQ → Lifetime	-.195	.099	-1.977	.05*
(c') Satisfaction → Lifetime	.003	.110	.026	.979

Note: \*  $p < .05$ , \*\*  $p < .01$ . BMQ = Beliefs about Medicines questionnaire.

**Table 4.** Bootstrap Estimates of the 95% CIs for the Indirect Effects.

<b>Indirect effects</b>	<b>OR</b>	<b>B</b>	<b>SE</b>	<b>CI (LB)</b>	<b>CI (UB)</b>
<i>Adherence</i>					
1a Trust → BMQ → 7-day Adhere	-	1.169	.872	-.197	3.429
1b Trust → BMQ → 30-day Adhere	<b>.184</b>	-	<b>.990</b>	<b>.251</b>	<b>4.140</b>
2a Satisfaction → BMQ → 7-day Adhere	-	<b>.961</b>	<b>.634</b>	<b>.126</b>	<b>2.710</b>
2b Satisfaction → BMQ → 30-day Adhere	<b>.127</b>	-	<b>.084</b>	<b>.021</b>	<b>.344</b>
<i>Intentional Nonadherence</i>					
3a Trust → BMQ → Past month	-	-.989	1.073	-3.155	.966
3b Trust → BMQ → Lifetime	-	-.099	.064	-.262	.004
4a Satisfaction → BMQ → Past month	-	-.854	.667	-2.630	.104
4b Satisfaction → BMQ → Lifetime	-	<b>-.056</b>	<b>.036</b>	<b>-.153</b>	<b>-.004</b>
<i>Alternative Models</i>					
BMQ → Trust → Past Month		<b>1.731</b>	<b>1.101</b>	<b>.232</b>	<b>4.860</b>
Trust → Necessity & Concerns → Past Month		<b>.194</b>	<b>.148</b>	<b>.012</b>	<b>.604</b>

*Note:* CI (LB) and CI (UB) represent the lower and upper bound of a 95% bootstrapped confidence interval with 10,000 resamples. BMQ = Beliefs about Medicines questionnaire.

## Appendix A.

### Patient-Provider Relationship Scale

Tinst1. We are interested in your relationship with your HIV care providers. The following questions ask about your relationship with the providers who are most involved in your HIV care. For example, the people who talk to you about how to take meds or get you started on meds; or the people who see you when you have an emergency. Remember, your responses will not be shared with any of your providers. We want to know how you truly feel about your HIV care providers.

- 1  Poor
- 2  Fair
- 3  Good
- 4  Very Good
- 5  Excellent

#### **How are your HIV care providers at...**

##### *Overall Communication*

- T1. ...explaining the results of tests in a way that you understand?
- T2. ...giving you facts about the benefits and risks of treatment?
- T3. ...telling you what to do if certain problems or symptoms occur?
- T4. ...demonstrating caring, compassion, and understanding?
- T5. ...understanding your health worries and concerns?

##### *HIV-specific Information*

- T6. ...talking with you about your sex life?
- T7. ...asking about stresses in your life that may affect your health?
- T8. ...at asking about problems with alcohol?
- T9. ...at asking about problems with street drugs like heroin and cocaine?

##### *Adherence*

- T10. ...giving you information about the right way to take your HIV medicines?
- T11. ...understanding the problems you have in taking your HIV medicines?
- T12. ...helping you solve problems you have taking your HIV medicines the right way?

##### *Participatory Decision-making*

T13. How often do your HIV care providers ask you to take some of the responsibility for your treatment?

- 1  Never
- 2  Rarely
- 3  Sometimes
- 4  Often
- 5  Very often

T14. If there was a choice between treatments, would your provider ask you to help make the decision?

- 1  Definitely Not
- 2  Probably Not
- 3  Uncertain
- 4  Probably Yes
- 5  Definitely Yes

T15. How often do your HIV care providers make an effort to give you some control over treatment decisions?

- 1  Never
- 2  Rarely
- 3  Sometimes
- 4  Often
- 5  Very often

T16. How often do your HIV care providers offer choices in your medical care?

T17. How often do your HIV care providers discuss the pros and cons of each treatment option with you?

T18. How often do your HIV care providers get you to state which treatment option you would prefer?

T19. How often do your HIV care providers take your preferences into account when making treatment decisions?

- 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

*Overall Satisfaction with Provider*

- 1  Poor
- 2  Fair
- 3  Good
- 4  Very Good
- 5  Excellent

T20. Overall, how would you rate your provider's personal manner (e.g., courtesy, respect, sensitivity, friendliness)?

T21. How would you rate your provider's communication skills (e.g., listening carefully, answering questions, giving clear explanations)?

T22. How would you rate your provider's technical skills (e.g., thoroughness, carefulness, competence)?

*Trust in Provider*

Tinst2. Thinking about how much you trust your HIV care provider, how strongly do you agree or disagree with the following statements?

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

T23. I can tell my HIV care provider anything, even things that I might not tell anyone else.

T24. My HIV care provider cares more about holding down costs than about doing what is needed for my health.

T25. My HIV care provider cares as much as I do about my health.

T26. All things considered, how much do you trust your HIV care provider?

- 1  Not at all
- 2  Only a little
- 3  Somewhat
- 4  Quite a bit
- 5  Completely



## Appendix B.

### Beliefs about Medications Questionnaire

Rinst1. 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. There are no right or wrong answers. Please tell us how you really feel about medications for HIV.

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

- C R1. My HIV meds give me unpleasant side-effects.
- N R2. My health depends on HIV medications.
- C R3. Taking HIV meds is embarrassing.
- N R4. Without HIV meds, I would become very ill.
- N R5. My health in the future will depend on HIV medications.
- C R6. HIV medications are a mystery to me.
- N R7. HIV medications keep HIV under control.
- N R8. HIV meds can keep me alive.
- C R9. Having to take HIV meds worries me.
- C R10. I sometimes worry about the long-term effects of HIV medications.
- C R11. HIV medications disrupt my life.
- N R12. Missing HIV medications for a day won't matter in the long run. (R)
- C R13. I sometimes worry about becoming too dependent on HIV medications.
- C R14. I am **unlikely** to get a bad side-effect from my meds in the next month. (R)
- N R15. HIV meds are my best hope for the future.
- C R16. Taking HIV meds has been much worse than I expected.
- C R17. I have received enough information about HIV medications. (R)
- N R18. My life would be impossible without HIV meds.
- C R19. The taste of my meds makes me feel unwell.

## Appendix C.

### Intentional Nonadherence

#### **Instructions**

The next questions will ask about your HIV meds. We understand that there are many challenges to taking HIV medications and many people struggle to take their pills as prescribed. Some people find it hard to take their pills according to all the special instructions. Some people get busy and forget to carry their pills with them and others decide to skip doses to avoid side effects or to just not be taking pills that day. Telling us about your actual experiences with HIV meds will help us to get a better understanding of what is needed to improve HIV care. So please answer honestly and do not worry about telling us that you don't take your pills perfectly, your answers are completely confidential.

People have different experiences regarding the decision to start taking HIV medications. Please take a moment to think about your own experience deciding to start taking HIV medications. Think about **all** the times that you and your doctor or nurse practitioner talked about HIV medications since you were diagnosed.

**O1.** Has your doctor or nurse practitioner ever recommend that you start taking HIV medications and you decided that it was not the right time for you?

- No (skip to **O2**)                       Yes

**O1a.** On how many separate occasions has your doctor or nurse practitioner discussed the need for you to begin HIV medications and you decided not to?

# \_\_\_\_\_

**O2.** Thinking again about the time since you very first started taking HIV meds, have you ever **stopped** taking one or more of your meds for any reason?

- No (skip to **O3**)                       Yes

**O2a.** On how many separate occasions have you stopped taking one or more of your HIV meds for more than a day?

# \_\_\_\_\_

**O2b.** On how many of these occasions was your decision to stop based on a recommendation from your HIV doctor?

# \_\_\_\_\_

**O2c.** On how many of these occasions did you decide not to tell your doctor or nurse practitioner that you had stopped taking one or more of your HIV meds?

# \_\_\_\_\_

**O3.** Some people we have talked to say that they sometimes take “medication vacations”

– meaning that they decide to take a break from taking some or all of their medication for a period of time.

Since you started HIV meds, have you ever taken a break from your meds, even for just one day?

1  No (Skip to O3b)

2  Yes

**O3a.** How many separate times have you taken a break from your HIV meds for one or more days

(Go to O3c) **O3b.** Even if you haven't actually taken a break from your HIV meds, how often do you think of taking a break?

1  Almost everyday

2  At few times a month

3  A few times a year

4  A few times ever

5  Never

**O3c.** Have you ever discussed taking a break from your meds with your doctor or nurse?

1  No

2  Yes

### Instructions

Some people we have talked to say that sometimes they make small adjustments to how they take their HIV medications because they are having side effects, because they had a change in their plans for the day, they were feeling depressed, or for other reasons.

O4a. *Since you started taking HIV medications, have you ever...*

...taken less of a medication than was prescribed?  Yes  No

O4b. *Since you started taking HIV medications, have you ever...*

...taken a medication dose significantly later than you had scheduled?  Yes  No

O4c. *Since you started taking HIV medications, have you ever...*

...taken two doses at the same time to make up for a previous missed dose?  Yes  No

O4d. *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”  Yes  No

## Appendix D.

### Last Month Adherence

**Instructions.** For the next question, please look at **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.

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 Click 'Continue' once

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

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.

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

Click 'Continue' once you have completed HANDOUT B.

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

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

In the past month, HOW OFTEN have you skipped a dose of your HIV meds because you were having side effects, had a change in your plans, felt depressed, or for some other reason?

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 Click 'Continue' once you have completed**

OK, you've made it to the last questions about your meds! Great work!

## **Appendix E.**

### **Past week Adherence**

For this last section, please look at the calendar that you filled out with the research assistant just a few minutes ago. Remember that you filled in the number of pills that you are supposed to take for your HIV for each day in the past week.

**O5a.** How many of your pills did you forget to take OR decide to skip on DAY 1?

**O5b.** Day 2

**O5c.** Day 3

**O5d.** Day 4

**O5e.** Day 5

**O5f.** Day 6

**O5g.** Day 7

## HANDOUT A

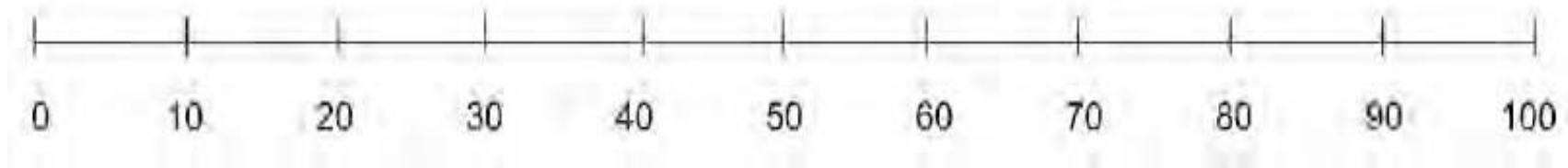
Put a mark on the line below at the point that shows your best guess about how much of your prescribed HIV medication you have taken in the last month. We would be surprised if this were 100% for most people.

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



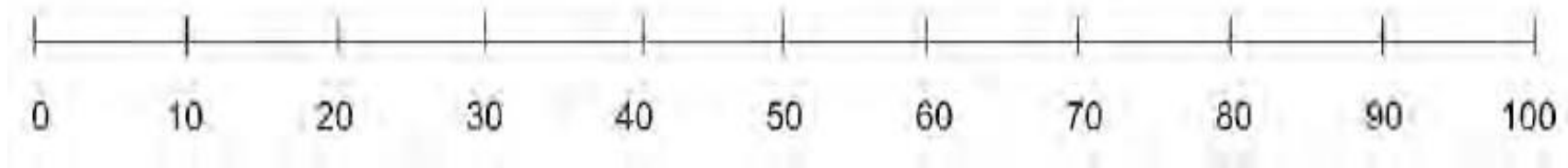
## HANDOUT B

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

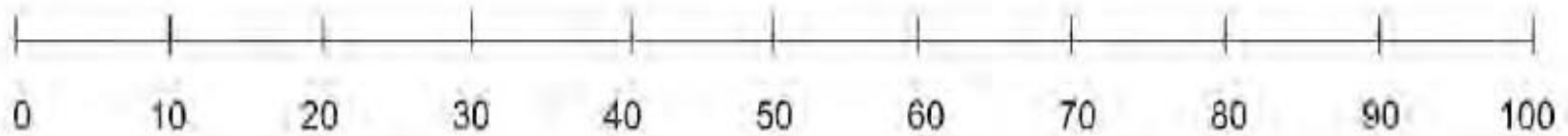
100% means that you always make small adjustments to your regimen



## 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, felt depressed, 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





## Appendix F.

### Demographic & Health History Questions

- A1. What is your gender?    1  Female                      2  Male                      3  Transgender
- A2. How old are you?                      \_\_\_\_\_ years old
- A3a. In what year were you born?    \_\_\_\_\_
- A3b. In what month were you born? \_\_\_\_\_
- A3c. On what day of the month were you born?    \_\_\_\_\_
- A4. What is the highest level of education that you have completed?
- 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
- A5. Which of the following BEST describes your racial/ethnic background? Is it...
- 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
- A6. Do you consider yourself to be Hispanic/Latina/Latino?
- 1  No    2  Yes
- A7. Which of the following statements applies best to you?
- 1  I am sexually attracted to men.
  - 2  I am sexually attracted to men and women.

3  I am sexually attracted to women.

A8. Which best describes your current relationship status?

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

A9. Are you married?

1  No

2  Yes

A10. Is English your first language?

1  No

2  Yes

A11. Are you currently employed?

1  No (skip to A12)

2  Yes (go to A11a)

A11a. On average, how many hours per week do you work?

1  Less than 10 hours

2  10 – 20 hours

3  21 – 39 hours

4  40+ hours

A12. 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.

Monthly income: \$ \_\_\_\_\_

A13. From which of the following sources do you regularly receive income? (check all that apply)

1  Wages or salary from job

2  Unemployment

3  Welfare

4  Disability

5  Spouse/Partner

6  Family

7  Friends

A14. In what year were you diagnosed with HIV? \_\_\_\_\_

A15. What was your most recent viral load result?

1  Undetectable

2  Detectable

3  Don't know

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