RUNNING HEAD: AABT FOR HAART ADHERENCE

Acceptance-Based Behavior Therapy to Promote HIV Medication Adherence

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ABSTRACT

A significant number of adults with HIV in the U.S. do not maintain adherence to highly active antiretroviral therapy (HAART) at adequate levels. Although traditional cognitive behavioral interventions have shown promise in promoting HAART adherence, acceptance-based behavior therapy (ABBT) may be particularly useful in this population. ABBT has the potential to overcome common avoidance-based barriers associated with poor adherence, including denial of various illness-related factors and avoidance of stigmatization. We describe the rationale for promoting psychological and behavioral acceptance in HIV-positive populations; outline an ABBT to promote HAART adherence targeting primary care patients from urban, minority, low socio-economic backgrounds; and report preliminary qualitative observations of treatment feasibility and acceptability.

Keywords: HAART; adherence; primary care; behavior therapy; acceptance and commitment therapy

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More than one million people in the United States are estimated to have HIV/AIDS infection, and up to 27% of those infected are unaware of their diagnosis (CDC, 2006). Most people require medications for effective HIV management, consisting of highly active antiretroviral therapy (HAART), which has demonstrated significant success in inhibiting HIV viral replication. HAART's benefits include reductions in morbidity, mortality, and overall healthcare costs for HIV-positive persons (Crum et al., 2006; Mocroft et al., 2003). However, adherence to HAART regimens is of paramount importance for treatment to be effective. Although there is some debate (e.g., Bansberg, 2006), it has been estimated that adherence (i.e., missing doses, late doses) to antiretroviral therapy must approach 95% for optimal effectiveness (Paterson et al., 2000), a very high level for any medical treatment.

Adherence in the U.S. to HAART remains relatively low; most researchers estimate median adherence to be 60% to 70% (Bartlett, 2002). Although there is no single behavioral intervention that has emerged as the gold standard for improving HAART adherence in this population, most studies have employed a treatment package that includes several core elements of traditional cognitive behavior therapy (CBT), including cognitive restructuring, motivational interviewing, and behavioral self-monitoring via pill diaries. Meta-analytic reviews of the efficacy of traditional CBT interventions for HAART adherence show small to medium effect sizes (Amico, Harman, and Johnson, 2006; Simoni, Pearson, Pantalone, Marks, and Crepaz, 2006), suggesting significant room for improvement. We review below common psychological HAART adherence barriers and discuss how they provide a roadmap for new directions in behaviorally-based HAART adherence interventions. Undoubtedly, systemic variables such as access to medications and dosing complexity influence adherence (see Haynes, 1974 for a review). Here we focus on psychological factors that may also affect adherence.

Self-care motivation

The cognitive appraisal model of stress and coping (Lazarus and Folkman, 1984) has received a great deal of attention from researchers in explaining various aspects of chronic illness. The model,

according to Lazarus and Folkman (1984), assumes that when confronted with a particular stressor, such as an HIV diagnosis, people will respond in various ways based on their motivational beliefs.

Beliefs about control are particularly relevant to HIV self-care. Because of HIV's notoriety, most patients have preconceived notions about how much control they will have over the disease process, its prognosis, and treatment options. Taylor and colleagues (2000) demonstrated that positive beliefs about one's self-efficacy in response to HIV diagnosis were associated with improved mental health and improved disease self-management. Malcolm et al. (2003) examined the role of beliefs in individuals with excellent HAART adherence records. A predominant theme was that successful adherence was motivated by the belief that the individual had control over his/her health.

Another important motivator may be the desire to practice a value-driven life, and the degree of clarity one has about one's personal values and associated goals. Many individuals lack clarity with respect to their values, as well as the link between those values and specific goals that emanate from them. Values can be thought of as broad life directions that point to patterns of behavior that will contact positive environmental consequences (Hayes, Strosahl, and Wilson, 1999). Values are distinct from goals in that the former can never be fully realized, whereas the latter can be accomplished. Ideally, one is clear with respect to his or her freely chosen values, has derived goals consistent with those values, and has in turn aligned his or her behavior to be consistent with those goals. One's values may affect appraisals of negative situations such that when something highly valued is threatened, beneficial action is motivated. In this population, a fearful response to HIV infection and its long-term implications could provide the impetus to strictly follow medication regimens. However, we hypothesize that value-inconsistent behavior is not uncommon in the HIV population. Specifically, many individuals with HIV may behave in a way inconsistent with their core values in order to avoid the psychological stress of accepting their HIV diagnosis and its implications (e.g., strict adherence to medication).

Avoidance-based coping

Health promoting behavior may be undermined by avoidance-based coping. An important individual factor to consider is the meaning behind taking HIV medications: acceptance of the diagnosis

and its related stresses (e.g., stigmatization (Madru, 2003; Schuster et al., 2005)). Such acceptance requires a willingness to acknowledge the cause of infection, the implications of infection on one's future, and openness to altering behaviors to fit the needs of maintaining healthy living. Acceptance of infection is not automatic and is undermined by denial, or the need to repress the realities of living with HIV. Therefore, the intentional control of distressing cognitions and emotions related to HIV may be a significant barrier in effective medication adherence. For instance, suppression of fear associated with HIV might lead to an unrealistic perception of one's health, causing the person to be lackadaisical about adhering to a medication regimen.

Wegner and Zanakos (1994) found suppression of emotional thoughts magnified the emotionality and accompanying physiological reaction of the suppressed thoughts. Further, attempts at thought suppression often exacerbate symptoms, producing a "rebound effect" in which thought frequency increases (Clark, Ball, and Pape, 1991; Zeitlin, Netten, and Hodder, 1995). Thus, individuals who attempt to ignore or suppress the stresses of living with HIV are at risk for feeling worse about their illness, having a worsened overall psychological state, and poor HAART adherence.

Avoidance-based coping is associated with lower adherence (Amir, 1997) and higher levels of distress (Holahan and Moos, 1983; Thompson, Gil, Abrams, and Phillips, 1992) in the HIV positive population. Weaver and colleagues (2005) assessed the degree to which coping style was associated with adherence to HAART among a sample of 322 HIV positive adults. Results revealed that a higher degree of avoidance-oriented coping was associated with lower levels of adherence, whereas approach-oriented coping was not associated with adherence. Jones and colleagues (2003) found that avoidance behaviors such as behavioral disengagement and self-blame were negatively correlated with adherence to HAART among a sample of 174 women. Johnson and colleagues (2005) examined the effects of coping style on adherence, and how this relationship may be mediated by the experience of HAART associated side effects. In a sample of 2,765 persons with HIV, those who reported severe side effects were significantly less likely to achieve at least 90% adherence. This relationship is particularly important to understand, as most persons treated with HAART will experience at least minimal side effects, which may or may not

resolve. Clearly avoidance-based coping puts individuals with poor side effect tolerance at risk for reduced adherence, as the only way to fully avoid side effects is to not take the medication. Such attempts to regulate private experiences (e.g., bodily sensations, feelings, thoughts) have been termed "experiential avoidance" (Hayes, Strosahl, and Wilson, 1999).

Rationale for psychological and behavioral acceptance

In summary, a variety of psychological factors that likely influence adherence to HAART regimens warrant attention in behavioral interventions. Extant literature indicates that avoidant coping styles have an adverse effect on adherence to HAART. We suggest that a lack of acceptance of the diagnosis and its implications, in addition to ongoing fear of stigma and associated community reactions, limit the openness of many HIV/AIDS patients about their disease and its management. Due to fear of stigmatization and judgment, many individuals avoid discussing their diagnosis and suppress thoughts associated with living with HIV. In fact, thought suppression might serve to exacerbate symptoms and lead to poorer overall mental and physical health. These factors support the rationale for an acceptance-based behavior therapy (ABBT) intervention designed to foster psychological acceptance and mindfulness (Herbert, Forman, and England, 2009). Such technology contrasts with existing interventions, most of which have focused primarily on changing or even suppressing thoughts regarding the disease and its implications.

Psychological acceptance refers to the ability to accept distressing subjective experiences (thoughts, feelings, sensations, memories, etc.) without efforts to avoid, escape, or otherwise change the content of such experiences, in the service of personally-relevant valued goals. Successful adherence to HIV medications is likely dependent on such psychological acceptance, as well as acceptance of the diagnosis itself, acceptance of various stressors associated with treatment, and acceptance of the stigma associated with HIV. Therefore, interventions targeting avoidance - both psychological avoidance of distressing experiences and behavioral avoidance of health-promoting behaviors - are warranted in this population.

The present pilot investigation involved the development of a brief acceptance-based behavior therapy (ABBT) intervention rooted in acceptance and commitment therapy (ACT; Hayes, Strosahl, and Wilson, 1999), which has emerged as the most widely practiced and researched of the new acceptance-based CBT treatments. ACT encourages patients to "defuse" from distressing psychological experiences and to adopt an accepting stance towards one's experience as it unfolds in real time, while pursuing behavioral goals derived from personal life values. This contrasts with traditional models of CBT, which are predicated on the assumption that therapeutic effects are mediated by changes in cognitions, including thoughts, beliefs, and schemas, and the corresponding emphasis on cognitive change efforts (Forman and Herbert, 2009). ACT also stresses exercises aimed at identifying and crystallizing key personal values, translating these values into specific behavioral goals, and designing and implementing behavior change strategies to realize those goals.

There is no standard approach to ABBT, as interventions vary in length from as little as a single session to open-ended formats of indeterminate duration, and are conducted in individual and group formats and across a variety of settings. Outcome research has demonstrated the efficacy of ABBT in behavioral medicine applications including chronic pain (McCracken and Eccleston, 2006), cigarette smoking cessation (Hernández-López, Luciano, Bricker, Roales-Nieto, and Montesinos, 2009; Gifford et al., 2004), Type 2 diabetes management (Gregg, Callaghan, Hayes, and Glenn-Lawson, 2007), substance abuse (Hayes et al., 2004), and weight loss (Forman, Butryn, Hoffman, and Herbert, 2009) (see Hayes, Luoma, Bond, Masuda, and Lillis, 2006, for a review). Furthermore, experiential avoidance has been shown to be a mediator in several studies involving a range of psychopathology (Levin, Yadavaia, Hildebrandt, and Hayes, 2007) and in chronically ill populations (e.g., Gregg, et al., 2007). However, ABBT has not yet been applied to promoting HAART adherence among an HIV positive population.

To the extent that experiential avoidance is associated with medication adherence among those with HIV disease, an acceptance-based intervention may represent a particularly good match for this population. The primary goal of the current study was to adapt an ABBT program for HAART adherence

and to examine the feasibility and acceptability of this new, acceptance-based behavioral intervention to promote HAART adherence in a racially diverse, low income sample.

METHOD AND RESULTS

Participants

Participants were recruited from a large primary care clinic for uninsured individuals with HIV disease living in the Philadelphia, Pennsylvania community. We recruited patients who were having difficulties adhering to their treatment regimens and were not treatment naïve (i.e., they had not initiated medication use within the past month). Referrals came from primary care providers, case managers, or self-referral from flyers posted in the clinic. Patients with severe mental illness (i.e., active psychosis, schizophrenia), mental retardation, AIDS dementia, and pregnant women were not eligible for participation. Active substance abuse was not an exclusion criterion, and was assessed via patient charts and documented when present.

Demographic variables

Sixteen participants were recruited. Average age of participants was 52 years (*SD* = 5.0), and 87.5% were male. A majority of the sample was African American (87.5%), single (37.5%) or separated/divorced (37.5%), and disabled (62.5%). All participants' income was below $15,000 per year. The educational attainment of the sample was mixed, with 37.5% having completed 11 years of schooling or less, 25.0% having completed high school, and 37.5% having completed at least some college. Two participants were homeless.

HIV variables

Participants had been diagnosed with HIV for an average of 12.1 years (*SD*=5.7); 12 of the participants had been diagnosed with AIDS, meaning their CD4 count had fallen below 200 at some point. Participants acquired HIV through sex with men only (37.5%), via sex with men and women (25.0%), and via IV drug use (37.5%).

The most commonly reported barriers to medication adherence among all participants were: being too busy (50.0%), side effects and other bad events related to the pills (37.5%), and stigmatization fears

(25.0%). Self-report measures were used to assess demographic information. With patients' written informed consent, medical charts were also reviewed to assess CD4 levels and viral load count. These biological measures were taken within 10 days of initiation of treatment (see Table 1 for summary of baseline characteristics). In some cases, previous CD4 and viral load data were available, but we chose to gather most recent CD4 levels and viral load counts because previous biomarker measurements were potentially outdated (e.g., >2 years old) and likely confounded by past treatment that might have been ongoing at the time of measurement.

Although this study focused on feasibility and acceptability of the intervention, we did examine changes in CD4 and viral load from baseline to end of treatment. Results showed a promising trend for both measures (CD4 (cell/mm3): baseline mean=372.3 (*SD*=167.4), end-of-intervention mean=487.3 (*SD*=225.3); viral load (c/ml): baseline mean=148.8 (*SD*=130.1), end-of-intervention mean=16.0 (*SD*=24.8)).

Insert Table 1 about here

Procedures

Treatment was offered free of charge. ABBT was implemented by a doctoral candidate in clinical psychology who was trained and supervised by a licensed clinical psychologist with recognized expertise in ACT. Each ABBT session was free-standing and participants could begin treatment at any session because the sessions were offered in successive weeks. An ideal course was deemed to consist of attending five sessions and was considered minimally complete via attendance of three sessions (i.e., treatment completers were defined as those who attended at least three sessions). Ten participants attended at least three sessions (62.5%) and four individuals attended four or more sessions (25%).

Treatment

ABBT consisted of three to five weekly 60-minute sessions conducted in a group format, with groups consisting of three to five patients. Each session served as a free-standing intervention in which

the overall acceptance-based principles were discussed and implemented. These core principles included developing "creative hopelessness" to highlight the problems associated with direct cognitive and emotional control strategies, fostering a willingness to accept HIV-related distress, and directing patients towards clarifying and focusing on life values. Treatment included experiential group exercises, role playing exercises, and homework (see Table 2 for further description of treatment elements).

Insert Table 2 about here

Reactions to intervention

Six participants reported the groups were very helpful (37.5%), six reported the groups to be moderately helpful (37.5%), and four reported the groups to be minimally helpful (25%). Qualitative observations suggested that acceptance-based intervention strategies were well-suited to this population. One key point made in each session was that attempts to avoid the realities of living with HIV are futile, leading to worsened health. Many participants corroborated this as they noted that their initial reaction to finding out they were HIV positive was to withdraw from social supports and medical care. For some, they only sought treatment when their health significantly worsened and they could no longer live without medication. Indeed, acceptance was not a new concept to participants as they recognized that taking an initial step towards HIV care required some level of acceptance that their HIV status would not change.

Considering none of the participants were treatment naïve, the crux of their HIV self-care was not necessarily admitting they needed HAART; instead, it depended on their commitment to taking the medication regardless of its side effects and seeking to live with HIV knowing the stigma and shame it could provoke. Participants enjoyed commiserating about which medications worked, which ones were notoriously harsh on the body, and which ones tasted bad. Relationships were the most important factor they discussed when troubleshooting life with HIV. These discussions focused on familial relationships (e.g., sharing one's HIV status with parents) and romantic relationships. New romantic relationships, in which one had not yet shared his/her HIV status, were particularly anxiety-provoking for some

participants. This connected well with the intervention's emphasis on living a value-driven life. Specifically, we discussed why people naturally seek intimate connections with others. We noted the importance of developing trust, confidence, and support from romantic partners and how not admitting one's HIV status would limit how close we can be to others. A frequent theme focused around the question: Do you want to avoid divulging your HIV status (due to fear of rejection, etc.), knowing that this may limit how close you can be to someone? Or, are you willing to admit you are HIV positive, despite the obvious risks in doing so, because it will afford the opportunity to be closer to someone and allow you to care for your disease openly?

One concern we had in developing this treatment was whether or not it would be too abstract for a relatively low functioning cohort. Acceptance-based interventions rely heavily on metaphors and experiential exercises, making them prone to abstraction and theoretical discussions. However, in our experience, this ABBT protocol was easily disseminable to patients. Although we used metaphors and indirect language at times to discuss problems, we connected these to concrete points about HIV and HAART. Patients appeared to experience these discussions as intellectually stimulating without being overly confusing. In many respects, speaking about HIV in abstract terms felt appropriate because it was a new perspective for most patients. Many reported past experience in which healthcare providers "finger-wagged" to convince them to take their medications. They noted their perception of such approaches as overly blunt, insensitive, and even patronizing, and several contrasted it with the less judgmental approach of ABBT.

DISCUSSION

The current study was a pilot trial to develop and investigate the feasibility of an acceptance-based intervention to promote HIV medication adherence delivered in a group format, co-located in a primary care clinic for HIV positive, uninsured individuals living in a large urban area.

As noted above, the ABBT intervention was designed to be highly experiential, which encouraged a high level of treatment engagement. This made for many enjoyable, productive, and engaging sessions in which we discussed the power (or lack thereof) of simple words like "AIDS" and

how our minds naturally relish in the opportunity to struggle with thoughts and feelings. This treatment had a self-reported effect on some participants because it was counterintuitive, challenging their conventional way of thinking about their disease and its relationship to their larger life. It allowed participants to think critically about their HIV experience, to acknowledge their concerns without dismissal or minimization, and to develop pragmatic solutions to everyday struggles.

Limitations

The small sample size limited our ability to examine treatment effects, and the focus of the project was treatment development rather than evaluation of efficacy. However, results of HIV biomarker measurements at baseline compared to end-of-treatment showed a promising trend. We chose a group format for the intervention to maximize efficient delivery of the intervention and because we expected participants to benefit from group-based discussions of disease management. However, this design could have impeded recruitment or undermined treatment acceptability for some potential participants.

Implications and Future Directions

HIV continues to be a significant health issue for millions of people worldwide. In the United States, living with HIV is possible because of the advent and availability of HAART. However, the success of HAART is dependent on adherence; if patients do not take their medication as prescribed at least 90% of the time, the medications do not work well and can in fact lead to negative health consequences. Consequently, considerable behavioral health research has targeted the promotion of medication adherence. Some data suggest behavioral and cognitive approaches do lead to increased adherence, but psychological acceptance has not been addressed in this literature.

As such, the present project sought to examine the feasibility and acceptability of an acceptance-based intervention to promote HIV medication adherence, co-located in a primary care clinic. Qualitative observations suggested that patients responded well to the intervention and it appeared to be a promising new direction in behavioral treatment to promote HAART adherence. Further research is now needed to examine the intervention's efficacy.

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Table 1. Demographic and baseline variables for ABBT (n = 16)

Variables	*M*	S.D.
Age	52.5	5.0
HIV variables[a]		
Years since HIV Diagnosis	12.1	5.7
CD4 (cell/mm^3)	372.2	167.4
Viral Load (c/ml)	148.8	130.1
Prescribed doses per 2 weeks	38.5	20.1
	%	*N*
Gender		
Female	12.5	2
Male	87.5	14
Race/Ethnicity		
African-American	87.5	14
Caucasian	12.5	2
Marital Status		
Single	37.5	6
Live w/partner/Married	25.0	4
Separated/Divorced	37.5	6
Education		
≤ 11th Grade	37.5	6
High School	25.0	4
Some College	37.5	6
4 Year College	0	0
Employment		
Part-time	37.5	6
Disabled	62.5	10

Note: M, mean; S.D., standard deviation. [a] HIV variables are based on participant self-report. Data were corroborated via medical chart review.

Table 2. ABBT exercises included in each session

Exercises	
a. Creative hopelessness	A core element in ABBT in which people are guided to recognize their control strategies have not helped their psychological and physical health, and in many cases have made them worse. In this population, it is theorized that inconsistent medication adherence is related to an avoidance of thoughts and discussions of HIV+ status, an unwillingness to accept the HIV diagnosis, and unhealthy behaviors including drug use.
b. Cognitive defusion	Defined as the ability to distance oneself from internal stimuli. Essentially, this means viewing "thoughts as thoughts," products of the mind that are not necessarily true, and therefore, should not dictate behavior. HIV+ patients are likely to be "fused" to fears regarding their disease, the stigma that it entails, and future concerns.
c. Psychological acceptance	Embracing the full range of one's ongoing experience, including distressing thoughts, feelings, sensations, memories, etc., fully and without defense or avoidance. Psychological acceptance relies heavily on the development of willingness. The goal of willingness is not to feel better; instead, patients focus on experiencing all feelings, whether good or bad. Patients with low medication adherence rates can be expected to be low in acceptance/willingness because they likely avoid the psychological distress associated with living with HIV. A willing, accepting perspective directly confronts denial. This avoidance may be experiential (i.e., they refuse to acknowledge their disease and its responsibilities) and/or behavioral (i.e., they refuse to attend medical appointments, take their medications, etc. because it would mean admitting illness).
d. Mindfulness	Used in this treatment to improve patients' abilities to be aware and accepting of present-moment experiences. Bringing attention to the many moments in life, fully and nonjudgmentally, facilitates psychological acceptance. Mindfulness connects to medication adherence because healthy self-management behaviors depend on nonjudgmental awareness of internal and external experiences.
e. Committed action	Incorporates the techniques listed above into a concrete behavioral plan. Each plan was individualized according to the patients' specific needs.
e. Values homework	Provide an impetus for assuming an accepting perspective towards life. Specifically, if a patient is accepting of his/her disease management responsibilities, he/she is more likely able to focus on developing a meaningful life, rather than simply avoiding taking medication. Values are chosen life directions that guide our behaviors. Due to their illness, many HIV+ patients can be expected to be "stuck" in their lives, having lost sight of their values and what they want to experience in life. By accepting their disease and its responsibilities, patients can be expected to gain freedom to focus on other aspects of their lives in such areas as family, career, education, spirituality, etc.