



HIV Treatment Outcome Disparities: Using Web-based Technology to Promote Adherence and Engagement with Care among African American Patients

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## HIV Treatment Outcome Disparities: Using Web-based Technology to Promote Adherence and Engagement with Care among African American Patients

### Abstract

Ethnic minorities continue to be disproportionately affected by the HIV epidemic and those individuals living with the virus experience differential outcomes in treatment. Technology-based approaches have been used to address a variety of health problems, but few studies have focused on the application of these approaches in addressing HIV treatment disparities. Using a sample of African-American patients identified as lost to follow-up for HIV treatment (n=33), this study examined the feasibility and acceptability of a web-based program designed to assess and improve treatment engagement. Participants were randomly assigned to either the web-based assessment program or the control group. Measures of behavior change intentions and motivation were administered to all participants. Assessment group participants completed additional measures to determine personal reactions and perceived credibility related to the web-based program. Findings indicated that assessment group participants reported significantly higher behavior change intentions than those in the control group. In addition, assessment group participants viewed the program favorably and rated it highly as a credible approach to improve their adherence and engagement with care. Findings from this pilot study indicate that the web-based program is feasible and acceptable as a clinical tool to improve engagement among African American patients with HIV.

### Keywords

Antiretroviral adherence health behavior change; health disparities; HIV/AIDS; motivation

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**ABSTRACT**

Ethnic minorities continue to be disproportionately affected by the HIV epidemic and those individuals living with the virus experience differential outcomes in treatment. Technology-based approaches have been used to address a variety of health problems, but few studies have focused on the application of these approaches in addressing HIV treatment disparities. Using a sample of African-American patients identified as lost to follow-up for HIV treatment (n=33), this study examined the feasibility and acceptability of a web-based program designed to assess and improve treatment engagement. Participants were randomly assigned to either the web-based assessment program or the control group. Measures of behavior change intentions and motivation were administered to all participants. Assessment group participants completed additional measures to determine personal reactions and perceived credibility related to the web-based program. Findings indicated that assessment group participants reported significantly higher behavior change intentions than those in the control group. In addition, assessment group participants viewed the program favorably and rated it highly as a credible approach to improve their adherence and engagement with care. Findings from this pilot study indicate that the web-based program is feasible and acceptable as a clinical tool to improve engagement among African American patients with HIV.

**Keywords:** Antiretroviral adherence; health behavior change, health disparities, HIV/AIDS, motivation.

## INTRODUCTION

Much attention has been directed toward evidence of disparities in HIV treatment outcomes experienced by racial/ethnic minorities and individuals with low socioeconomic status (Cargill, 2013; Millett, 2013; Steele et al., 2007). Factors cited as accounting for these disparities include differences in access to care and treatment delivery as well as poor adherence (Cargill, Stone & Robinson, 2004; Simoni et al., 2012). Antiretroviral therapy (ART) for HIV/AIDS requires adherence rates of 95% or higher for a patient to achieve immunological benefits and virologic suppression (Bartlett, 2002; Chesney et al., 2003). Research indicates, however, that more than half of patients are unable to meet these stringent standards (deBruin et al., 2010). Suboptimal adherence and poor treatment engagement adversely affect the health of individual patients in addition to undermining the objectives of strategies aimed at reducing the likelihood of onward transmission of HIV (Gardner et al., 2011). Patients who are not adherent at optimal levels are less likely to derive the immunological benefits of their regimens, and they risk developing treatment resistant strains of the virus that could be transmitted to others during sexual contact and drug use (Cohen, McCauley, & Gamble, 2012; Sethi et al., 2003).

The Internet and other forms of technology have been used to deliver innovative health interventions at a growing pace (Griffiths et al., 2006). The use of technology is increasingly viewed as filling a gap left by traditional interventions due to limited resources and access barriers. Despite the promise of the Internet, mobile devices, and other forms of technology in addressing HIV treatment engagement, there have been no studies to date that focus on how technology-based approaches could be used to improve treatment engagement and adherence among ethnic minorities lost to follow up for HIV care. Treatment engagement represents the extent to which patients actively participate in care by, for example, seeking treatment, maintaining regular contact with health providers, keeping appointments, actively communicating with health providers, and pursuing information and resources. Research indicates that ethnic minorities are more likely than others diagnosed as HIV seropositive to drop out of care or to decline treatment initiation (Cargill, 2013; Millett, 2013; Gardner, et al., 2011). For many of these individuals, motivation to initiate treatment or follow treatment goals consistently may be adversely affected by competing life goals and psychosocial stressors. Such stressors may include those related to meeting basic survival needs, such as securing food and shelter, as well as those related to coping with racial/ethnic discrimination, depressive symptoms, HIV-related stigma, fears of disclosure, and the sometimes adverse physiological demands of antiretroviral regimens (Cargill et al., 2004; Schilder et al., 2001; Siegel et al., 2000; Thrasher et al., 2008). Developing approaches that fully assess for the factors influencing treatment motivation among individuals vulnerable to poor treatment outcomes may be the first step in improving patient retention and engagement with care. These factors may not be readily apparent to health providers and their role in treatment-related behaviors may not become clear until they have adversely affected patient health outcomes (Houston, et al., 2011).

### Multidimensional scaling and treatment motivation

Research suggests that while traditional assessments of motivation have much value, they also have shortcomings that reduce their ability to fully capture motivation. These shortcomings include social desirability response bias (Del Boca & Noll, 2000; Rand, 2000), and a tendency of traditional assessment instruments to focus on motivation to “approach” or engage with a given health goal while ignoring the effect of competing goals, roles, relationships, and the motivation for avoidance behavior (Berg et al., 2012; Penedo et al., 2003). Multidimensional scaling (MDS;

Kruskal & Wish, 1978; Rosenberg, 1977; Stalans, 1995) is an exploratory data analysis technique that can be used to capture patient thoughts and beliefs that may either lead to treatment engagement or avoidance. Previous research has demonstrated that MDS can be employed to assess an individual's underlying cognitions because in an MDS study, where individuals are not provided instructions on how to judge or determine the similarity of their thoughts, the similarity ratings are viewed as natural, unconstrained, and fueled by implicit or nonconscious criteria (Jones & Koehly, 1993; Lease, McFall, Treat, & Viken, 2003).

In multidimensional scaling, patients are presented with each possible pairing of their own cognitions, thoughts, and beliefs about treatment and asked to rate the similarity of each pair. MDS uses these ratings to generate visual configurations that depict an individual patient's motivation both for and against treatment. In doing so, MDS could serve as an alternative assessment approach and provide immediate information that traditional techniques may have more difficulty capturing. The visual configurations generated by MDS could be used to aid patients in increasing their awareness of the factors that influence their treatment-related behaviors. In this way, such an assessment tool could serve as a springboard to the development of patient-centered behavioral interventions aimed at improving treatment engagement.

Using a sample of African Americans living with HIV/AIDS, the aim of this pilot study was to explore the feasibility of employing a web-based assessment program to assess the nature of antiretroviral treatment motivation among patients lost to follow up for HIV care and those with histories of poor treatment adherence. Our goal was to determine whether the web-based program could be used to identify the various factors that influence a patient's motivation for treatment and determine the potential of the assessment tool in promoting treatment engagement.

## **METHODS**

### Participants

Study participants consisted of 33 African Americans living with HIV. A participant was eligible for the study if he or she was 16 years or older, HIV seropositive, and had missed more than half of all scheduled appointments during the past year with a health provider (e.g., physician, nurse practitioner) responsible for their care or antiretroviral therapy for HIV. Eligible participants were identified by case managers and health care workers at both hospitals from lists of patients who had been identified as lost to follow up. Participants enrolled in the study reported that they were not receiving care elsewhere.

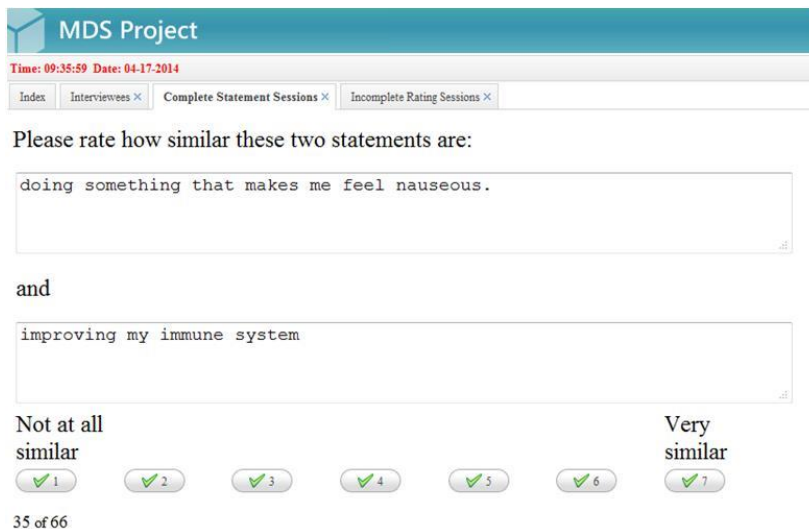
### Design and Procedures

All potential participants were randomly assigned to either the experimental group that received the web-based assessment program or a control group prior to being contacted for study participation. Participants in both groups met with a study interviewer for a single session. Participants randomized to the control group were only asked to complete four measures designed to obtain demographic data, adherence information during the past four days, treatment motivation, and behavioral change intentions. Participants in the assessment group completed identical measures in addition to four measures designed to gauge their views of the web-based program. The web-based treatment motivation assessment program was not administered to control group participants. Participants were administered informed consent subsequent to the administration of questionnaires. All procedures for recruitment, data collection and confidentiality were reviewed and approved by the Institutional Review Boards of Mercy Hospital and Medical Center and Mt. Sinai Hospital Medical Center in Chicago.

Prior to using the web-based program, assessment group participants were asked by the interviewer to provide short phrases or sentences that described what they were doing whenever they followed their ART regimen. Participants who had not initiated treatment were instructed to provide short phrases or sentences that described what they could be doing if they were on antiretroviral therapy. Participants were instructed to select brief phrases and sentences that reflected their own thoughts, beliefs, or appraisals related to treatment. After their treatment descriptions were elicited, participants were asked to review the list of statements which were subsequently entered into the web-based assessment program. Participants used a laptop computer to access the assessment program which presented, in random order, all possible paired combinations of their descriptive statements and phrases (i.e., treatment-related thoughts and appraisals) as well as six conceptual markers that study investigators added to the computerized program to aid in the interpretation of mappings generated by multidimensional scaling analysis. Conceptual markers were used to examine the extent to which a participant's treatment-related thoughts or appraisals corresponded to: 1) intrinsic versus extrinsic motivation; 2) approach- versus avoidance-oriented behavior with regard to their regimens; and 3) positive versus negative emotions.

Figure 1 provides an example of a screen from the web-based program showing two treatment descriptions from a specific study participant. Participants rated the similarity of each of pairings of treatment descriptions and conceptual markers to one another using a seven-point rating scale ranging from *not at all similar* (1) to *very similar* (7). To determine the extent to which a participant viewed a given thought or appraisal as representing their typical views of treatment, participants were also asked to compare treatment descriptions to a self-referent item (“...describes the way I usually think about my HIV treatment plan”).

**Figure 1. Screen capture from web-based program**



MDS used the ratings entered into the web-based program to generate a geometric configuration that visually mapped how a participant's own thoughts about treatment were related to one another as well as their treatment behaviors. In this study, the participant's treatment descriptions represented treatment-related cognitions or appraisals. The interviewer explained the MDS map to each web-based participant, using the conceptual markers to serve as a guide in interpretation.

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Participants in both groups received an incentive upon completion of their study session. Participants in the assessment group received a \$60 incentive while participants in the control group received a \$15 incentive. The difference in incentive amounts was due to the significantly greater time commitment required from assessment group participants versus control group participants who were only asked to complete four brief questionnaires.

### **Measures**

#### Descriptive demographics

A brief 13-item questionnaire was used to obtain participants' basic demographic data, including age, ethnicity, education, income, marital status, number of children, and computer usage.

#### Treatment adherence

Self-reported adherence was assessed with the AIDS Clinical Trials Group (ACTG) adherence questionnaire (Chesney et al., 2000). Participants were asked to indicate within a four-day period the number of doses missed for each antiretroviral medication prescribed, the number of days all doses were missed, and how closely the prescription was followed (i.e., according to schedule and special instructions).

#### Exploratory outcome evaluation measures

We explored the effect of the web-based assessment program on treatment motivation by employing the 15-item Treatment Self-Regulation Questionnaire (TSRQ; Williams, Freedman, & Deci, 1996; Williams, et al., 1998). The TSRQ provides a standard measure of intrinsic and extrinsic motivation for following treatment. A sample item from the subscale designed to gauge intrinsic motivation is: "Improving my health is something that I am doing by my own choice." A sample item from the subscale designed to assess extrinsic motivation: "I feel pressure from others to take the medications." Items were rated on a 7-point Likert scale, with higher ratings indicating greater endorsement.

To evaluate the effect of the assessment program on treatment behavioral change intentions, we adapted a single-item measure that has been used in previous research to assess individual intentions for behavior change (Willey et al., 2000). Using a 10-point scale, participants were asked to rate their intention to either (a) initiate HIV treatment, or (b) improve their antiretroviral therapy adherence behaviors within the next six months.

#### Feasibility and acceptability

To assess the feasibility and acceptability of the web-based program, we administered the Credibility Scale (CS; Addis & Carpenter, 1999) to gauge the extent to which participants viewed web-based assessment program as credible. A sample item in the measure, which was modified to reflect the content of the web-based program, included: "How effective do you think this evaluation program would be for most people in understanding how they view HIV treatment?" Participants rated each of the seven items on a 7-point scale, ranging from 1 (not at all) to 7 (extremely). In addition, we employed an adapted version of the Personal Reactions to Rationale (PRR; Addis & Carpenter, 1999) to assess the extent to which participants believed the program would be effective in their own lives. Sample items included: "How helpful do you think this program would be for you?" and "If you were to seek help with managing your HIV treatment regimen or deciding whether to start treatment, how open would you be to using this type of program?" Participants rated each of the five items on a 7-point scale, ranging from 1 (not at all) to 7 (extremely).

#### Data analytic strategy

Due to the exploratory nature of the study and the corresponding small sample size, we focused primarily on descriptive analyses. To evaluate feasibility, we recorded the number of

participants who completed the elicitation procedure and all paired comparisons as required by the web-based assessment program. We also recorded the extent of their activity during each of these tasks (e.g., number of treatment-related cognitions and appraisals compared). To assess acceptability, we calculated mean scores on the two quantitative measures for credibility and participant reactions.

To evaluate the preliminary impact of the assessment program, we used independent samples t-tests to examine differences between the assessment and control groups on measures of treatment motivation and behavior change intentions. For multidimensional scaling analyses, participant ratings of treatment-related descriptions were analyzed using SMACOF (Scaling by MAjorizing a COmplicated Function). SMACOF is an MDS program that minimizes stress by using majorization, an optimization strategy used in MDS. SMACOF provides such an algorithm (de Leeuw & Heiser, 1980; de Leeuw & Mair, 2009). We generated two-dimensional configurations for participants in this study to simplify interpretation. The configuration examined in this study had acceptable goodness-of-fit measures, with stress values ranging from 0 to 0.15.

## **RESULTS**

### **Sample Description**

The sample consisted of 33 individuals who were randomized to either the web-based assessment group ( $n = 18$ ) or control group ( $n = 15$ ). Among the study participants, the mean age was 35 years ( $SD = 12.5$ ; range 16-62); all were African American; and most were male (67%;  $n = 22$ ). The majority of participants (61%) self-identified as being heterosexual, 36% as gay or bisexual, and 3% as “other.” Eighty-two percent of participants reported being single, and 58% had children. Most participants reported continuing their education beyond high school (51.5%;  $n = 17$ ), but only two indicated earning a baccalaureate or higher level degree. Eighty-eight percent of the sample had annual incomes below \$20,000. There were no statistically significant differences between participants in the web-based assessment and control groups.

All participants had been identified as lost to follow-up during the past year by their health providers. Mean self-reported adherence during the four days prior to study enrollment was 58%. Participants on the average reported poor engagement with care, with the majority missing medical appointments for at least six consecutive months. The mean length of time participants reported being diagnosed as HIV seropositive was 8.9 years (range, 5 months – 31 years).

Computer usage among participants was common with nearly half (49%) reporting using the Internet, computers, or iPad tablet devices “very often/every day” during the previous week, followed by 9% who described use as “sometimes/occasionally” during this period. When asked to rate their skills with regard to using the Internet and computer devices, 58% characterized their skills as “very strong.”

### **Feasibility of web-based assessment program**

Participants completed all study procedures. During the elicitation procedure with assessment group participants, the number of treatment-related cognitions ranged from 10 to 16. In general, participants compared a mean of 188 paired combinations ( $SD = 39$ ; range 137 to 253), including the conceptual markers that were included in the computerized rating program. The total time for participants to complete the paired comparisons ratings ranged from 45 minutes to one hour. Cognitions reported by participants included descriptions of treatment in concrete terms (e.g., “swallowing a pill”) to those framed in terms of the purpose and consequences of following treatment (e.g., “staying alive”). Other treatment-related cognitions described treatment in terms of



experiencing aversive side effects and feeling the need to conceal one's serostatus due to concerns about stigma. Table 1 provides examples of a specific participant's cognitions that convey treatment descriptions.

**Table 1. Descriptions of treatment: Cognitions and appraisals for selected participant.**

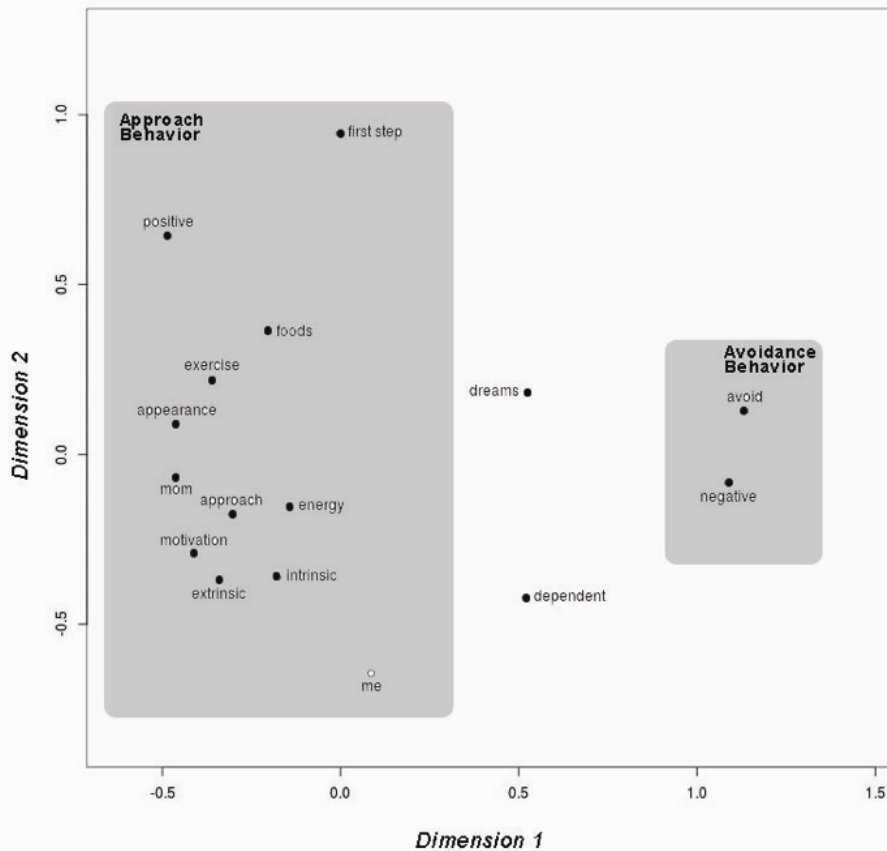
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First step: "Something I do before breakfast"
Appearance: "Keeping up appearances"
Energy: "Getting energy to do my daily tasks"
Foods: "Eating healthy foods"
Motivation: "Something I do for my kids"
Dependent: "Being dependent on this one pill"
Exercise: "Exercise"
Mom: "Something I do for my mom"
Dreams: "Taking it in the morning to avoid negative dreams"
Appraisal statements
Positive: "Something that is positive or pleasant to me"
Negative: "Something that is negative or unpleasant to me"
Avoid: "A thought that makes me want to avoid my HIV treatment plan"
Approach: "A thought that makes me want to stick with my HIV treatment plan"
Intrinsic: "Something I choose to do in order to get what I really want out of life"
Extrinsic: "Something I do because it is required of me or someone else wants me to do it"
Me: "Describes the way I usually think about my HIV treatment plan"

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After rating these treatment descriptions to one another, MDS was used to generate a two-dimensional configuration that mapped the participant's underlying view of treatment based on the relationship between the descriptions and appraisal statements (see Figure 2). The proximity of items on the map to one another indicates the degree to which the participant viewed these items as similar to one another. The left side of the participant's mapping depicts clusters of cognitions (such as "keeping up appearances," "something I do for my mom," "something I do for my kids") which were associated with treatment approach-oriented behaviors due to their proximity to this appraisal statement. Similarly, the right side of the map contains cognitions that were associated with treatment avoidance and perceived as negatively valenced due to their proximity to these appraisal statements (e.g., "being dependent on this one pill," and "taking it in the morning to avoid negative dreams").

**Figure 2. MDS mapping of participant treatment cognitions and appraisals.**



Acceptability: Personal reactions and perceived credibility

Based on the PRR, participants on the average viewed the web-based assessment program in very positive terms ( $M = 6.42$  out of 7 points;  $SD = 0.66$ ). Seventy-two percent ( $n=13$ ) of assessment group participants believed that the program would be “extremely” helpful to them based on the highest rating. Twenty-eight percent gave the program ratings of “5” or “6”. Sixty-one percent ( $n=11$ ) of assessment group participants indicated that the program could help them learn effective ways of managing their treatment regimen or deciding whether to initiate it. Scores from the CS indicated that participants viewed the assessment program as having high levels of credibility ( $M=6.5$ ;  $SD = 0.66$ ).

Treatment behavior change intentions and treatment motivation

Compared to the control group, web-based assessment group participants reported greater levels of change intentions ( $p = .02$ ; Cohen’s  $d = 0.84$ ). Using a median split, high levels of behavioral change intentions were indicated by 83% of assessment group participants in contrast to 47% of control group participants. There were no statistically significant differences between the two groups of participants with regard to either intrinsic or extrinsic treatment motivation. Results for the effect of the assessment on behavioral change intentions and treatment motivation are shown in Table 2.

**Table 2. Treatment behavioral change intentions and treatment motivation**

Measure	Sample (n=33)	Assessment (n=18)	Control (n=15)	Test Statistic	p
Change intentions	8.7 (2.4)	9.6 (1.3)	7.6 (3.1)	2.44	0.02
Intrinsic motivation	6.6 (0.8)	6.7 (0.6)	6.4 (0.9)	0.81	0.43
Extrinsic motivation	4.2 (0.8)	4.1 (1.4)	4.2 (1.6)	-0.13	0.90

Note. The p values are values on independent samples t-tests. Motivation and change intention scores were transformed before conducting statistical tests to account for skewed distributions. Mean values are presented in original units.

## DISCUSSION

To strengthen both individual- and community –level outcomes of antiretroviral therapy, retaining HIV seropositive patients in care and helping them attain optimal levels of adherence on a consistent basis is essential (Das et al., 2010; Granich, et al., 2009; Metsch et al., 2008; Montaner et al, 2010). Using a sample of African American patients identified as lost to follow up for HIV care, this pilot study explored the feasibility and acceptability of a novel web-based program in assessing patient treatment motivation. In addition, the study examined the potential viability of this program in promoting adherence and treatment engagement among patients at risk for poor treatment outcomes. The majority of participants viewed the web-based program as positive, and compared to participants in the control group, assessment group participants reported significantly greater intentions to either improve their adherence or initiate ART within the next six months.

Participants in this study indicated that the web-based program, particularly the visual mappings generated by multidimensional scaling, could be helpful in developing strategies either for better managing their regimens or deciding whether to initiate treatment. In addition, use of this web-based assessment program was successful in busy clinical settings. The study, which was conducted at two large hospitals, required minimal resources and staff to generate patient-centered assessments of treatment motivation. The automated nature of the web-based program may make it well suited for resource-limited settings burdened by poor patient engagement and inadequate staff numbers needed to conduct individual assessments.

## CONCLUSION

The findings presented in this study need to be interpreted with caution. The study used a cross-sectional design which prevented us from evaluating the effect of the web-based assessment approach over time in terms of adherence, appointment keeping, and other indicators of engagement. In addition, given the small sample size, the study may be limited in its ability to generalize to a larger population of HIV seropositive patients lost to follow up. These limitations notwithstanding, the results indicate that a web-based treatment motivation assessment program using multidimensional scaling could be helpful in improving behavioral change intentions among patients vulnerable for poor treatment outcomes. Such an approach could serve as a viable tool in efforts to engage lost to follow up patients.

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Given the promising findings presented in this preliminary study, future research should focus on evaluating this web-based program in a larger randomized controlled trial. Such research could examine how assessments provided by MDS exert their effect on individual behavioral change intentions. It would be valuable to determine how an individual's awareness of underlying cognitive processes may affect treatment-related behaviors. Another area for investigation involves how mappings of treatment-related cognitions could be used as part of clinical interventions. The mappings generated by MDS provide visual representations of cognitions that both compromise and facilitate adherence. In many cases, individuals may not be aware of these mental processes (Levesque, Copeland & Sutcliffe, 2008; Sheeran, Gollwitzer & Bargh, 2013). Psychosocial stressors, including poverty, discrimination, stigma, and negative affect, may make individuals more susceptible to the influence of these implicit or nonconscious processes (Bongers & Dijksterhuis, 2009; Philips, Hine, & Thorsteinsson, 2010). Future research should examine how health care providers could use maps developed for individuals living with HIV to develop patient-centered behavioral interventions and approaches aimed at increasing engagement with care.

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