

PRELIMINARY FEASIBILITY AND ACCEPTABILITY OF A CULTURAL ADAPTATION OF ACCEPTANCE AND COMMITMENT THERAPY FOR LATINXS WITH HIV AND DRUG USE DISORDERS IN PUERTO RICO*

VIABILIDAD PRELIMINAR Y ACEPTABILIDAD DE UNA ADAPTACIÓN CULTURAL DE LA TERAPIA DE ACEPTACIÓN Y COMPROMISO PARA LATINXS CON VIH Y TRASTORNOS POR USO DE DROGAS EN PUERTO RICO

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ABSTRACT

Acceptance and Commitment Therapy (ACT) has shown promising evidence for self-stigma among people with human immunodeficiency viruses (HIV) and drug use disorders (DUD). However, uncertainty remains regarding the appropriateness of this intervention for Spanish-speaking Latinxs. In this proof-of-principle study, we assessed the feasibility and acceptability of a culturally adapted ACT intervention developed to reduce HIV and DUD self-stigma in a sample of Spanish-speaking Latinxs. Eight primary care patients with HIV and DUD participated in this proof-of-principle study. Outcomes included feasibility and acceptability measures, as well as session attendance rates. All participants described the intervention as plausible, achievable, easy to use, and were open to treatment. The culturally adapted ACT appears to be acceptable and feasible intervention for Spanish-speaking Latinx primary care patients. A randomized control trial is warranted to better explore its efficacy.

KEYWORDS: Behavioral interventions, Drug use disorders, HIV, Self-stigma.

RESUMEN

La Terapia de Aceptación y Compromiso (TAC) ha demostrado ser una intervención prometedora para el estigma internalizado en personas con virus de la inmunodeficiencia humana (VIH) y trastornos por uso de drogas (TUD). Sin embargo, hay incertidumbre sobre si esta intervención es apropiada para latinxs hispanxs hablantes. Este estudio preliminar evaluamos la viabilidad y aceptabilidad de una intervención TAC culturalmente adaptada y desarrollada para reducir el estigma internalizado del VIH y TUD en una muestra de latinxs de habla hispana. Ocho pacientes de clínicas primarias con diagnóstico de VIH y TUD participaron en este estudio. Se recopiló medidas de viabilidad y aceptabilidad, así como tasa de asistencia. Todas las personas participantes describieron la intervención como aceptable, alcanzable, fácil de usar e indicaron estar receptivas a la terapia. La TAC parece ser una intervención aceptable y viable para las personas pacientes de atención primaria de descendencia latina de habla hispana. Un estudio de control aleatorizado es requerido para explorar mejor la eficacia de la intervención.

PALABRAS CLAVE: Estigma internalizado, Intervenciones conductuales, Trastorno por uso de drogas, VIH.

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Human Immunodeficiency Virus (HIV)-related stigma continues to be a major factor hindering HIV treatment and affecting the overall wellbeing and physical/mental health of persons living with HIV (PLWHIV) (International Planned Parenthood Federation, 2014). Compared to all people with HIV, Latinxs have lower viral suppression rates. For every 100 Latinxs with HIV, 61 received some HIV care, 49 were retained in care, and 53 were virally suppressed (Center for Disease Control and Prevention, 2020). According to the 2019 Center for Disease Control and Prevention (CDC) HIV Surveillance Report, Puerto Rico (PR) is one of the top ten states/territories with the highest HIV prevalence and related deaths (CDC, 2021). Injection drug use is also the third HIV transmission risk factor among males in PR, and a common risk factor among women with sexual partners that use contaminated injection equipment (HIV/AIDS Surveillance Program-Puerto Rico Department of Health, 2019). Consequently, people who inject drugs should be the focus of HIV prevention and treatment strategies. Lack of attention to drug use disorders (DUDs) are associated with disability, unemployment, a host of other social problems, extensive comorbid health conditions (Room, 2005; SAMHSA, 2016), and increased risk for contraction of HIV (National Institute of Drug Abuse, 2020; Andrinopoulos et al., 2014). Engaging people with co-occurring HIV/DUDs in evidence-based treatments is highly relevant to public health.

PLWHIV who have DUDs face multiple forms of stigma. One of them is self-stigma, defined as the internalization of the stereotypes and judgments made by society towards a stigmatized group and fear of being rejected; and it may constitute a barrier for DUDs treatment engagement and retention (Tsai et al., 2019). Furthermore, self-stigma is considered a common risk factor in individuals with mental illness, especially in highly stigmatized groups (e.g., ethnic minorities and PLWHIV), often leading to low self-esteem and self-efficacy (Batinić et al., 2014; Watson et al., 2007), shame (Luoma & Platt, 2015),

social avoidance (Corrigan & Watson, 2012) and poor quality of life (Holubova et al., 2016).

Persons experiencing self-stigma are frequently unaware of its deleterious health effects and its association with suicide risk (Latalova et al., 2014; Oexle et al., 2017). Experts recommend addressing self-stigma as a modifiable target for treatment and suicide prevention efforts. Meta-analysis of studies on Antiretroviral Therapy (ART) adherence from Africa and North America (Mills et al., 2006) suggests that treatment adherence may be improved by placing it within a framework of patient-centered treatment that considers self-stigma as a moderator of intervention effectiveness. Therefore, reducing self-stigma needs to be prioritized as a critical component of treatment for DUDs in this vulnerable group.

Acceptance and Commitment Therapy (ACT) is an evidence-based behavioral intervention that uses acceptance and mindfulness strategies together with commitment and behavior change strategies. It is a well-researched treatment that has shown to reduce stigma-related emotions such as shame, hopelessness, and behavioral avoidance in PLWHIV who also present people with DUDs (Hayes et al., 2006; Lillis & Hayes, 2007; Luoma et al., 2008; Skinta et al., 2015; Luoma et al., 2012; Lee et al., 2015). Luoma and colleagues' (2008) preliminary outcomes study with 88 participants found medium to large effects in self-stigma and shame, the primary outcome variables. Subsequently, a Randomized Clinical Trial (RCT) demonstrated that this acceptance-based treatment protocol was efficacious at improving treatment adherence and reducing substance use (Luoma et al., 2012). Although the evidence base supporting the usefulness of ACT for reducing self-stigma has grown over the past years, there remains uncertainty regarding the appropriateness of these interventions for Spanish-speaking Latinxs since they have been routinely excluded in treatment outcome studies (Masuda et al., 2009; Guerrero et al., 2013;

Alegría et al., 2006). ACT is one of the emerging third-wave cognitive-behavioral therapies (Hayes et al., 1999). Unlike traditional cognitive-behavioral therapies, ACT emphasizes psychological inflexibility as the source of human suffering (Hayes et al., 2006; Hayes et al., 1999). Therefore, the priority of ACT interventions is developing a meaningful life while accepting and being in contact with internal events as they arise (Hayes et al., 2012).

The present proof-of-principle aims to assess the preliminary feasibility and acceptability of the acculturation of an ACT-based psychosocial treatment manual for Latinxs with HIV/DUD who also present self-stigma associated with drug use identity. We report results from preliminary work involving translation from English to Spanish and culturally adapting the ACT intervention manual, developed by Drs. Luoma, Kohlenberg and Hayes (Luoma et al., 2008).

METHOD

The current study investigated the preliminary feasibility and acceptability of a protocol to reduce self-stigma in persons with HIV and DUDs. The university's Institutional Review Board (IRB) approved the study (Protocol Number: A3890118), and consent was obtained from participants before initiating protocols.

Participants and recruitment sites

Persons in the Central and Northern areas of Puerto Rico were recruited from primary care centers, which received funds from Health Resources and Services Administration (HRSA). These centers are community-based health care to provide primary care services in underserved areas. They provide comprehensive primary health care treatment that integrates behavioral services for low-income and vulnerable populations, including persons with HIV and DUDs. Eligible participants were adults 21+, who live with HIV and DUDs, receive treatment at a primary care center, and had endorsed items of the Substance

Abuse Self-Stigma Scale (SASSS; Luoma et al., 2013).

Procedures

Case managers from the primary care centers where HIV and DUDs treatment services are available identified eligible subjects and provided initial information about the study with a script approved by the IRB. Those who expressed further interest in the study were given additional details, including contact information and appointments with the research staff for initial interviews. The research staff did not have access to clinical records or any identifiable information before meeting the participants. Screening interviews were conducted in private offices to ensure confidentiality.

Study data were kept on the study coordinator's password-protected computer, also kept inside research facilities. An independent Data Safety Monitoring Board was set up to review safety reports during the project year 2018-2019. The committee was comprised of five persons to be made up of expert members not related to the study (i.e., mental health professional, ethics expert, statistician, a representative of persons with HIV and DUDs, an experienced researcher), representative of the funding agency and/or, community people with knowledge of research activities.

Participants had a consent form where the study and their rights were clearly explained. It is also important to note that risks associated with the study were minimal and mainly were linked to the possibility of feeling uncomfortable or embarrassed while being recruited or answering some of the study's questions during assessments or intervention. The questionnaire was verified with a panel of experts in the treatment field to minimize any risks or adverse reaction related to the questions. No questions that might threaten their current relationship with the primary care center were made. Participants were instructed at the initiation of their participation about the importance of confidentiality in the

study. Participants received incentives (\$20.00 per interview) when completing the pre- and post-assessments to cover time and transportation. Participants who started the first assessment and did not meet all the eligibility criteria to participate in this study also received an incentive for the time spent. Participants could withdraw from the intervention at any time and continue with the study assessments.

Cultural Adaptation of the Intervention

Cultural adaptation is the systematic modification of an evidence-based intervention that considers language, culture, and context compatible with the client's cultural patterns, meaning, and values (Bernal et al., 2009). The inability to provide culturally competent and culturally adapted interventions leads to a disparity in services for people from ethnic minority cultures, leading to poor access to available services, poor outcomes, and increasing costs to society (Handtke et al., 2019). A translation and cultural adaptation of the ACT treatment protocol and intervention materials was completed following the tenets of the Ecological Validity Model (EVM; Bernal et al., 1995). The EVM consisted of eight culturally sensitive elements that are important to strengthen the cultural relevance of interventions. These elements include language (whether it is appropriate and culturally syntonic); person (if the patient is comfortable with the therapy relationship); metaphors (symbols and concepts included in the treatment manual are common to Latinxs); content (cultural relevance for Spanish); concepts (treatment concepts consonant with Latinx culture and context); goals (support of positive and adaptive cultural values); methods (cultural appropriateness of treatment methods); and context (consideration of contextual aspects, such as economic and social context). Psychologists and a clinical social worker reviewed the ACT manual to examine the cultural appropriateness of the various components of the intervention. Clinicians involved in this task had previous experience adapting therapy

manuals for major depression, generalized anxiety disorder, and psychological trauma. In addition, a focus group was conducted to explore the participants' familiarity and understanding of the term stigma. Participants seemed familiar with some of the characteristics and manifestations of perceived and self-stigma, describing their own experiences. We also examined the duration and frequency of the session's intervention, feasibility and acceptability measures, participants' understanding of key terms used throughout the intervention, and alternative terms that might be used and understood by Latinxs living in Puerto Rico. A term that some participants did not understand well was "mindfulness o atención plena." The participants suggested using "no distraerse, enfocarse" instead of the original term. "Willigness o disposición" they suggested "acceder, hacer lo que haya que hacer para ayudarse". The participants understood the terms "acceptance," "flexibility," and "avoidance patterns." Overall, this process allowed revising the content, technical, and cultural appropriateness of the intervention for our study population and identifying alternate wording for manual sections that were found to be challenging to comprehend. The aim was to use standard or neutral Spanish that Latinxs could easily understand.

ACT Intervention

The original intervention consisted of three two-hour sessions scheduled during a single week. As part of the information obtained during the focus group and the structural challenges faced by the participants, such as the access to public transportation, we decided to offer the intervention one session per week. We also reduced the content of the sessions and duration to achieve a greater understanding and emotional processing of the topics among the participants. The adapted intervention consisted of six individual sessions of 90 minutes.

The intervention followed a manualized ACT intervention focused on reducing the harmful effects of self-stigma. The ACT intervention also recognizes the behavioral mechanisms through which self-stigma could impact psychosocial functioning, including poor adherence behaviors. Processes central to treatment, such as experiential acceptance, values clarification, and attention to the present moment, were targeted with a variety of clinical methods, including psychoeducation, self-monitoring, mindfulness practices, and behavior change strategies to help participants learn to respond to their stigmatizing thoughts and behaviors in a way that would not obstruct recovery. While maintaining fidelity to the core elements of the English ACT manual, the Spanish version includes language, idioms, examples, and exercises relevant to Latinx culture (Bernal et al., 2009). For example, the first element of the EVM framework, language, allowed us to examine if the vocabulary of the treatment manual was clear and understandable, particularly if participants would understand the language, idioms, and words used. Other

elements discussed in the cultural adaptation process of the manual were the content and the use of metaphors such as the “passengers on the bus,” a common metaphor within the ACT. It brings information about the relevance of recognizing our thoughts and emotions while maintaining our focus on taking action throughout our core values. The participants agreed and identified with the exercise since most use public transportation (buses).

Although ACT includes behavioral elements derived from traditional CBT, cognitive strategies that focus on correcting dysfunctional thoughts and emotions were replaced with strategies that promote psychological processes based on acceptance and mindfulness. The focus was on increasing engagement in personally meaningful actions by facilitating behaviors consistent with participants’ values rather than motivated by worry, self-devaluation, and avoidance of thoughts, sensations, and feelings viewed as threatening and dangerous. Table 1 summarizes the themes covered in each session.

TABLE 1.
Components of the ACT intervention and the adaptations made.

Session	Themes covered in the original intervention	Themes covered in the adapted intervention
1	<ul style="list-style-type: none"> Introduces the concept of stigma and self-stigma and why it is an important topic Teach control as the problem 	<ul style="list-style-type: none"> Introduces the concepts of fear of being rejected (enacted stigma) and self-stigma and their impact on different domains of life.
2	<ul style="list-style-type: none"> Undermine fusion of self and language Teach healthy distance and nonjudgmental awareness 	<ul style="list-style-type: none"> Presents the tendency to avoid thoughts, emotions, and social interactions to protect themselves and how it is ultimately self-defeating using experiential exercises.
3	<ul style="list-style-type: none"> Discuss what values are Help participants clarify values, specifically in relation to the treatment Allow participant to acknowledge their past avoidance, identify goals and intentions, and make a public commitment to a new direction 	<ul style="list-style-type: none"> Creates empathy and self-acceptance by introducing the experience of sharing uncomfortable thoughts or feelings instead of controlling them. Teach healthy distance and nonjudgmental awareness.
4 & 5	--	<ul style="list-style-type: none"> Discuss what values are Establish values and structured, individualized behavioral goal plan using experiential exercises.
6	--	<ul style="list-style-type: none"> Presents what assertive communication is In-Vivo practice of assertive communication and problem-solving skills commonly identified in health care settings.

This refers to the extent to which an intervention is implemented as intended. It is essential to consider fidelity when evaluating the implementation of behavioral interventions because it enhances and assesses fidelity to the original intervention to minimize dilution of effects while balancing to enable appropriate adaptation for the local context (McCrabb et al., 2019). Steps to enhance ACT intervention fidelity by the therapist included the following. The therapist received formal training to provide the ACT intervention and was supervised weekly by a clinical psychologist and researcher trained to deliver ACT-based interventions and other contextual therapies. All treatment sessions were recorded, and a random sample was reviewed to ensure that the required components were covered. For 100% of ACT participants, one session was randomly chosen. For each session, an adherence checklist listed the required components which were considered as proxy measures for therapy essential elements. Around 95% of the required components were covered.

Measures

Quantitative Assessments or Measures

Feasibility and Acceptability measures were assessed every two sessions. Acceptability of Intervention Measure (AIM) and Feasibility of Intervention Measure (FIM) (Weiner et al., 2017) are four (4) question instruments often considered as indicators of implementation success (Proctor et al., 2011). These versatile and pragmatic measures can be used together or separately to determine whether participants believe an intervention is acceptable and feasible. Responses are categorized in a 5-point Likert scale ranging from Completely disagree to Completely agree. No cutoff scores are available, but higher scores indicate greater acceptability and feasibility. The research team culturally adapted both measures to ensure they were relevant and sensitive.

Both measures were adapted with the following steps: (a) translation of the English

version of AIM and FIM measures into Spanish by an independent professional, (b) review of the translation by a bilingual expert committee comprised of experienced researchers with social sciences backgrounds and clinical experience, (c) focus group among people with similar characteristics to our population of interest reviewing the translated instrument and we explored if there were difficulties in understanding and responding to the questions, (d) discussion of the focus group findings by the expert bilingual committee and incorporation of accepted changes into the translated instruments, (e) back-translation of the measures by a different independent professional translator, and (f) review of the back translation by the bilingual expert committee. Feasibility and Acceptability measures were completed in sessions 1, 3, and 6.

Statistical Analysis

The statistical analyses were performed using the Statistical Package for the Social Sciences (SPSS), version 27. For the purpose of this study, only descriptive analyses were performed.

RESULTS

Feasibility and Acceptability

The sample included 8 participants (4 males and 4 females) whose ages ranged from 45-59 ($M=54$, $SD=5.07$). Six of the 8 participants completed the ACT intervention and participated in pre-and post-measures. Seven of the eight participants (87.5%) attended at least four of the six sessions. Participants Totally agree (83.3%) or Agree (16.7%) "therapy was plausible" and "achievable", while 100% of them Totally agree "therapy seems possible." All participants Totally agree (50%) or Agree (50%) "therapy was easy to use". All participants (100%) Totally agree "the intervention was attractive," had their "approval," were "open to therapy," as well as "liked the therapy." Internal consistency of all measures was examined to ensure adequate reliability values. AIM and FIM exhibited

excellent internal consistency with $\alpha=.98$ and $\alpha=.99$, respectively.

DISCUSSION

Meta-analyses and systematic reviews on culturally adapted treatments studies have concluded that culturally adapted interventions have positive effects on patients' engagement in therapy, retention, and satisfaction (Healey et al., 2017; Hall et al., 2016). Findings from this preliminary study are relevant because they provide initial empirical data regarding the implementation feasibility and cultural acceptability of a promising intervention for the treatment of self-stigma, a common barrier to HIV/DUDs treatment entry and retention. Results suggest that once people are integrated into the therapy, their acceptability increases significantly. Another strength of this intervention is brevity, and preliminary studies indicate that it is acceptable and effective in low-resource and primary care settings (Smout, 2012; Howarth et al., 2019). The majority of PLWHIV and DUDs suffer from health, social and economic inequalities; therefore, a brief intervention implemented in primary care settings is well suited for this vulnerable population. One of the strategic objectives of these primary care centers is to assure access to and treatment adherence to ART that is responsive to the patient's needs. These primary care centers intend to expand services for the recovery of people with HIV/DUDs based on the recovery model established by SAMHSA (2021): (1) focus on the person, not in treatment; (2) based on scientific evidence; (3) significant involvement of individuals and/or family; (4) systems anchored in the community (accessibility); (5) continuous care; and (6) benefits and constant monitoring. Due to the lack of evidence-based interventions for this population, our future research agenda is to collaborate with our community partners to strengthen their research capacity and expand clinical skills that enable continued involvement in the adoption of evidence-based practices in the HIV/DUDs treatment sector.

This study has limitations that affect the generalizability of the findings. First, the sample was composed of a small proportion of Latinxs in Puerto Rico, mainly from low-income urban areas, limiting information for participants from other socio-economic groups. Future studies with larger sample sizes and a control group are needed to offer a more definitive, well-powered test of the current promising findings. Second, current findings are limited to quantitative intervention satisfaction reports of 8 participants. Quantitative and qualitative information with a larger sample of participants as well as feedback from providers in primary care settings will be needed. Additional patient and provider feedback is recommended to continue modifying and refining the ACT intervention manual. For example, additional areas to explore in qualitative interviews or focus groups are: patient and provider preferences for ACT intervention components; patient feedback on worksheets materials; current provider approaches to enhance drug treatment adherence in primary care; and strategies for communicating with primary care providers. This approach will optimize medication adherence by placing it within a framework of patient-centered treatment, which considers the heterogeneous interests and needs of Spanish-speaking Latinxs. Also, group format sessions must be considered to provide additional benefits since they work by reducing shame and social isolation, enhancing positive affect, and peer support to encourage behavior change, which is critical for addressing the consequences of self-stigma and the distress of living with chronic medical conditions (Yalom & Leszcz, 2005). Fourth, to reduce the confounding of therapist effects, at least two trained facilitators must deliver the intervention. A fifth limitation was that study recruiters did not systematically select patients for screening in primary care reception rooms. This may subject the data to some selection bias. A sixth limitation was that measures were not validated, however were culturally adapted and with an excellent internal consistency. Despite these limita-

tions, findings from this preliminary study suggest that the culturally adapted ACT is feasible and acceptable as an intervention to reduce self-stigma. Future research would benefit from including a longer-term follow-up.

Our findings are important because they provide evidence in favor of the potential benefits of ACT for low-income, Spanish-speaking Latinxs who present self-stigma associated with HIV/DUDs in primary care settings. Evidence sustains that Latinxs' mental health care needs are mainly unfulfilled. In contrast to non-Hispanic Whites, studies have demonstrated that Latinxs rely more on primary care settings for mental health care and are less likely to receive evidence-based treatments for mental health problems (Jones et al., 2018; Cook et al., 2017; Alegría et al., 2016; Cabassa et al., 2006; Institute of Medicine, 2003). According to researchers in the field, a significant factor contributing to the persistence of mental health care disparities is the mistaken assumption that evidence-based treatments are readily available for diverse populations and the scant availability of linguistic and culturally competent services for minority populations in primary care settings (Alegría et al., 2016; Vera et al., 2021).

Research Ethical Standards

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Informed Consent/Assent: Consent was obtained from participants before initiating protocols.

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