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Overcoming Barriers to HIV Treatment Adherence: A Brief Cognitive Behavioral Intervention for HIV-Positive Adults on Antiretroviral Treatment

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Abstract

Maximizing HIV treatment adherence is critical in efforts to optimize health outcomes and to prevent further HIV transmission. The Balance Project intervention uses cognitive behavioral approaches to improve antiretroviral medication adherence through promoting adaptive coping with medication side effect and distress related to HIV. This 5-session intervention has been documented to prevent nonadherence among persons living with HIV who experience high levels of distress associated with their antiretroviral medication side effects. We describe the theoretical underpinnings of the intervention, provide details of the training and session protocols with a case example, and discuss implications for future applications of the intervention in both research and clinical settings.

Keywords

HIV; medication adherence; cognitive behavioral intervention; randomized controlled trial

Many of the foundations of cognitive behavioral therapy—identifying and changing negative thoughts, improving adaptive coping skills, and problem solving—are a good fit when addressing challenges to medication adherence and improving health outcomes. Changing one's beliefs about a chronic health condition and its treatment can help increase motivation to actively engage in care, and providing specific skills can facilitate greater success in adherence to treatment regimens (Johnson, Dilworth, Taylor, & Neilands, 2011; Johnson, Gamarel, & Dawson-Rose, 2006). In this paper, we describe an intervention that employs cognitive behavioral approaches to improving medication adherence among persons living with HIV who report high levels of side-effect-associated distress.

There is a critical need to maximize HIV treatment adherence in efforts to optimize HIV primary and secondary prevention. Timely initiation of pharmacologic treatment and high levels of adherence to antiretroviral therapy (ART) can substantially reduce viral load on

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both an individual and a community level (Volberding et al., 2012). For primary prevention (i.e., averting new infections), a reduction in both individual and community viral load can reduce the likelihood of HIV transmission following exposure (Cohen et al., 2011). From a secondary prevention standpoint (i.e., mitigating the negative outcomes for those who have been diagnosed with a condition or disease), reducing viral load early in the course of HIV disease has been documented to have a positive impact on reducing morbidity and mortality over time among HIV-infected persons (AIDSinfo, 2012; Volberding & Deeks, 2010). For antiretroviral medications to be most effective at achieving these goals, they must be taken consistently, as poor adherence is linked to lower survival, higher morbidity, viral resistance, greater health care costs, and diminished quality of life (Gardner, McLees, Steiner, Del Rio, & Burman, 2011; McNeil, 2011; Volberding, et al., 2012; Volberding & Deeks, 2010). However, adherence to ART is difficult due to factors such as the complexity of the regimens, side effects, HIV-related stigma, and competing priorities (Johnson et al., 2003; Malta, Strathdee, Magnanini, & Bastos, 2008; Reisner et al., 2009; Simoni, Amico, Pearson, & Malow, 2008).

The past two decades have resulted in a rich literature on the predictors and correlates of HIV treatment adherence (Fogarty et al., 2002; Johnson, et al., 2003; Simoni et al., 2008). Among these well-documented predictors of poor adherence is the presence or anticipation of adverse effects of ART, including gastrointestinal distress, fatigue, and neuropathic pain (Ammassari et al., 2002; Johnson et al., 2005; Johnson & Neilands, 2007; Remien et al., 2003). Although current ART regimens have much lower side-effect profiles than previous HIV treatment, treatment uptake and adherence remain suboptimal, and medication side effects remain among the top reasons for poor ART adherence across a wide range of HIV-infected populations (Gari et al., 2013; Lenzi, Wiens, & Pontarolo, 2013).

In addition to medication side effects, adherence is threatened by multiple factors, including financial problems, housing instability, substance use, mental illness, poor access to support, and negative perceptions of treatment efficacy. If individuals are unable to adhere to treatment recommendations, they are more likely to develop resistance, succumb to other illness and infections, and more easily transmit HIV to others. Adjuvant treatments and assistance can truly help people living with HIV find meaningful ways to cope with unwanted side effects and manage other life stressors that affect their adherence to ART (Antoni et al., 2002; Chesney, Chambers, Taylor, Johnson, & Folkman, 2003). These adaptive coping tools and strategies provide opportunities for HIV-positive individuals to optimize ART efficacy, feel empowered by their options, and reinforce their beliefs that side effects can be manageable.

The purpose of this article is to describe the Balance Project intervention, which uses cognitive behavioral approaches to improve antiretroviral medication adherence by promoting adaptive coping with side effect and HIV treatment-related distress. The intervention has been documented to prevent nonadherence among persons living with HIV in San Francisco, CA, who experience high levels of distress associated with their antiretroviral medication side effects (Johnson et al., 2011). In a randomized controlled trial, those receiving the Balance intervention reported higher rates of ART adherence over time than participants randomized to the no-intervention condition. In the efficacy trial, HIV-

positive adults reporting side-effect-related distress were randomized to the Balance intervention or a treatment as usual (TAU) control. At the conclusion of the final study assessment, we offered a condensed version of the Balance intervention to individuals in the control condition.

In this article, we describe the theoretical underpinnings and structure of the intervention and offer a case example based on a composite of participants seen in the trial. We provide details of the training and session protocols, and discuss implications for future applications of the intervention in both research and clinical settings.

Theory

Cognitive behavioral therapy was used as a fundamental source in the development of this intervention, with a focus on Coping Effectiveness Training (CET; Chesney, et al., 2003) derived from Stress and Coping Theory (SCT; Lazarus & Folkman, 1984) and elements drawn from Social Problem Solving Therapy (Nezu, 1986, 2004; Nezu, Nezu, Friedman, Faddis, & Houts, 1998). SCT posits that the relationship between a stressful situation or problem (i.e., a stressor such as HIV diagnosis or HIV treatment side effect) and outcome is influenced by two processes: appraisal and coping. CET teaches specific skills to help people better appraise a stressful situation and find the most effective coping strategies on the fit between appraisal and coping as well as the social aspects of coping (Folkman et al., 1991).

Appraisal

Appraisal refers to an individual's evaluation of a stressor in terms of its personal significance and one's available options for coping. The appraisal process involves an exploration of the meaning of the stressor, the ways in which the stressor influences physical, emotional, and social well-being, and the degree to which a stressor is perceived as changeable or controllable (Folkman et al., 1991; Lazarus & Folkman, 1984).

Coping

Coping can take the form of instrumental thoughts and actions aimed at removing the stressor or reducing its intensity (problem-focused coping), regulation of distress resulting from the stressor without removing the stressor (emotion-focused coping), or the maintenance of well-being in the face of the stressful condition (meaning-based coping), which is a newer facet of SCT (Park & Folkman, 1997).

Problem-Focused Coping—The construct of self-appraised social problem-solving ability has been linked to higher ART adherence and lower sexual risk among HIV-infected men in prior research (Johnson, Elliott, Neilands, Morin, & Chesney, 2006). Problem-focused coping strategies include problem solving, in which a systematic approach to defining a problem and clarifying a desired outcome is followed by a rational exploration and evaluation of potential solutions (i.e., brainstorming). The decision-making process facilitates identification and implementation of a solution. Other skills related to problem-focused coping include assertive communication and support seeking. In the context of HIV treatment side effects, problem-focused coping may involve asking for clarifying

information from one's medical provider about whether there is another medication option that does not result in nausea (assertive communication and information seeking), searching online for herbal remedies for a side effect (information seeking), or asking a neighbor for a ride to an urgent care clinic when experiencing an acute side effect (social support seeking).

Emotion-Focused Coping—Emotion-focused coping approaches aim at addressing the problematic affective/emotional responses to the stressor—such as anxiety, depression, fear, and helplessness—without necessarily altering or removing the actual stressor (Folkman et al., 1991). Examples of emotion-focused coping strategies related to HIV treatment side effects might include relaxation, exercise, use of humor (some participants reported that laughing with friends about some of the embarrassing aspects of chronic diarrhea helped normalize it), venting of frustration to a friend or care provider, and getting additional psychotherapeutic support. Potentially less adaptive strategies such as denial of the distressing emotions or substance use to buffer the negative emotions also serve as examples of emotion-focused coping. As with problem-focused coping, social support is important to emotion-focused coping; sharing and validating emotional responses can be effective in reducing the level of distress experienced with treatment side effects, thus promoting greater adherence to ART (Johnson et al., 2011).

Meaning-Based Coping

Meaning-based coping strategies aim at integrating the situational meaning of a stressful event into one's global meaning system. Situational meaning refers to one's appraisal of the personal significance of an event. Global meaning concerns one's fundamental beliefs and understandings about the way the world works and one's place in the world. Global meaning has also been called “assumptive worlds” or “schemata” (Park & Folkman, 1997). For example, some participants reported a global belief that they had survived with HIV up to this point because the universe or god had a reason why they needed to be here in the future. There are a variety of situational beliefs about medication side effects that are congruent with this particular global belief, such as, “Learning to deal with the diarrhea must be part of the larger plan set out for me,” or, “I have survived so many challenges already, I will get through this one too.” When situational meaning conflicts with an individual's global meaning, the individual experiences stress (Park & Folkman): “I have diarrhea because I am being punished for something I did wrong.”

Intervention

The Balance Project efficacy trial was conducted in the urban San Francisco Bay Area with a generally White (55%), male (91%), gay-identified (77%) sample of 249 HIV-positive adults, with some representation of women and racial and ethnic minorities. Details of the trial population and outcomes have been published previously (Johnson et al., 2011). Here we will describe application of the intervention protocols, therapist training in the manualized sessions and motivational interviewing, and implementation of quality assurance.

The Balance Project intervention is a five-session, one-on-one, theory-based protocol that uses cognitive behavioral techniques delivered weekly following a structured manual. Each

session lasts between 60 and 90 minutes. While previous interventions have been designed and proven effective at addressing general stress related to coping with HIV, the Balance Project intervention was developed to apply the specific cognitive behavioral techniques of CET and social problem solving to medication-related side effects and stressors. The definition of a HIV treatment-related stressor was based on the HIV-positive person's perception of how a specific stressor was connected to adherence or side effects. A stressor could be directly related to taking the medications, such as fatigue or neuropathic pain, or less directly related to medications, such as relationship problems or unstable housing. These distally related stressors could impact adherence because the individual experiences increased levels of distress and becomes less organized about taking medications. So, while the ultimate target of the intervention was to address medication side-effect-related distress, the intervention activities and skills-building exercises were directly applicable to other stressors. Often these other stressors were more salient to participants and were thus the context used to introduce the skills, which were subsequently applied to HIV treatment-related stressors.

The intervention, though manualized with specific tasks outlined for each session, was designed to have flexibility in its implementation. Guided by previous work with manualized individual interventions (Johnson & Remien, 2003), therapists (with collaboration from the participants) were able to decide the specifics of topics discussed and the depth to which skills building was exercised based on assessment of the individual's needs and ability.

Intervention Therapists and Training

Three therapists implemented the Balance Project sessions. All had master's degrees in psychology, counseling, or social work, with experience and knowledge of HIV-related issues and ART treatments and concerns. Session implementation was guided by an intervention manual adapted from the Healthy Living Project, an earlier HIV intervention trial that included members of the Balance Project research team (Johnson et al., 2003). The therapists were trained in the use of the intervention manual through readings, didactics, videos of mock sessions, and role-plays, with training materials developed by the Principal Investigator and clinical supervisor. Therapists were certified once the supervisors were assured that they were able to deliver the intervention according to quality assurance standards. Weekly group supervision and biweekly individual supervision with the clinical supervisor assured continued therapist evaluation throughout the duration of the trial.

Motivational Interviewing—The therapists were also trained to use a nonconfrontational style in the delivery of the intervention. This included the use of motivational interviewing techniques such as expressing empathy, developing and amplifying discrepancies, supporting self-efficacy and working with ambivalence and resistance (Miller & Rose, 2009). The therapists were tasked with forming a collaborative relationship with participants for this relatively brief number of sessions. Understanding the context in which each participant experienced side effects and other medication-related challenges was essential in this process. This included understanding participants' experiences of stigma and discrimination, access to resources, and complicating factors such as mental health and

substance use. Participants' hopes for the future, and current meaningful experiences or relationships were also instrumental in developing motivators for change.

Quality Assurance—All intervention sessions were audiotaped and a representative sample (approximately 10%) was reviewed by the clinical supervisor. The supervisor used a standardized checklist and feedback form to monitor protocol adherence. The therapists' competence at delivery of the specific components of the intervention was also monitored. Therapists notified the supervisors when special circumstances arose and received supervisory feedback. The feedback forms were reviewed with the therapists during individual supervision.

The quality assurance process also consisted of weekly group supervision sessions in which therapists had an opportunity to play session recordings and get feedback from the clinical supervisor and the other therapists. The therapists reported that, given the dynamic nature of this intervention, the group supervision was particularly important in helping them think through any decisions that may have varied from the specific protocols.

The therapists also participated in ongoing training (e.g., readings and seminars) to stay informed of changes in treatment of side effects and other issues relevant to working with people with HIV. For example, information regarding new treatment guidelines and newly approved medications was distributed for discussion at supervision meetings. Likewise, as topics emerged in the delivery of the intervention (e.g., domestic violence and crisis intervention), opportunities for training in these areas were explored.

Intervention Content and Delivery

Intervention sessions were based on a standard structure (outlined in Table 1) and then individually tailored to meet participants' needs.

Check-in

With the exception of Session 1, which is detailed in the case example, the therapist used the beginning of each session to establish rapport and check in on progress made towards the goal set in the previous session. If the participant accomplished the goal, the therapist used the opportunity to praise the participant in the hopes of shaping behavior towards meeting the participant's goal. The therapist explored the participant's feelings about meeting the goal; motivational factors; challenges and barriers; and the impact goal accomplishment may have had on other aspects of the participant's life, functioning, health, or stress level.

If the participant reported being unable to complete the goal, the therapist explored whether the participant had made any progress related to it. A participant may have taken steps towards a goal without even realizing it—for example, talking to friends about their experiences with acupuncture, but not actually making an acupuncture appointment as planned. The therapist would use this as an opportunity to give positive reinforcement. It also provided an opportunity to revisit the original goal, and ideally increased the participant's sense that they were on a path to successful goal completion.

Even if the participant made no progress towards the goal, discussion often revealed progress towards a previous goal, or in an area related to an aspect of the intervention. The therapist was then able to explore whether the participant had made any steps toward improved coping with medication-related stress or specific side effects; and/or ways to improve other aspects of health, social support, communication, or adherence. The participant may also have learned something about goal setting (e.g., that they tend to set unrealistic goals). The therapist would be able to reframe the unmet goal as an opportunity to reassess and better understand the barriers to meeting that goal, and could begin the process of troubleshooting with the participant. This included looking at what may have gotten in the way of the goal, identifying if something needs to happen first before the participant could complete the goal, and if the goal was realistic for the participant at that time.

Skills Building

Using worksheets and handouts (see Appendices), a new skill was introduced in each session to address HIV treatment adherence and medication side effects management. The therapist always began with an overview of the specific skill (e.g., stress and coping, social support, assertive communication, health provider relationships, identifying cognitions and evaluating beliefs). Personal and cultural context were then explored. For example, while introducing the topic of communication, the therapist explored how gender, ethnicity, sexual orientation, age, and regional differences influenced the participant's definition of "assertive communication" and might pose challenges to effective implementation. How to ask for something respectfully may have a different meaning for an African American woman from the rural south than for a gay white man from New York City.

Another example of how cultural and personal experiences influenced the skills building exercises was that a fair number of gay male participants over 50 reported that the impact of the AIDS epidemic played a significant role in social support seeking. It was common for them to describe substantial losses in their social support network due to the death of friends and partners. In these cases, therapists made sure to fully understand how this loss impacted the participant's current ability to access support, and how the ensuing emotional pain may have created ambivalence about developing new sources of support.

Participants always had an opportunity to practice the new skills in session by rehearsing implementation of the skill in the context of HIV treatment and coping with side effects.

Problem Solving

The problem-solving component of the sessions consisted of the following seven steps, which were listed on a Problem Solving Worksheet (see Appendix B) provided in each session.

1. Identify the stressor, trigger, barrier, or challenge. The therapist assisted the participant in identifying and stating the problem.
2. **Determine the goal.** The therapist assisted the participant in clarifying a realistic goal within the participant's life context. For example: If the participant was

problem solving about medication-related diarrhea, the therapist would explore whether the participant's goal was to end the diarrhea completely, or to decrease how much the diarrhea impacted the participant's daily life, or to find ways to cope with the diarrhea.

3. **Brainstorm alternative solutions.** The therapist helped the participant identify a broad range of options. The therapist sometimes needed to initially model the generation of alternatives, encouraging and reinforcing participation in this process.
4. **Evaluate solutions.** The therapist engaged the participant in a discussion of each possible solution, often framing this in terms of cost/benefit analysis or making a pros/cons list. The therapist was expected to refrain from judgment during this process, as these solutions needed to make sense in the participant's life context. Something that seemed like a negative aspect of a solution to the therapist may not have been perceived as such by the participant. It was essential that the participant do the evaluating. There was room, however, for gentle prompts by the therapist. The therapist was encouraged to ask clarifying questions such as, "Do you imagine this might be a problem?" or "What about the cost of doing this?"
5. **Choose the best solution(s).** The therapist asked the participant to prioritize solutions.
6. **Develop an action plan.** The therapist asked the participant to map out a step-by-step plan of how the goal could be successfully completed, and assisted the participant with troubleshooting potential obstacles.
7. **Act.** The therapist asked the participant to determine how much of the plan could be realistically accomplished. If the participant decided they were not able or willing to act on the plan immediately, other possible goals were explored with questions such as, "What do you realistically feel you can do between now and the next scheduled session?"

Evaluate progress—This was done at the beginning of the next session, and generally involved revisiting each goal to evaluate the effectiveness of the solution, and whether a new plan needed to be considered.

By leading the participant through each of the seven steps (with the assistance of the worksheet) in all five sessions, the participant became familiar with the problem solving process and began to use it in their own decision-making.

Goal Setting

The goal-setting process was always collaborative and based on the participant's perception of what was a priority. When setting a goal, the therapist ensured that the participant develop goals that offered opportunities for success. The therapist asked if the goal was realistic enough to be reasonably completed between sessions, and clear enough that the participant understood exactly what steps must be taken to successfully complete it. Ideally, the goal was challenging, but not impossible or too global, and had a clear end point. The participant was asked to identify how they would know when the goal had been successfully completed.

While defining goal completion was primarily determined by the participant, the therapist would assist by asking clarifying questions and providing feedback.

Positive Affect Amplification

In this exercise—the final activity of each session—the participant identified a recent or upcoming event with positive associations. The therapist then guided the participant through a visualization exercise to recall/imagine that experience and its accompanying emotions and physical sensations. The Positive Affect Amplification exercise was developed to help the participant capitalize on a positive experience, which has been shown to increase the association between events and positive affect. This was also an opportunity to connect the participant with a meaningful event that could potentially become a motivator for change (Charlson et al., 2007; Langston, 1994). For example, when a participant imagined and emotionally reexperienced her daughter's recent birthday as a positive experience, the therapist discussed the participant's hopes to experience other important events in her daughter's life, such as high school graduation, and increase her motivation to make positive health changes. The therapist made note of each of the participant's Positive Affect Amplification experiences and reflected back on them when relevant.

Case Example¹

We have provided a case example, based on a composite of study participants, to help illustrate the intervention process. While the case is in many ways representative of the study sample, the specific demographic and contextual background details are unique and provide an opportunity to illustrate how the intervention can be tailored to specific individual and cultural contexts.

Rudi, a 42-year-old gay-identified Mexican American male, has been HIV-positive for 8 years and on antiretroviral medications for the past 4 years. He was currently on a regimen of Reyataz, Norvir, and Truvada, and reported missing 30% to 40% of doses on this regimen. Rudi described past problems with fatigue from the medications, but on his new regimen primarily experienced diarrhea and occasional nausea. After his initial diagnosis, he went through a period of frequent injection methamphetamine use. He had been participating in outpatient drug treatment for 2 years and had successfully abstained from methamphetamine use, with one relapse about 8 months prior to beginning the intervention. Rudi was single and had been out of the workforce for 4 years.

Session 1

Rudi was provided with an overview of the intervention, followed by a discussion of expectations for attendance and participation. The therapist completed the Life Context form (see Appendix A), briefly assessing Rudi's life history and HIV treatment history. Rudi and the therapist generated a list of individual strengths and current medication side effects and health-related stressors. This list served as the basis for problem-solving activities, which included developing a health-related goal for the next session and assessing how a particular

¹Details about the case have been modified to protect the identity of the client.

stressor might impact adherence or side effect management. By taking note of Rudi's self-identified strengths, the therapist began to construct a framework of self-concept for Rudi, which could serve as a way to link positive self-image and self-talk with overall coping effectiveness. The ongoing examination of Rudi's current medication side effects afforded the opportunity to identify any potential negative self-talk, such as all-or-nothing or catastrophic thinking. Flagging these self-statements and the meaning attributed to the side effects allowed the therapist to engage Rudi in rich discussions around self-sabotage and barriers to initiating change.

THERAPIST: You stated that diarrhea was at this point the only side effect that causes ongoing distress. Could you tell me more about how it affects you and how it impacts your adherence?

RUDI: Well, it makes it really hard to plan activities with friends. I used to love to go out dancing, but it can be embarrassing to have to use the bathrooms at the clubs and people start knocking, asking what's going on in there. It also makes it really hard to go on a date.

THERAPIST: It sounds like the diarrhea is really interfering with both your social life and an activity you really enjoy. That must be pretty frustrating. Does that have an impact on your taking the medications?

RUDI: Well, if I know I am going to go out to a club or on a date, I often will skip my meds that day, so I don't have to worry so much about it. It also makes it really hard to feel sexy when you have bad diarrhea.

[The therapist now had an opportunity to express empathy with Rudi and at the same time articulate the current belief linked to the behavior of nonadherence.]

THERAPIST: Okay, so right now it seems like you feel you have to choose between having a social life and adherence.

After hearing more details about Rudi's past attempts to manage the diarrhea, the therapist helped Rudi derive a comprehensive list of options. At first, Rudi felt stuck, as he believed he had already made several attempts to change the problem. The therapist was able to help the participant start to generate ideas.

THERAPIST: Let's just throw all options out, even if they seem pretty unrealistic, and we will go back later and cross some of them off the list.

RUDI: Well, I could just not take my meds at all, or not eat for 24 hours before a date.

THERAPIST: Okay, great, that's two options, let's think about some other ones. Have you talked to your doctor recently about how the diarrhea is impacting you, or asked about new treatments for it?

RUDI: It has been a while since I have talked to her about it. Maybe there are new regimens coming out that are less of a problem that way?

THERAPIST: Now we have four possible options—can you think of any others?

Once the list had been generated, the therapist had Rudi identify the cost/benefit of each solution. For example, not eating before activities would lessen the diarrhea but would deplete his energy and could impact his health in other ways. The therapist reflected back all the options, including the identified pros and cons, and asked Rudi to select the one/s he felt fit best.

RUDI: I guess, it would be talking to my doctor about changing to a new regimen or adding a medication for the diarrhea. I also like the idea of doing research online.

THERAPIST: Does that sound like a goal you would be interested in pursuing?

RUDI: Yes.

[After writing Rudi's goal on the goal card, the therapist introduced the Positive Affect Amplification exercise.]

THERAPIST: So far in our session, we have focused on stressful and often negative things in your life. We are beginning to understand the important role that positive feelings and events play in one's life, even in the face of stressful circumstances. In coping with stress, it can be very effective to take time to think about positive things so that they help balance out the negative aspects. Let's start by thinking back over the past week about something you did, heard, or saw that made you feel good. Does anything come to mind?

RUDI: Last week I had a really good conversation with my brother.

THERAPIST: Take a moment and just recall that experience.

[After waiting 30 to 60 seconds, the therapist asked, "Can you tell me what you remembered about that experience?"]

RUDI: Things got pretty strained between us when I was using drugs and so I was thinking about how good it feels to have him back in my life, and he was saying that my niece keeps asking when she can see Uncle Rudi again.

THERAPIST: How did it make you feel?

RUDI: It reminded me how bad things were and how much better I am doing.

THERAPIST: When you talk about it now, what do you feel?

RUDI: It's kind of silly, but I feel proud of myself.

THERAPIST: Where do you feel that sense of pride?

RUDI: In my chest.

THERAPIST: It sounds like your brother and your niece are pretty important to you.

RUDI: Yeah, I am really hoping to see them again over the holidays.

The therapist finished the session with a brief discussion of Rudi's relationship with his niece and how this might be a potential motivator to stay healthy.

Session 2

This session focused on CET. The therapist began by reviewing the previous session and assessing the progress made towards Session 1's goal. The therapist then introduced the Stress and Coping Model and explained its components, walking Rudi through the model with a medication stressor identified in Session 1. Rudi thus had the opportunity to witness the model in action and to gain confidence in using the model's techniques.

RUDI: I saw my doctor on Friday, but I forgot I was going to ask about new meds.

THERAPIST: Okay. I would like to hear more about the doctor's visit in a moment, though I was also wondering whether you had a chance to do some research about options online?

RUDI: I did a bit, but it got a little overwhelming. But I did ask my friend Charlie what meds he is on these days and if he still has problems with diarrhea.

THERAPIST: So it sounds like you did do some research—some online, and some from someone in your support network. We are going to be talking more about social support today.

After reinforcing the progress Rudi had made towards his goal, the therapist further explored the barriers Rudi perceived to asking his doctor about new treatment options. Rudi reported that he got anxious when his doctor seemed rushed, which made him forget to ask about new medications. The therapist helped Rudi identify some of the beliefs contributing to his anxiety: "The doctor has patients whose needs are more important than mine. He is already frustrated with me for not taking my meds all the time, so I shouldn't take up too much time." The therapist briefly addressed these beliefs and noted that in Session 4 there would be more opportunity for Rudi to practice talking with his provider. The therapist then transitioned into the problem-solving section of the session.

THERAPIST: Last session you identified diarrhea as a major stressor. Can you tell me specifically what is stressful for you about diarrhea?

RUDI: As I said last time, it makes it really hard to go out on a date, or go dancing, and any time I go out somewhere, I always have to worry about whether there will be a bathroom if I need it. I don't really go out that much anymore.

THERAPIST: And how does that affect you?

RUDI: I feel isolated, depressed sometimes. It's hard! I used to be very social.

THERAPIST: Are there other ways the diarrhea affects you?

RUDI: Not being able to go on dates has been hard in that I feel pretty lonely and it's lowered my self-esteem.

THERAPIST: It sounds like there really are a lot of difficult aspects to having diarrhea. I could see where it feels like too much to deal with at times. Let's go over this list and see which ones feel like there is something you can do to change it, and which ones feel unchangeable. Starting with having to skip doses of your meds before going on a date—is there anything that can be done to change that, or is it completely out of your control?

After listing all the diarrhea-related stressors, the therapist asked Rudi to assess whether each specific stressor (i.e., no longer being able to go dancing, always needing to be close to a bathroom, feeling isolated) was changeable or unchangeable. The therapist then aided Rudi in choosing appropriate coping tools (problem- or emotion-focused) to match the type of stressor (changeable versus unchangeable).

By the end of this exercise, Rudi had come up with a plan that highlighted problem-focused coping: taking his medication earlier in the day so that he would allow plenty of time to elapse before going out; and emotion-focused coping: reaching out to friends who understand his situation and can visit him at home to offer company and distraction.

Session 3

This session focused on Rudi's social support networks and coping. The session began with the structured format of check-in, progress made on Session 2's goal, and a brief review of Session 2 content. The therapist then introduced new material by defining and describing the three types of social support: emotional (provision of emotional comfort, validation or strength); informational (accurate and useful information that serves as a valuable resource); and tangible (a concrete skill or service providing a measurable benefit). The therapist explained that "like the effectiveness of coping, the effectiveness of social support as coping assistance depends on a fit between the need of the social support seeker and resources of the social support provider" (Folkman et al., 1991, p. 249); the therapist also described how mismatched social support can make a stressor worse.

THERAPIST: Let's think about the people who are currently in your life. Let's start with what we refer to as your inner circle. This could be family members, close friends, or what some refer to as family of choice. Who would you include in this circle?

RUDI: My brother would be in there.

THERAPIST: Great! And what type of support are you able to get from your brother? Emotional, informational, tangible?

RUDI: I used to be able to get all three. I took advantage of his support back when I was using a lot of drugs, so now he isn't as open to it.

THERAPIST: I'm going to list him for all three types of support, and put a question mark next to it for now. Who else would you put in your inner circle?

Marking the brother's name with a question mark allowed the therapist to continue to identify Rudi's entire support network, and later return to further discuss the barriers to accessing support—in this case, past history with his brother—and to guide Rudi through problem-solving options to overcome that barrier.

After the therapist identified Rudi's full support network, he reviewed Rudi's list of medication side effects and health-related stressors and helped him to identify the type of support and person/people best matching each specific stressor. At the end of this activity, the therapist summarized their discussion:

THERAPIST: In your experiences of dealing with the side effect of diarrhea, it sounds like talking to your doctor about other options or ways to mitigate the diarrhea would be a source of informational support. We've also talked about your friends coming over and spending time with you when you are not feeling up to going out, and this would be considered a form of emotional support.

Session 4

This session focused on health care provider relationships and communication. The session began with the structured format of check-in, progress made on Session 3's goal, and a brief review of Session 3 content. The therapist then gathered a history of Rudi's experiences with current and former health care providers, asking about the challenges and successes of provider relationships. The therapist introduced the components of assertive communication and active listening, and asked Rudi to identify barriers to communicating treatment or medication concerns with health care providers. The therapist then helped Rudi practice communicating with a provider via role-play, highlighting the ways negative and/or assumptive thinking may influence Rudi's ability to advocate for his needs.

THERAPIST: We've discussed how you have some anxiety about bringing up your concerns about diarrhea. What has happened when you brought this up with your doctor in the past?

RUDI: When I brought it up with her before, she didn't really say much about it. She seemed more concerned about how low my t-cells were.

THERAPIST: It sounds like that was quite a while ago, and that she felt that getting your t-cells up were a priority. I wonder if it was clear to her how important trying to do something about the diarrhea is to you? Maybe if you can explain, using "I" statements, just how problematic diarrhea is for you and how it impacts your daily life, your doctor might slow down and listen?

RUDI: It is a priority for me, but I'm not sure how I would do that.

THERAPIST: What if we practice? You can be your doctor and I can pretend I am you, and then we can switch roles.

After rehearsing in session, Rudi felt more confident about addressing his concerns with his health care provider, and agreed to set that as his goal for the next session.

Session 5

This final session focused on an intervention overview and identifying how cognitive distortions impact medication adherence and coping with side effects. The session began with the structured format of check-in, progress made on Session 4's goal, and a brief overview of the first four sessions. The overview highlighted the exercises from each of the sessions and provided an opportunity for Rudi to review successes in skills building and goal acquisition. The therapist discussed future health and HIV treatment goals with Rudi, and helped him identify and troubleshoot potential barriers. The therapist then introduced examples of self-defeating and self-enhancing thought processes (see Appendices C1, C2) related to medications and side effects, and assisted him in identifying his own similar types

of thinking. The therapist emphasized the usefulness of these empowering self-statements and affirmations, and offered the opportunity to practice self-statements in the context of coping with side effect or adherence concerns.

Rudi reported that he made progress with his goal to start working again: he had secured a part time job as a barista at a local coffee shop. He said he spoke with his doctor and had just started a new medication regimen. He had successfully made some changes to his diet and had noticed some improvement with the diarrhea.

After teaching him about automatic thoughts and giving examples of them in the context of HIV treatment, the therapist asked Rudi to further discuss his current situation and to identify where he may have been engaging in self-defeating thinking.

RUDI: Just this morning I felt a little sick to my stomach after taking my meds. I started to spin in my head. All these thoughts like, "These new drugs aren't going to work for me. I probably shouldn't be going back to work. What was I thinking?"

THERAPIST: When you look at this list of self-defeating thoughts, what do the thoughts you just described remind you of?

RUDI: I guess there may be some catastrophizing going on.

The therapist helped Rudi identify strategies for recognizing and countering his automatic thoughts. The techniques introduced at this time included positive self-talk, present-focused statements, breathing exercises, and "finding the exception."

The intervention ended with Rudi engaging in a final Positive Affect Amplification exercise.

THERAPIST: Over the past five weeks you have started to make some significant changes, and have said that you have more of a sense of hope about a healthy future. Before we wrap up and say goodbye, can you think of something coming up or something you hope to do that you are excited about?

RUDI: As I mentioned in our first meeting, I really want to see my niece again.

THERAPIST: Okay, great! I want you to just take a moment and imagine getting to see her. Picture yourself in that situation and just notice what comes up.

RUDI: It would be great if it could be for Christmas. I haven't been around children for the holidays in so long.

THERAPIST: I remember that one of your main motivators for going back to work was to save money for a plane ticket and Christmas presents. I wonder if there is a way that you can continue to use this exercise to keep you motivated?

Whenever possible, the therapists used this final exercise as an opportunity for the participants to envision a positive outcome of improved health. Some participants envisioned spending future time with family members or loved ones, while others imagined going back to work or traveling. Some participants simply pictured themselves looking and feeling healthy again.

To close the session, Rudi received a Certificate of Completion, and was invited to share his experience of the intervention with the therapist.

Discussion

Challenges and Recommendations

The session structure was designed to implement the intervention content and skills-building exercises efficiently. However, a number of circumstances presented obstacles to this structure, and the therapists used a set of innovative strategies to engage participants and address challenges specific to this study population, such as chaotic life situations, ongoing health problems, and uncertainty about benefit from intervention (Johnson & Remien, 2003; Olem, Sharp, & Johnson, 2009). If a participant had difficulty adhering to the intervention due to missing scheduled sessions, the therapist might explore the barriers to keeping scheduled appointments. For example, if a participant states she often forgets things she is scheduled to do, perhaps this is related to chronic substance use or cognitive impairments. The therapist would then engage the participant in problem solving around the specific barrier. This would also give the therapist an opportunity to explore how this challenge may be affecting adherence to her medical regimen as well. Is she also missing medical appointments, or forgetting to take her medication? By collaborating on a plan to increase adherence to the intervention, the therapist tracks and acknowledges the participant's successes towards a specific goal, discovers additional barriers, and identifies ways in which she may apply these strategies to her own medical treatment adherence.

Clinical Implications and Applications

The Balance Project intervention employed cognitive behavioral approaches to managing HIV treatment side effects with the aim of optimizing medication adherence. The use of a treatment manual allows for standardization of procedures, and the one-on-one format promotes tailoring to specific client needs, concerns, and priorities. Likewise, although developed and implemented with HIV-positive persons on treatment, elements of the intervention may be useful to HIV-positive persons considering initiating treatment and who are concerned about side effects. Further research is needed to evaluate how well this approach works with other populations and in settings other than the San Francisco study, which included a majority of White, gay men. Adaptations to address population- or geography-based differences in such factors as HIV stigma, racism, sexism, and restricted access to treatment options are needed.

While the intervention was designed and implemented in the specific context of distress related to HIV treatment side effects, this approach has the potential to address a range of contexts in which medical treatment adherence is necessary. These applications may include optimizing treatment engagement and adherence in diabetes or cardiovascular disease, or mitigating the adverse effects of challenging medical treatments such as chemotherapy. Future work to adapt, implement, and test the intervention in these other contexts is needed to determine the potential impact of this approach across settings in which cognitive behavioral approaches to disease management offer promise.

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Appendix

a. LIFE CONTEXT FORM

b. BACKGROUND:

- *Family/Childhood (Where did you grow up? Where were you born? Who is in your family? Current Relationship with family members):*

- *Current living situation (Where? What type of housing? Who lives there? How do you feel about it?):*

- *Significant relationships (Partner, Close friends, Surrogate family):*

c. EDUCATION/WORK HISTORY:

- *Past school/ work:*

- *Current work:*

LIFE CONTEXT FORM CONT.**PSYCHIATRIC/SUBSTANCE ABUSE HISTORY:**

- Past therapy or counseling (When? For how long? How was the experience?):

- Hospitalizations (When? Where? What precipitated hospitalization?):

- Current and past psych meds:

- Substance use/treatment past/present:

- Suicidal ideation/attempts past/ present:

LIFE CONTEXT FORM CONT.**Article II. MEDICATIONS AND SIDE EFFECTS:**

- Date of HIV diagnosis:
- History around Diagnosis (Was this a routine test? Were you expecting a positive result?):

- How did you find out?

- How did you initially cope with being positive?

- When did you begin accessing medical services for HIV/AIDS?

- Who are your current health care providers?

- How long have you been working with them?

- How would you describe your relationship with your providers?

-
-
- When did you 1st start taking HIV meds? _____
 - What went into the decision to start taking medications? Was it an easy decision? Did you feel you had a choice? _____
-
-

- Current/past medications: _____
-
-

LIFE CONTEXT FORM CONT.

- Side effects: _____
-
-
-
-

- How often do you miss doses? _____
 - When/why do you miss doses? _____
-
-

- Alternative/nonwestern therapies and medications (herbs, acupuncture, chiropractor): _____
-
-

- Describe your beliefs around effectiveness of alternative/nonwestern /treatments (How do you integrate the two?): _____
-
-

- Describe your beliefs around medications and staying healthy (diet, exercise, meditation): _____
-
-

BELIEFS AND SUPPORT:

- Who is helpful in your life? _____
-
-

- Spiritual Beliefs/ Personal philosophy: _____
-
-
-
-

- Interests and Hobbies: _____
-
-

PROBLEM SOLVING WORKSHEET

1. IDENTIFY STRESSOR _____

2. Identify Goal _____

1. Brainstorm Solutions

2. Evaluate Solutions

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

3. Choose Best/Most Appropriate Solution(s)

4. Develop Action Plan

5. Act

6. Evaluate _____

1. **FILTERING:** You take the negative details and magnify them while filtering out all positive aspects of a situation. (For example, your doctor informs you that your t-cells are up, your viral load is down, your blood pressure is down, but your cholesterol levels have gone up slightly, and you leave the appointment only thinking about the cholesterol increase.)
2. **POLARIZED THINKING:** Things are black or white, good or bad. There is no middle ground. (For example, you miss one dose of your medications, and you decide that you are unable to stick to a medication regimen.)
3. **OVERGENERALIZATION:** You come to a general conclusion based on a single incident or piece of evidence. If something bad happens once, you expect it to happen over and over again. (For example, you are really tired one day after starting a new medication, so you decide that all HIV meds cause fatigue.)
4. **CATASTROPHIZING:** You expect disaster. You notice or hear about a problem and start "what if's:" What If tragedy strikes? What if it happens to you? (For example, you find out that your t-cells have dropped, and start thinking "this is the beginning of the end".)
5. **SHOULD'S:** You have a list of rules about how you and other people should act. People who break the rules anger you and you feel guilty if you violate the rules. (For example, the receptionist at your doctor's office does not say "good morning" to you, so you decide that she is rude and refuse to deal with her again. You miss an appointment, and feel so guilty, that you don't call back to reschedule.)
6. **GLOBAL LABELING:** You apply an overall label to someone or something based on a small amount of information. (For example, your new doctor cannot find a pen, so you conclude that "she is disorganized and therefore not competent".)
7. **MIND READING:** Without them saying so, you think you know what people are feeling and why they act the way they do. In other words, you make assumptions without checking them out. (For example, your doctor seems distracted while you are asking a question, rather than commenting on it, you assume that what you said was unimportant, and stop asking questions.)

1. **SITUATION-ORIENTED STATEMENTS:** help reduce the potential level of threat or severity of the anticipated situation.
 - "It won't be that bad"
 - "It can be a challenge"
2. **TASK-ORIENTED STATEMENTS:** refer to the plans, steps or behaviors a person will need to demonstrate during the stressful situation.
 - "I am not going to worry about that yet"
 - "I am going to concentrate on what I want to say or do"
3. **COPING-WITH-BEING-OVERWHELMED STATEMENTS:** help a person stay calm and relaxed during tense moments.
 - "Keep cool"
 - "Relax, it won't be that bad"
 - "Stay calm"
 - "Take a deep breath"
4. **POSITIVE SELF-STATEMENTS:** are used to encourage ourselves or reinforce our coping efforts.
 - "Great, I did it"
 - "I got through that OK"

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Highlights

- Adherence to HIV treatment is critical in primary and secondary HIV prevention.
- We developed a cognitive behavioral intervention to improve HIV treatment adherence.
- We describe the theoretical underpinnings of the cognitive behavioral intervention.
- We give a detailed description of the cognitive behavioral intervention's structure.

Table 1

Session-by-Session Content of the Balance Project Intervention

	Session 1	Session 2	Session 3	Session 4	Session 5
Check in and assessment	Introduction and history gathering	Recent events Progress around goal	Recent events Progress around goal	Recent events Progress around goal	Recent events Progress around goal
Skills Building	Introduction to problem solving and goal setting	Stress and coping	Social support	Assertive communication Health Provider Relationships	Recognizing and changing cognitive distortions
Problem Solving	Problem solve one HIV treatment-related stressor	Problem solve one changeable and one unchangeable stressor	Problem solve one barrier to accessing support in the context of HIV	Problem solve one barrier to communicating with a provider	Problem solve barriers to future treatment success
Goal Setting	Set goal based on treatment-related stressor	Set goal based on treatment-related stressor	Set goal based on increasing support	Set goal based on improving communication with providers	Set goals for future
Positive Affect Amplification	Introduce positive affect amplification	Recall and amplify one positive event	Recall and amplify one positive event	Recall and amplify one positive event	Apply Positive Affect Amplification to future health success