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Coping with HIV treatment side effects:

Conceptualization, measurement, and linkages

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Abstract

Side effects from HIV treatments impact quality of life (QOL) and adherence to care, and influence decisions about health care. The purposes of this study are to describe the development of a measure of coping with HIV treatment side effects, the SECOPE, and to provide support for the reliability and validity of the measure. Based in Stress and Coping Theory, the 20-item measure assesses strategies for coping with HIV treatment side effects, and includes scales of Positive Emotion Focused Coping, Social Support Seeking, Nonadherence, Information Seeking, and Taking Side Effect Medications. The factor structure was supported by exploratory and confirmatory factor analyses with two samples of HIV+ individuals on treatment ($N_s = 173$ and 233). The SECOPE has demonstrated reliability (internal consistency and test-retest), and its validity is supported through construct and criterion-referenced analyses. Nonadherence as a strategy for coping with side effects was associated with poorer provider relations, lower treatment knowledge, and higher beliefs of treatment effectiveness. Findings have the potential to inform investigations and interventions in the context of treatment of HIV disease and other medical conditions.

Keywords

HIV; AIDS; Side Effects; Coping; Adherence

Introduction

While the life-extending benefits of antiretroviral therapy (ART) for HIV disease are well-documented, aversive side effects accompany drug benefit (Johnson & Gerber, 2000; Volberding, 2003). In prior research with HIV+ patients on ART, side effects were related to several aspects of quality of life (QOL), including physical and social functioning and illness intrusiveness (Johnson & Folkman, 2004; Johnson, Stallworth, & Neilands, 2003). Other studies have found that ART medications for HIV are associated with neurologic and psychiatric changes such as delirium and peripheral neuropathy (Treisman & Kaplin, 2002). Still others found that diarrhea and fatigue are associated with diminished QOL (Breitbart, McDonald, Rosenfeld, Monkman, & Passik, 1998; Grady, Anderson, & Chase, 1998; Groopman, 1998; Watson, Samore, & Wanke, 1996). In a nationally representative sample of 2267 HIV+ adults in the US, multiple symptoms (not separated by disease or treatment causes) were related to diminished QOL which was, in turn, significantly predictive of days on disability (Lorenz, Shapiro, Asch, Bozzette, & Hays, 2001). The potential impact of side effects on QOL is often cited as a primary deciding factor on when to start ART among HIV+ individuals with middle range CD4 counts of 200-500 (Chene et al., 2002).

The presence of side effects is associated with nonadherence to ART. The high adherence demands associated with ART make treatment success challenging. Side effects are consistently linked to nonadherence in the literature about HIV treatment and other diseases. In a substantial number of published reports, an association between side effects and nonadherence is evident (Ammassari et al., 2001; Fogarty et al., 2002; Johnson et al., 2005), and the belief that one has found ways to manage side effects has been linked to better rates of ART adherence (Johnson et al., 2003). The link between side effects and nonadherence seems to be one of which HIV+ individuals are aware, with side effects being consistently cited as a reason for nonadherence to ART (Chesney, 2000). Unlike disease-related symptoms, side effects may be coupled with a belief that the problems are necessary to stay healthy (i.e., they are inevitably tied to the medication). Side effects may also be viewed as ultimately controllable, that is, that one has the power to stop taking medication and consequently eliminate side effects. A better understanding of how patients cope with undesirable side effects from treatment can inform interventions to remediate the negative impact of side effects on treatment adherence and quality of life.

Stress and coping research findings offer a good framework from which to view the management of side effects. Stress and coping theory (Lazarus & Folkman, 1984) posits that the relationship between stressor and outcome is influenced by two processes: appraisal and coping. Appraisal refers to an individual's evaluation of a stressor in terms of significance and the options for coping. Coping refers to the cognitive and behavioral responses that an individual employs to deal with the stressor. Coping can take the form of active behavior (problem-focused), regulation of distress (emotion-focused), or the maintenance of well-being (meaning-based). It is important to assess how an individual deals with a specific set of circumstances rather than stressful situations in general. Maes, Leventhal, and DeRidder, in a review of coping with chronic illness, write that "only studies that take into account characteristics of the stressor can lead to a full understanding of the coping process and its success" (Maes, Leventhal, & de Ridder, 1996; page 242). The present study seeks an understanding of coping in a very specific situation: when a side effect is perceived from HIV treatment.

There is not a clear understanding of how people manage the adverse effects of medications. For example, how one copes with the undesirable effects of ART may be similar to how one deals with the symptoms of a chronic disease. There are fundamental differences, however, between coping with an ongoing disease and side effects from a treatment regimen. The individual taking medications, which cause serious side effects, may elect to stop or reduce the medications, thereby relieving the side effects. This is not the case with the symptoms of a disease; there is often no clear way to avoid disease-related symptoms. Thus, side effects management presents a coping challenge that is distinct from coping with symptoms of a disease. The purposes of this paper are to describe the development of the SECope, a measure of coping with HIV treatment side effects, to provide support for the reliability and validity of the measure, and to present findings resulting from administration of the measure to samples of HIV-infected individuals.

Methods

Using standard principles of summated scale construction (Allen & Yen, 1979; Foddy, 1993; Spector, 1992), the following steps were taken through a series of three studies.

Study 1

Study 1 Procedures—The initial method of developing items for this instrument was through qualitative interviews with a sample of 20 HIV positive persons on ART who reported side effects from their ART regimen. Recruitment was conducted via flyers placed in HIV

clinics and agencies serving HIV-infected persons. Flyers stated that individuals could earn cash for participating in an interview about HIV treatment issues. HIV status and treatment regimen were confirmed by either an official medication list from the provider or pharmacy or through an examination of prescription bottles bearing pharmacy information and participant names. The qualitative interview was based on Stress and Coping Theory and was designed to elicit candidate items. Sample open ended questions included “tell me about your experiences with your HIV medications,” “what side effects have you experienced?”, “what do you do when you are experiencing that side effect?” Qualitative interviews were conducted by trained interviewers and then transcribed professionally. Interviewers were trained by the PI with the use of a detailed assessment manual, and review and certification of audiotaped mock interviews. Participants were paid \$30 in cash upon completion of the interview.

Study 1 Data Analysis—The qualitative data were coded by the PI and two interviewers who were experienced with coding of textual data. Transcripts of the interviews were reviewed to identify primary coding categories across the broad range of topics covered. Identified coding categories and themes were organized into a formal code book. A coding team of 2 evaluated each transcript as a team, in order to establish coding consensus and refine coding schema. New themes that did not appear to fit into this original coding framework were discussed by the coding team and modifications were made when deemed appropriate. Thematic categories were refined, merged, or subdivided when suggested. Among those coded as strategies for coping with side effects that were reported at least two times, items for the SECOPE were generated and discussed. To achieve a final number of items in the 20-25 item range, at least three times that number of items were targeted at this phase of the study.

Study 1 Results—Descriptive information for the study samples is provided in Table 1. From the coding of the qualitative data, 87 items reflecting strategies for coping with side effects were generated. The items were designed such that respondents were first required to identify the single side effect that caused them the most distress and were asked to consider that side effect when the item referred to “side effect” in each of the items. Response categories were constructed on a Likert scale reflecting how often a respondent reported using each coping strategy where 0 = Never, 1 = Rarely, 2 = Sometimes, 3 = Often, and 4 = Very Often.

Study 2

Study 2 Procedures—The 87-item pool was administered to a sample of 175 HIV+ persons on ART recruited from the waiting room at a local HIV clinic at a publicly funded hospital. An interviewer was stationed at the clinic waiting room during selected clinic hours. Interested individuals who approached the interviewer were screened in a private room and those who met eligibility completed the paper and pencil assessment. Eligible respondents were on ART, able to identify at least one side effect and were paid \$10 in cash for completing this assessment, which included the 87 candidate items and basic background/demographic items.

Study 2 Data Analysis—An initial exploratory factor analysis (EFA) of the SECOPE item responses from Study 2 was conducted to identify a likely factor structure. Principal axis factoring with promax rotation of factor loadings was performed using SPSS. The 171 respondents who provided complete data on the 87 SECOPE items comprised the analysis sample.

Study 2 Results—Descriptive information for the study sample is provided in Table 1. As previously noted, respondents were required to identify one side effect to consider when responding to the SECOPE items. For Study 2, the most commonly referenced side effects for the SECOPE were nausea (28%), diarrhea (19%), neuropathy (10%), bloating, stomach pain or gas (5%), and lipodystrophy (5%).

Based on a prior expectations arising from stress and coping literature and informed by an empirical scree plot of the factor eigenvalues, we retained five factors from this analysis. Items consistent with theory and with factor loadings exceeding $|.55|$ were retained (Comrey, 1973). Table 2 displays the SECOPE items and factor loadings. The five factors were labeled *Positive Emotion Focused Coping*, *Social Support Seeking*, *Nonadherence*, *Information Seeking*, and *Taking Side Effect Medications*. The Positive Emotion Focused Coping factor includes 5 items that assess positive reappraisal, benefit-reminding, humor, and distraction. The Social Support Seeking factor includes 5 items assessing the degree to which support from others, including close friends and family as well as professionals such as case managers and therapists, is sought in response to the side effect. The third factor, Nonadherence, contains 4 items that assess whether respondents report reducing the medication dose or taking a break from the medication in response to the side effect. The Information Seeking factor is comprised of three items to assess how actively one seeks out information about the side effect and what is causing it. Finally, the Taking Side Effect Medications factor includes 3 items covering the use of other medications (prescription and otherwise) to reduce the distress of the side effect.

We next fit a confirmatory factor analysis (CFA) to the data to assess global model fit of the EFA's implied factor structure to the Study 2 data. Global model fit was evaluated by a robust chi-square test (Flora & Curran, 2004; Muthen & Curran, 1997) and the following descriptive fit statistics to compare models: Tucker-Lewis Index (TLI; Bentler & Bonnett, 1980), Root Mean Square Error of Approximation (RMSEA; Browne & Cudek, 1993), and, when data are complete, the Standardized Root Mean Square Residual (SRMR; Hu & Bentler, 1999). Our CFA model using the data from Study 2 extended the EFA results reported above by assigning each of the 20 SECOPE items to the factor with which it was most strongly associated in the EFA results. The 173 respondents who provided complete data on the 20 selected SECOPE items served as the analysis sample. The overall fit of this model was generally good: $\chi^2(N=173; DF=44) = 108.70, p < .0001$; TLI = .95, RMSEA = .09, and SRMR = .08.

Optimal internal consistency reliability for the SECOPE scale and subscales were assessed via Raykov's coefficient ρ ; 95% confidence intervals for ρ were computed based on the bias-corrected bootstrap with 5,000 bootstrap replications (Raykov, 1997; Raykov & Shrout, 2002). Composite internal consistency reliability for the full SECOPE instrument for Study 2 was .87 (95% CI = .84, .90).

Study 3

Study 3 Procedures—The shorter measure, consisting of the 20 items comprising subscales supported by the principal axis factoring was administered to a new sample of 233 HIV+ persons on ART. This administration took place in the context of a baseline interview for a clinical trial of a side effects coping intervention and included other standard assessments (e.g., ART adherence, psychological distress and well-being) allowing us to determine the stability of the factor structure and to link the subscales to other variables. The full SECOPE is presented in the appendix. A subsample of 170 were re-assessed three months later, allowing the evaluation of the factor structure of the SECOPE over time and test-retest reliability assessment. The entire Study 3 comprised of 233 participants were not all due for the second assessment at the time of these analyses, accounting for the difference in sample sizes. Study 3 interviewers were trained with the use of a detailed assessment manual, practice with the computer programs, and review and certification of audio-recorded mock interviews based on standardized criteria. All interviews were audio-recorded and labeled with the respondent's study identification number, date of the interview, and the interviewer's identification number. A sample of recordings was reviewed for protocol adherence and feedback was provided to all interviewers on a regular basis. Participants were paid \$40 for each of the two Study 3 assessments.

Study 3 Measures—In addition to the SECOPE, the following measures were administered to Study 3 respondents in order to establish criterion-referenced validity estimates. The selection of measures used to support convergent validity is based on the HIV coping and treatment adherence literatures.

Demographics / Background: Detailed background and demographic data included items such as respondent age, race/ethnicity, gender, sexual orientation, relationship status, educational level, employment status, self-reported most recent CD4 count and viral load.

Perceived efficacy of treatment: was assessed by averaging responses on seven Likert-scaled items covering beliefs about the effectiveness of ART. Sample items include “Antiretroviral medications have **not** been proven effective” (reverse scored) and “Taking antiretroviral medications will keep me healthier longer.” Higher scores indicate greater perceived efficacy of ART ($\alpha = .65$). This measure was used because of the adherence and information seeking content of the SECOPE subscales.

Treatment necessity: was assessed with the Necessity scale of the Beliefs About Medications Questionnaire (BMQ; Horne, Weinman, & Hankins, 1999), which is based on the Self Regulation Model, and assesses treatment representations of concern and necessity and provides a scale score of each. Higher scores indicate greater treatment necessity ($\alpha = .84$). This measure was used because of the adherence and information seeking content of the SECOPE subscales.

HIV Treatment Knowledge: We administered a short inventory for assessed knowledge of ART and the concept of viral resistance (Stirratt et al., 2006). Participants indicate whether each of 12 statements was true or false, and the number of correct responses were summed ($\alpha = .72$). A score is calculated based on total number of correct responses, with higher scores indicating more accurate treatment knowledge. This measure was used because of the information seeking subscale of the SECOPE.

Positive Patient-Provider Interactions: Adapted from previous studies (Stall et al., 1996), we administered an 8 item scale to assess patients’ perceptions of positive interactions with their providers. Respondents were asked how often certain occurrences happened during recent contacts with health care providers, such as discussing side effects and other medication problems, getting providers to really listen to concerns, and feeling helped by their providers. Response choices are never (0), some of the time (1), most of the time (2), and every time (3). For these analyses, scores on each item are averaged for each respondent with higher scores indicating more positive provider interactions. Cronbach’s alpha for prior administration = 0.81 (Johnson, Chesney et al., 2006). This measure was used because of the information seeking subscale of the SECOPE.

Coping Self-Efficacy: was measured with the Coping Self-Efficacy scale (CSE; Chesney, Neilands, Chambers, Taylor, & Folkman, 2006). The CSE measures participants’ perceived self-efficacy in coping with psychological challenges and threats. Respondents are asked, “When things aren’t going well for you, or when you are having problems, how confident or certain are you that you can do the following?” The questionnaire then lists 13 coping behaviors that tap three distinct dimensions of adaptive coping: problem-focused coping (e.g., “Think about one part of the problem at a time”), emotion-focused coping (e.g., “Take your mind off unpleasant thoughts”), and social support (e.g., “Get emotional support from friends and family”). Respondents endorsed their confidence in carrying out these behaviors on an 11-point Likert scale, ranging from 0 (“Cannot do at all”) to 5 (“moderately certain can do”) to 11 (“certain can do”). Coefficient alpha values for the first two factors were high ($\alpha = .91$ for

both factors); the alpha for the social support factor was also strong ($\alpha = .80$). This measure was used because of the social support, information seeking, and adherence content of the SECOPE subscales.

Treatment Intrusiveness: The Illness Intrusiveness Rating Scale was administered to determine the degree to which treatment interferes with 13 life domains (Devins, 1983). This self-report measure consists of 13 items with a 7-point Likert response scale ranging from 1 = not very much to 7 = very much. A summary score was created for each respondent, with higher scores indicating greater intrusiveness. Previous research has provided evidence of the scale's internal consistency ($\alpha = .87$) and construct validity (Binik, Chowanec, & Devins, 1990; Devins, 1983; Devins, Armstrong, Mandin, & Paul, 1990; Devins, Mandin, Hons, & Burgess, 1990). In the present study, the directions were modified to query intrusiveness from treatment rather than from illness. This measure was used because of the adherence content of the SECOPE subscales.

Social support: The global score on the Social Provisions Scale (SPS; Cutrona, 1989; Cutrona & Russell, 1990; Russell & Cutrona, 1991) was used to assess level, type, and perceived satisfaction with social support from one's social network ($\alpha > .70$ on all subscales making up the global score). This measure was used because of the social support content of the SECOPE subscales.

Disclosure: We developed a single item to assess satisfaction with the number of people in one's life who know one's HIV status (Disclosure Satisfaction): "How satisfied are you with the number of people in your life who know you are HIV+?" Higher scores indicate greater satisfaction with degree of disclosure. This measure was used because of the social support content of the SECOPE subscales.

Adherence Self-Efficacy: A 12-item scale was used to assess confidence to carry out important treatment-related behaviors related to adhering to treatment plans, especially medication regimen adherence, in the face of barriers. Responses range from 1 (cannot do it at all) to 10 (certain can do it). Scores on each item were averaged for each respondent with higher scores indicating higher adherence self-efficacy. Cronbach's alpha = 0.91 for this scale, which has been used in other adherence reports (Johnson, Catz et al., 2003). This measure was used because of the adherence content of the SECOPE subscales.

Depression: was assessed with the 21-item Beck Depression Inventory (BDI; Beck, 1967; Beck & Steer, 1984) which has been widely used in studies with HIV-infected patients to evaluate the severity of depressive symptoms (Griffin & Rabkin, 1997). Higher scores indicate greater depressive symptoms. This measure was used because of the social support and positive emotion focused content of the SECOPE subscales ($\alpha = .85$).

Social Problem Solving: We administered the Social Problem Solving Inventory-Revised (SPSI-R; D'Zurilla, Nezu, & Maydeu-Olivares, 2002) a 25-item survey that provides scores for problem orientation: negative problem orientation (NPO; e.g., "I doubt that I can solve difficult problems no matter how hard I try") and positive problem orientation (PPO; e.g., "I try to see my problems as challenges"), problem solving styles: avoidant style (AS; e.g., "I put off solving problems for as long as possible") and impulsive/careless style (ICS; e.g., "When making decisions, I go with my gut feeling without thinking about what will happen") and rational problem solving (RPS; e.g., "Before trying to solve a problem, I set a goal so that I know exactly where I am going"). The measure has been widely used and has been meaningfully predictive of health and risk behaviors (Elliott, Johnson, & Jackson, 1997), including ART adherence (α 's = .72-.92) (Johnson, Elliott, Neilands, Morin, & Chesney,

2006). This measure was used because of the information seeking, social support, adherence, and positive emotion focused coping content of the SECOPE.

Medication Adherence: Adherence assessments were used because of the adherence content of the SECOPE subscales. Recent self-reported antiretroviral medication adherence was assessed over a three-day period using an adherence survey developed for use in the AIDS Clinical Trials Group (ACTG; Chesney et al., 2000). Respondents indicated how many antiretroviral pills they had skipped during each of the previous three days. This measure has been used widely with diverse samples. Adherence was assessed only for those ART medications that were reported in the adherence section of the interview. For the present study, we considered any missed pills in the prior three days as an indicator of higher nonadherence; therefore a higher score indicates worse adherence.

We supplemented the ACTG measure with a visual analog scale (VAS) developed by Walsh (Walsh, Pozniak, Nelson, Mandalia, & Gazzard, 2002) that assesses 30-day adherence reporting separately for each drug along a continuum anchored by “none of my doses” to “every one of my doses.” This measure has shown to be correlated with other measures of adherence, such as electronic medication monitors (Oyugi et al., 2004; Walsh, Mandalia, & Gazzard, 2002). For this scale, a higher score indicates better reported adherence.

Study 3 Data Analysis—The factor structure derived in Study 2 was fit to the Study 3 data in subsequent CFAs to verify the generalizability of the factor structure in the Study 3 sample. Optimal internal consistency reliability for the SECOPE scale and subscales were assessed via Raykov’s coefficient ρ . Temporal stability of the SECOPE’s factor structure was evaluated by testing the equality of factor loadings and item thresholds across the two measurements in Study 3 (Millsap & Yun-Tein, 2004). Test-retest correlations among the latent factors were then computed.

Following factor and reliability analyses, the latent SECOPE factors were correlated with the scale scores from the following instruments available in Study 3: HIV Treatment Knowledge, Positive Provider Interactions, Non-Adherence, Visual Analog Scale Adherence, Adherence Self-Efficacy, Social Provisions Scale, Disclosure, Regimen-Specific Social Support, Perceived Efficacy of Treatment, Social Problem-Solving Inventory (Rational Problem Solving; Positive Problem Orientation; Negative Problem Orientation); Beck Depression Inventory; BMQ Necessity subscale; Illness Intrusiveness Inventory, and Coping Self-Efficacy Scale (Problem-Focused Coping; Emotion-Focused Coping; Social Support). The selection of measures for validity analyses was guided by the relevant literature in HIV treatment adherence and stress and coping. *Mplus* version 4.1 was used for all latent variable analyses.

Study 3 Results—Descriptive information for the study sample is provided in Table 1. The most commonly referenced side effects were fatigue (17%), diarrhea (15%), neuropathy (13%), lipodystrophy (12%), and bloating, stomach pain or gas (8%).

Construct Validity Analyses: The 233 participants at baseline 1 constituted the analysis sample for analyses involving baseline 1 data. By contrast, 55 participants had not yet completed baseline 2; an additional eight participants supplied “not applicable” responses to the 20 SECOPE items (either respondents were no longer on ART or did not identify any problematic side effects at baseline 2), yielding a baseline 2 analysis N of 170. Results from the analysis of baseline 1 data indicated satisfactory model fit: $\chi^2(N=233; DF=53) = 167.15$, $p < .0001$; TLI = .95, RMSEA = .10, SRMR = .08. Results from fitting the same model to the baseline 2 data yielded similar though somewhat worse model fit: $\chi^2(N=170; DF=47) = 153.01$, $p > .0001$; TLI = .93, RMSEA = .12, SRMR = .12. Factor loadings from these analyses appear

in Table 2 and factor correlations appear in Table 3. In general, factor loadings and intercorrelations are very similar across the two samples and within Study 3.

A test of factor structure equality compared a factor analysis model replicating the SECOPE's factor structure across the two baseline measurements from Study 3 with no equality constraints to a more restricted model in which factor loadings and item thresholds were assumed to be equal. The fit of the less restricted model that did not assume measurement equality of the SECOPE factor structure over time was adequate: $\chi^2(N=233; DF=86) = 214.34, p < .0001$; TLI = .94, RMSEA = .08. By contrast, the fit of the more restricted model that assumed measurement invariance of the SECOPE factor structure was slightly better: $\chi^2(N=233; DF=94) = 218.33, p < .0001$; TLI = .95, RMSEA = .08. A chi-square difference test comparing the two models was not significant, $\chi^2(N=233; DF=36) = 36.08, p > .05, NS$, indicating that the more restrictive model assuming equality of the SECOPE's factor structure over time fit the data as well as the less restrictive model that did not make this assumption. Accordingly, we chose the model assuming equal factor loadings and item thresholds as the basis for the test-retest reliability correlations described below.

Reliability Analyses: Global composite reliability for Study 3 baseline 1 data was very similar ($\rho = .87$; 95% CI = .84, .89) as was reliability for the Study 3 baseline 2 data ($\rho = .87$; 95% CI = .84, .90). Internal reliability values for individual factors are shown in Table 2. Compared with the findings from Study 2, subscale reliabilities were somewhat lower in Study 3 for Positive Emotion Focused Coping and Self-Nonadherence whereas reliability was slightly higher for Taking Side Effects Medication. Reliability values across the two studies were generally comparable for Social Support Seeking and Information Seeking. Reliability values were highly similar across measurement waves of Study 3. Three month test-retest reliability was also very strong with r values ranging from .59 for Taking Side Effect Medication to .82 for Nonadherence. Taken collectively, these findings suggest that the SECOPE has robust internal consistency and test-retest reliability.

Convergent Validity Analyses: To assess concurrent validity, the latent factors in the Study 3 data were correlated with the available scale scores described previously in the Methods section. In selecting measures for concurrent validity testing, we identified constructs whose relationships with SECOPE subscales were consistent with Stress and Coping literature and with the content each subscale was purported to assess. Table 4 provides the correlation coefficients for all five factors with the variables of interest.

With the first factor, Positive Emotion Focused Coping, we observed moderate correlations in expected directions with Positive Problem Orientation and Rational Problem Solving on the SPSI-R, with all three subscales of the Coping Self-Efficacy Scale, with the measure of general social support, and with Positive Provider Interactions. Smaller but statistically significant correlations were found with lower depression, regimen specific support, adherence self efficacy, Negative Problem Orientation on the SPSI-R, and a small to moderate negative correlation was observed with HIV treatment knowledge. There were no observed associations with other scores, including either measure of adherence and perceptions of treatment efficacy.

The second factor, which was labeled Social Support Seeking (in response to side effect distress), was moderately associated with greater general social support and regimen specific social support, CSE social support, and perceptions that others understand their HIV treatment issues. A small but significant correlation was observed with Positive Provider Interactions.

The third factor encompasses non-adherence and self-reduction of dosages of HIV medications in efforts to reduce side effects. Scores on this factor were associated with poorer adherence using both the visual analog scale for the prior 30 days and the 3 day retrospective adherence

assessment. There was also a large negative association with adherence self-efficacy, a moderate negative association with lower perceptions of treatment efficacy, and small negative associations with treatment knowledge, provider interactions, problem-focused coping, and disclosure satisfaction. There was a small significant relationship with treatment intrusiveness.

The fourth factor assessed information seeking approaches to coping with side effects, and scores were positively associated with Rational Problem Solving and Positive Problem Orientation on the SPSI-R, social support measures, and perceived efficacy of treatment.

The fifth factor, which assessed taking other medications to counter the side effect demonstrated small but significant correlations with treatment intrusiveness and social support.

Discussion

The SECope has demonstrated reliability (internal consistency and test-retest) and its validity is supported through construct and criterion-referenced analyses. The factors that emerged from the qualitative and quantitative investigations are associated in logical ways with other measures of coping self-efficacy and social problem solving and are meaningfully linked to validated measures of ART adherence. The measure is based in Stress and Coping Theory and offers a mechanism for understanding how persons with HIV cope with side effects from their treatment. This information can, in turn, help guide inquiries and interventions to address medication adherence, side effects management, and clinical outcomes in HIV disease. Furthermore, the measure may be adapted and evaluated for use in other medical contexts in which treatment side effects potentially jeopardize treatment initiation, adherence, and outcome.

Of particular importance are the observed relationships between the non-adherence factor of the SECope and validated self-report measures of adherence. Side effects have consistently been cited as predictors of nonadherence to ART medications (Ammassari et al., 2001; Fogarty et al., 2002; Johnson et al., 2005). The current measure supports and extends that finding by quantifying the degree to which persons on ART intentionally skip ART medications to avoid the adverse effects they experience from the treatment. A second important finding from these analyses is that those who report greater non-adherence as a means to cope with side effects also demonstrate a poorer understanding of how HIV treatments work and report less positive interactions with their providers, greater intrusiveness of HIV treatment on their lives, and less satisfaction with their level of HIV disclosure to family and friends. Those with higher scores on the Non-adherence SECope factor also reported higher perceptions of ART effectiveness. It may be that those with poorer understandings of how ART works may also overestimate the effectiveness of ART and minimize the importance of adherence in their efforts to cope with side effects. These associations indicate intervention approaches that may reduce the likelihood of intentional nonadherence in response to side effects. For instance, providing greater education of HIV treatment and how to integrate treatment into daily lives, improving relationships with healthcare providers, and skills-building around productive HIV disclosure may lessen the potential enabling effects of these factors on intentional nonadherence as a side effect coping strategy.

In addition to the relationships of the SECope with ART adherence, the measure provides opportunities to investigate coping processes and quality of life among HIV-infected persons on ART. A better understanding of how coping with side effects relates to depression, social support, and other psychosocial factors can offer contributions to theory and, as with the discussion above regarding adherence, can inform interventions to improve psychosocial and health outcomes. The measure can allow for focus on specific side effects of interest. For instance, an investigation of coping strategies employed when a patient is dealing with

lipodystrophy will likely provide different information than when the SECope is framed around other side effects, such as diarrhea or fatigue. The availability of a measure that can be customized to the specific side effect of interest offers a tool to address a wide range of research questions focused on multiple or individual side effects and their relationships with varied psychological and clinical outcomes. Among these are questions such as how coping strategies change over time, how they relate to subsequent discontinuation of ART, and how amenable to change they are in response to intervention.

There are several limitations of note in the current study. First, we relied on patients' reporting of key data, including side effect reports and medication adherence. It is possible that more objective measures, including provider identification of side effects and electronic medication adherence monitoring may have yielded alternative results. Second, our use of convenience samples limits the degree to which our results can be generalized to other populations. In particular, the low numbers of women included in our samples, while reflective of the HIV epidemic in the area, limit the degree to which we can describe the suitability of the measure for women. Third, our measure of coping does not include all strategies of coping. Although our selection of items and factors was driven by empirical data, it is likely that some categories of coping are not captured by our measure. Similarly, the structure of our measure required respondents to select the single side effect that is most problematic. While this approach is informed by stress and coping theory, it is possible that the variability in selection of side effects influenced the responses provided. Finally, we do not yet have longitudinal outcome data to inform how the SECope predicts important treatment outcomes over time, including discontinuing medications, long-term adherence, and clinical outcomes such as viral load, CD4, and phenotypic resistance. Such data will provide additional support for the use of the SECope in a range of research and clinical contexts.

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Appendix: SECope Items

Please think about any symptoms that you have experienced in the past 30 days that you believe are caused by your HIV medications. If you have experienced more than one side effect, please choose the one that is most important (that is: which is the most bothersome or disruptive).

Specify here: _____

Please think about a time recently when you were experiencing this side effect. There are many things that people do in order to deal with problems such as side effects from treatment. Please listen to the following list and choose the number that best describes how often you use each way of dealing with this side effect. Again, please think about this side effect each time I say side effect.

- 0 Never
- 1 Rarely
- 2 Sometimes
- 3 Often

4 Very Often

When you experience this side effect, how often do you:

1. Remember that others have it worse than you do?
2. Decide that the medication is not worth the side effect and stop taking it?
3. Get support from other people?
4. Try to get more information about the medication or side effect?
5. Reduce the dose of the medication that is causing the side effect?
6. Remind yourself that the reason you are having this side effect is that you need the medications to stay healthy?
7. Talk to family, friends, loved ones about the problem?
8. Share your feelings and thoughts with others?
9. Take a break from the medication?
10. Take a medication that will make the side effect feel better or go away?
11. Take another medication to deal with the side effect?
12. Take less of the medication to see if the side effect is not so bad (smaller doses or less frequent)?
13. Talk to a counselor, therapist, or case manager?
14. Request a medication from your doctor to help the side effect?
15. Talk to your doctor or health care provider about the problem?
16. Think about good times in the past?
17. Try to find out as much as you can about the side effect and what is causing it?
18. Let others know what you are going through?
19. Try to have compassion for others who are suffering?
20. Try to keep your sense of humor?

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Table 1

Sample Characteristics

	Study 1 N = 21	Study 2 N = 173	Study 3 N= 233
Age—mean years (SD)	46 (7.3)	45 (7.7)	46 (8.2)
Gender-- n (%)			
Male	19 (90)	102 (58)	200 (86)
Female	2 (10)	67 (38)	27 (12)
Other	0	6 (4)	6 (3)
Race/Ethnicity --n (%)			
Black	3 (14)	71 (41)	42 (18)
White	14 (67)	70 (40)	127 (55)
Latino/a	0	28 (16)	38 (16)
Other	4 (19)	19 (11)	26 (11)
Sexual Orientation--n (%)			
Homosexual	15 (74)	59 (34)	171 (73)
Heterosexual	4 (19)	87 (50)	38 (16)
Bisexual/Other	0	29 (17)	24 (10)
Education --n (%)			
HS or less	4 (19)	115 (66)	17 (7)
> HS graduate	16 (81)	60 (34)	216 (93)
Viral Load Undetectable--n (%)	11 (52)	N/A	154 (66)
CD4 count --mean (SD)	390 (210)	N/A	416 (251)
Currently Not Working—n (%)	15 (71)	125 (71)	163 (70)

Table 2

SECOPE Scale: Standardized Factor Loadings and Reliability Coefficients with 95% Confidence Intervals

Factor	Study 2		Study 3	
	EFA	CFA	CFA BL1	CFA BL2
Positive Emotion Focused Coping		.86 (.81, .89)	.68 (.60, .74)	.69 (.59, .76)
Think about good times in the past	.86	.73 (.66, .80)	.64 (.54, .75)	.68 (.58, .78)
Think positively about the problem	.79	.86 (.79, .92)	.68 (.56, .80)	.82 (.70, .94)
Remember that others have it worse than I do	.82	.65 (.56, .74)	.59 (.47, .70)	.48 (.32, .64)
Remind myself that the reason I am having this side effect is that I need the medications to stay healthy	.81	.84 (.78, .91)	.56 (.45, .68)	.49 (.34, .64)
Try to keep my sense of humor	.86	.83 (.76, .89)	.51 (.38, .64)	.56 (.43, .69)
Social Support Seeking		.77 (.69, .83)	.81 (.77, .85)	.83 (.78, .87)
Talk to a counselor, therapist, or case manager	.69	.68 (.58, .79)	.53 (.42, .64)	.60 (.49, .71)
Let others know what I am going through	.79	.64 (.54, .75)	.64 (.56, .72)	.78 (.70, .85)
Share my feelings and thoughts with others	.68	.72 (.63, .82)	.93 (.89, .97)	.84 (.79, .89)
Get support from other people	.63	.64 (.53, .75)	.69 (.62, .76)	.70 (.61, .79)
Talk to my family, friends, and loved ones about the problem	.65	.68 (.56, .80)	.89 (.85, .93)	.83 (.77, .90)
Nonadherence		.82 (.75, .86)	.71 (.59, .78)	.74 (.61, .82)
Take less of the medication to see if the side effect is not so bad (smaller doses or less frequent)	.95	.81 (.74, .89)	.88 (.77, .99)	.87 (.79, .95)
Reduce the dose of the medication that is causing the side effect	.70	.82 (.75, .90)	.85 (.76, .95)	.92 (.83, 1.00)
Take a break from the medication	.83	.79 (.72, .87)	.62 (.48, .75)	.73 (.63, .84)
Decide that the medication is not worth the side effect and stop taking it	.64	.73 (.64, .82)	.65 (.54, .76)	.72 (.63, .82)
Information Seeking		.80 (.72, .85)	.76 (.70, .89)	.79 (.73, .84)
Talk to my doctor or health care provider about the problem	.58	.72 (.64, .80)	.66 (.55, .76)	.67 (.56, .78)
Try to get more information about the medication or side effect	.99	.79 (.72, .86)	.80 (.73, .87)	.85 (.76, .93)
Try to find out as much as I can about the side effect and what is causing it	1.02	.88 (.80, .95)	.83 (.76, .90)	.87 (.79, .94)
Taking Side Effect Medications		.73 (.60, .80)	.86 (.81, .89)	.82 (.75, .87)
Take another medication to deal with the side effect	.76	.57 (.46, .69)	.89 (.84, .94)	.84 (.74, .94)
Request a medication from my doctor to help the side effect	.62	.95 (.84, 1.06)	.80 (.73, .86)	.72 (.61, .84)
Take a medication that will make the side effect feel better or go away	.85	.67 (.57, .77)	.93 (.88, .98)	.94 (.84, 1.04)

Note: EFA = Exploratory Factor Analysis; CFA = Confirmatory Factor Analysis. For Study 2, $N = 171$. For Study 3, $N = 233$ at baseline measurement 1 (BL1). For Study 3, $N = 170$ at baseline measurement 2 (BL2). Item rows display factor loadings; factor rows display internal consistency reliability coefficients. For CFA loadings and reliability coefficients, lower and upper confidence limits are displayed in parentheses in the following format: (lower limit, upper limit).

Table 3
SECOPE Factor Intercorrelations and Test-Retest Correlations for Study 3

Factor	1	2	3	4	5
1. Positive Emotion Focused Coping	.79***	.49***	-.07	.53***	.08
2. Social Support Seeking	.50***	.72***	.19*	.62***	.33***
3. Nonadherence	.10	.28***	.82***	.19*	.08
4. Information Seeking	.42***	.55***	.32***	.66***	.32***
5. Taking Side Effect Medications	-.01	.17*	.40***	.37***	.59***

Notes: The lower diagonal displays results from baseline measurement 1 (N = 233); the upper diagonal displays results from baseline measurement 2 (N = 170). The main diagonal displays test-retest correlations among latent factors assuming measurement invariance of factor structures at baseline 1 and baseline 2 (N = 233).

*
p < .05
**
p < .01

p < .001.

Table 4

Concurrent Validity Results from Study 3

SECOPE Factor	1: Positive Emotion Focused Coping	2: Social Support seeking	3: Nonadherence	4: Information Seeking	5: Taking Side Effect Meds
Validation Scale					
HIV treatment knowledge	-.26**	-.03	-.25**	.01	.10
SPSI-R: Rational Problem Solving	.32***	.07	-.13	.24***	-.10
SPSI-R PPO	.41***	.05	-.01	.23***	.01
SPSI-R NPO	-.15*	.08	.15*	-.02	.04
Positive Provider Interactions	.33***	.20**	-.16**	.10	-.02
Non-Adherence	.08	-.03	.28***	-.02	.04
Visual Analog Adherence Scale	-.01	.04	-.42***	-.04	-.03
Adherence Self Efficacy	.17*	.01	-.55***	-.03	-.10
Social Provisions Scale	.40***	.35***	-.07	.24***	.17*
Perceived efficacy of treatment	-.12	.08	.36***	.19**	.12
BMQ Necessity	.08	-.01	.17*	.02	.03
Beck Depression Inventory	-.16*	-.08	.18*	-.06	.10
Illness Intrusiveness	-.11	.07	.22**	.12*	.14*
CSE: Problem-focused coping	.40***	.03	-.24**	.09	-.09
CSE: Emotion-focused coping	.33***	.04	-.01	.09	-.01
CSE: Social support	.32***	.39***	-.05	.23**	.09
Disclosure: Satisfaction	.13	.01	-.25**	-.04	.04

Notes: All instruments listed were measured at baseline 1, except for the BMQ and HIV Treatment Knowledge. $N = 233$ for all measures, except for CSE: Social Support ($N = 232$), BDI ($N = 231$), BMQ ($N = 178$) and HIV Treatment Knowledge ($N = 178$). SECOPE factor labels correspond to: 1. Positive Emotion Focused Coping; 2. Social Support Seeking; 3. Nonadherence; 4. Information Seeking; 5. Taking Side Effect Medications. SPSI: Social Problem Solving Inventory. BMQ: Beliefs about Medications Questionnaire. CSE: Coping Self-Efficacy scale.

* $p < .05$

** $p < .01$

*** $p < .001$.