

# The Role of Emotional Avoidance, the Patient-Provider Relationship, and Other Social Support in ART Adherence for HIV+ Individuals

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**Abstract** Adherence to antiretroviral therapy (ART) is associated with positive health outcomes among HIV+ patients. However, non-adherence remains high. Though factors that account for non-adherence remain unclear, social support has been consistently associated with ART adherence. As such, identifying malleable factors that hinder patients' ability to form supportive relationships may have consequence for improving ART adherence. Emotional avoidance (EA) may be one such factor given that it has been linked to difficulties in social situations. The present study examined relations among EA, the patient-provider relationship, other sources of social support, and ART adherence within a sample of HIV+ ARTprescribed patients. High EA was related to poor adherence and patient-provider relationships. EA was indirectly related to poor adherence through poorer patient-provider interactions. The indirect relation of EA to ART adherence through other sources of social support was not significant.

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Implications for developing targeted behavioral interventions focused on improving ART adherence are discussed.

**Keywords** Antiretroviral therapy · Adherence · Emotional avoidance · Patient–provider relationship · Social support

#### Introduction

Significant advances have been made in the treatment of HIV, including the introduction and availability of antiretroviral therapy (ART). However, patient adherence to the prescribed ART regimen is crucial in maximizing effectiveness. Non-adherence is related to increased viral load [1–5], lower CD4 count [5–7], quicker progression to AIDS [8] and lower quality of life [1, 9] relative to ARTadherent behavior. Even though a number of advances have been made in addressing factors commonly thought to contribute to non-adherence behaviors (e.g., lack of health insurance, inadequate patient-provider relationships, and complicated medication regimens [10, 11]), non-adherence remains high (on average, just 62% of patients report >90% adherence [2, 3, 12]). Extant research has also identified several patient-level factors that may negatively influence adherence behavior, including psychiatric symptoms (e.g., addiction and depression [13, 14]), social support [2, 15] and health-related quality of life [11], yet a substantial amount of variance in non-adherence remains unexplained. As such, identification of additional modifiable factors associated with ART-adherence (i.e., factors that are likely to be amenable to change through psychosocial interventions) may have relevance for the health of HIV+ populations.

As noted above, one factor that has consistently been identified as an important correlate of adherence behavior



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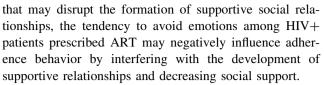
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is social support. In particular, research indicates that lack of social support from a patient's family, friends, and significant others is related to poor adherence behavior [2, 16], and socially isolated individuals are less likely to adhere to medication regimens than non-isolated individuals [17]. Conversely, self-reported satisfaction with social support is related to good adherence behavior within diverse populations [7, 11, 18, 19]. Notably, beyond the support provided by family, friends, and loved ones, relationships with medical providers can also serve as a primary source of support for HIV+ patients [15], and there is evidence that supportive and trusting relationships with providers promote higher levels of adherence [15, 17, 20–26]. Moreover, meta-analyses suggest that high overall satisfaction with health care providers is related to increased adherence behavior [27, 28]. Researchers have proposed a range of mechanisms through which social support may affect adherence behavior, including increased positive mood [29]; hope, motivation [18], and confidence [2] following the receipt of emotional support; and receiving tangible (e.g., physical) assistance [7] or information about HIV/AIDS and medication [2, 7] from members of one's social network. Given the demonstrated relations between the presence of supportive relationships and adherence behavior, identifying factors that may disrupt the ability of HIV+ patients to form supportive relationships may inform the development of targeted interventions to improve ART adherence. One factor that may interfere with the ability to form strong and supportive relationships is emotional avoidance (EA).

Research suggests that EA, a behavioral pattern of taking action to reduce or avoid both positive and negative emotional experiences [30], may influence the formation and maintenance of supportive interpersonal relationships [31]. Individuals who tend to suppress their emotions (a common form of EA [32, 33]) are less likely to divulge their emotions to others and more likely to avoid developing close relationships, relative to individuals with lower levels of emotional suppression [34, 35]. Likewise, experiential avoidance (i.e., efforts to alter the form, frequency, or intensity of unwanted thoughts, sensations, or emotions [36]), a broader construct that subsumes EA, is related to relationship-interfering behaviors, including coldness and hostility [37] and interpersonal aggressive behaviors [38, 39]. Experiential avoidance is also related to generally poor relationship adjustment following exposure to traumatic events [38]. In contrast, the willingness to approach and express emotions to others (i.e., emotionally expressive coping [40, 41]) is positively related to the size of an individual's social network, the formation of new relationships, increased intimacy in close relationships, and garnering support from others [42]. Given that the avoidance of emotions is associated with behavioral responses



In light of the literature reviewed above, research examining the relations among EA, support from providers and others, and ART adherence is warranted. The present study aimed to clarify these relations within a sample of ART-prescribed HIV+ patients from two HIV clinics in the U.S. We predicted significant negative relations between EA, support from providers and others, and ART adherence behavior. We also predicted significant indirect relations of EA to adherence through both the quality of the patient-provider relationship and perceived social support from others.

### Method

## **Participants**

Participants were 255 ( $M_{age}=42.20$ ;  $SD_{age}=10.54$ ) HIV+ patients recruited from two U.S. (located in the northeast and south) community-based clinics that specialize in the treatment of HIV/AIDS. Table 1 displays demographic information for the 207 (81.2%) participants who reported that they were prescribed ART. Participants were primarily male, heterosexual, and Black/African American. Participants reported being first diagnosed with HIV in 1998 (median) and receiving care in the recruitment clinic for one year or more. A majority of the participants had obtained at least a high school degree, though most were unemployed, on disability, or receiving public assistance.

#### Measures

The Emotional Avoidance Questionnaire [30] (EAQ) is a 20-item self-report measure of cognitive and behavioral expressions of EA. Participants respond to items using a 5-point Likert-type scale ( $1=not\ true\ of\ me$  to  $5=very\ true\ of\ me$ ). EAQ items assess avoidance of positive and negative emotions, negative beliefs about emotion, and social concerns about displaying emotion. High scores, calculated as the sum of all items (range 20–100), represent more EA. Evidence supports both the validity (e.g., theoretically consistent relations with avoidant personality disorder symptoms, anxiety symptoms, PTSD symptom severity, and behavioral expressions of avoidance) [30, 43] and reliability of the EAQ (Chronbach's  $\alpha=0.87-0.92$ ) in both psychiatric [43] and non-psychiatric [44] populations. Cronbach's  $\alpha$  was 0.93 in the present study.



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Table 1 Characteristics of ART-prescribed participants by recruitment site

Characteristics	Total sample ( $n = 207$ )	Southern site $(n = 111)$	Northeastern site $(n = 96)$	Statistic	p
Age in years (SD)	0) 43.33 (10.00) 42.94 (9.33) 43.78 (10.75)		t(205) = 0.61	0.55	
Gender (male)	125 (60.4%)	58 (52.3%)	67 (69.8%)	$\chi^2(1) = 6.62$	0.01
Race/ethnicity				$\chi^2(2) = 100.49$	< 0.001
African American	129 (62.3%)	104 (93.7%)	25 (26.0%)		
White	46 (22.2%)	5 (4.5%)	41 (42.7%)		
Other	32 (15.5%)	2 (1.8%)	30 (31.3%)		
Sexual orientation <sup>a</sup>				$\chi^2(1) = 3.38$	0.07
Heterosexual	126 (60.9%)	74 (66.7%)	52 (54.2%)		
Gay/Lesbian	58 (28.0%)	25 (22.5%)	33 (34.4%)		
Bisexual	18 (8.7%)	7 (6.3%)	11 (11.5%)		
Unsure	5 (2.4%)	5 (4.5%)	0		
Education				$\chi^2(2) = 0.93$	0.63
<high school<="" td=""><td>58 (28.0%)</td><td>28 (25.2%)</td><td>30 (31.3%)</td><td></td><td></td></high>	58 (28.0%)	28 (25.2%)	30 (31.3%)		
High school graduate	63 (30.4%)	35 (31.5%)	28 (29.2%)		
At least some college	86 (41.5%)	48 (43.2%)	38 (39.6%)		
Employment <sup>b</sup>					
Full or part time work	45 (21.8%)	26 (23.4%)	19 (19.8%)	$\chi^2(1) = 0.40$	0.53
Unemployed	60 (29.0%)	32 (28.8%)	28 (29.2%)	$\chi^2(1) = 0.003$	0.96
Disability or public assistance	87 (42.0%)	45 (40.5%)	42 (43.8%)	$\chi^2(1) = 0.22$	0.64
One year or more in clinic	176 (85.0%)	93 (83.8%)	83 (86.5%)	$\chi^2(1) = 0.29$	0.59
Method of contracting HIV <sup>b</sup>					
Sex with HIV+ partner	157 (75.8%)	95 (85.6%)	62 (72.8%)	$\chi^2(1) = 12.39$	< 0.001
Shared nonsterile needles	36 (17.4%)	6 (5.4%)	30 (31.3%)	$\chi^2(1) = 23.93$	< 0.001
Other	19 (9.2%)	9 (8.1%)	9 (9.4%)	$\chi^2(1) = 0.10$	0.75
Unsure	18 (8.7%)	11 (9.9%)	7 (7.3%)	$\chi^2(1) = 0.44$	0.51

Tests of significance compare differences between the two recruitment sites

The Engagement with Health Care Provider [45] (EHCP) scale was used to assess the quality of the patient-provider relationship. Participants rate 13 aspects of their interactions with their providers using a 4-point Likert-type scale  $(1 = always\ true\ to\ 4 = never\ true)$ . Research indicates that the EHCP is reliable (Chronbach's  $\alpha = 0.96$ ), valid (e.g., associated with patients willingness to discuss substance use with their provider) [46], and items load onto a single factor [45]. The present study reverse coded the EHCP such that high scores (range 13–52) reflect higher quality relationships during the medical appointment. Internal consistency was excellent in the present study ( $\alpha = 0.96$ ).

The 12-item Multidimensional Scale of Perceived Social Support [47] (MSPSS) is a self-report measure of perceived adequacy of social support. Participants indicate their level of agreement with items using a 7-point Likert-type scale (1 = very strongly disagree to 7 = very strongly agree). The MSPSS assesses perceptions of support received from family, friends, and significant others, which reflect distinct reliable and valid factors in college [47] and community

[48] samples. Subscale scores are calculated as the item mean (range 1–7), with higher scores representative of greater perceived social support. Subscale internal consistency ranged from  $\alpha = 0.92$ –0.95 in the present study.

ART adherence was operationalized as the percentage of HIV medication participants took in the month preceding the medical appointment (see "Procedure" section). Participants responded to a single item using a 10-point scale (0 = 0% to 9 = 100%). Research indicates that self-reported adherence measures correlate with more objective assessment methods, including medical chart-obtained CD4 counts and viral loads [49], unannounced pill counts [50], and medication event monitoring systems [51]. Selfreport methods also reduce clinic and participant burden compared to alternative assessment methods [50, 52] and appear adequate for use in multicultural samples [53]. A one-month time frame has been found to correlate with objective adherence assessments [49] and results in more accurate self-reported adherence than shorter formats (i.e., 3- or 7-day) [51, 54].



<sup>&</sup>lt;sup>a</sup> Evaluated as heterosexual versus other due to low frequency counts of some categories

<sup>&</sup>lt;sup>b</sup> Responses were not mutually exclusive, precluding an omnibus test of group differences

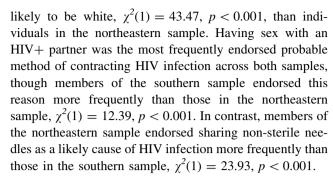
#### **Procedure**

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Furthermore, the Institutional Review Boards at all data collection sites approved all procedures. Informed consent was obtained from all individual participants included in the study. Data were collected from 2009 to 2010 as part of a larger study designed to examine emotional, cognitive, and behavioral factors that influence the patient-provider relationship and other HIV-relevant health risk behaviors. Participants were recruited during routine HIV care visits at specialized medical clinics. Upon appointment check-in, patients were presented with an informational flyer that described the study. Researchers approached potential participants in private examination rooms prior to their visit with the medical provider in order to provide them with more information about the study. Following their healthcare appointment, patients interested in participating in the study were escorted to a private research room where they provided informed consent and completed an anonymous survey battery using either an audio computer assisted selfinterview [55, 56] or traditional paper and pencil method.

### **Results**

All variables except EA were negatively skewed, and both ART adherence and the quality of the patient-provider relationship were leptokurtic. Yet, no substantive differences in outcomes were observed when transformed variables were used in the models presented below. Thus, to aid interpretation, all reported results retain original metrics. Most participants reported 100% adherence to the HIV medication regimen during the previous month (Median = 9). As seen in Table 2, patient-provider relationship scores were in line with those reported in other HIV+ samples [45]. EA scores were in the range observed in psychiatric clinical samples [30, 43, 57]. Perceived social support was marginally lower than found in normal comparison samples [48].

SPSS Statistics 22.0.0.2 for Mac was used to identify group differences (northeast versus south) in demographic characteristics (see Table 1). Individuals in the northeastern sample were more likely to be male (vs. female) than were individuals in the southern sample,  $\chi^2(1) = 6.62$ , p = 0.010. A significant group difference in ethnic distribution was also found,  $\chi^2(2) = 100.49$ , p < 0.001, with participants in the southern sample more likely to be Black/ African American,  $\chi^2(1) = 100.33$ , p < 0.001, and less



A multiple mediation model was evaluated using ordinary least squares path analysis (PROCESS Model 4) [58]. EA was entered as the predictor of ART adherence. The quality of the patient-provider relationship and perceived support from family, friends, and significant others were entered as potential parallel mediators of the EA-adherence relation. Results indicated that EA indirectly influenced ART adherence through its relation to the quality of the patient-provider relationship. As shown in Fig. 1, higher EA related to poorer patient-provider relationships, a = -0.06, t(205) = -2.38, p = 0.02, which, in turn, related to lower ART adherence, b = 0.07, t(201) = 2.83, p = 0.01. The bias-corrected bootstrap confidence interval (based on 10,000 samples) for the indirect relation, ab = -0.004, was entirely below zero, -0.011 to -0.001. No support was provided for an indirect relation of EA to ART adherence through perceived social support. EA was not significantly related to any aspect of perceived social support, all ps > 0.09, social support was not related to ART adherence, all ps > 0.09, and the biascorrected bootstrap confidence intervals for each indirect relation contained zero. The direct path from EA to ART adherence was not significant in the final model, c' = -0.017, t(205) = -1.86, p = 0.06, suggesting that EA did not influence ART adherence independently of its relation through the quality of the patient-provider relationship. Finally, a conditional processes analysis (PRO-CESS Model 8) [57] was conducted to evaluate recruitment site as a moderator of the paths from EA to each mediator (i.e., a paths) and ART adherence (i.e., c path). The biascorrected bootstrap confidence intervals based on 10,000 samples each contained 0, indicating that recruitment site did not moderate any evaluated path, all ps > 0.11. Full moderation analyses are available by contacting the first author.

# Discussion

Notwithstanding advances in the identification of factors associated with ART adherence, non-adherence remains a significant issue among individuals living with HIV infection. Improving ART adherence through the development of novel clinical interventions will require an adequate understanding of the multitude of factors that

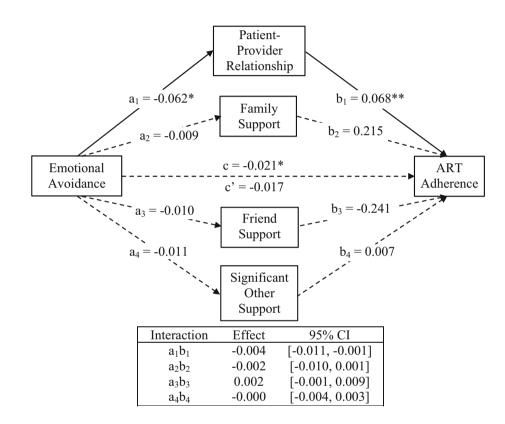


**Table 2** Descriptive data and correlations between primary variables of interest (N = 207)

Measure	1	2	3	4	5	6
ART adherence	_					
Emotional avoidance	-0.16*	_				
Patient-provider relationship	0.22**	-0.16*	_			
Family support	0.10	-0.09	0.18**	_		
Significant other support	0.02	-0.12	0.13	0.59**	_	
Friend support	-0.00	-0.11	0.19**	0.66**	0.70**	_
M	7.25	57.00	47.40	4.94	5.23	4.85
SD	2.71	20.60	7.85	2.02	1.85	1.87

<sup>\*</sup> *p* < 0.05. \*\* *p* < 0.01

Fig. 1 Ordinary least squares path model of the multiple mediation analysis examining the indirect relation of emotional avoidance to self-reported antiretroviral therapy (ART) adherence through various sources of support. Dashed lines indicate non-significant relations. CI = confidence interval. \* p < 0.05, \*\* p < 0.01



influence individuals' adherence behavior [59]. However, surprisingly little research has investigated specific, modifiable, patient-level factors that may be leveraged to improve ART adherence [60]. The present study evaluated EA as one such factor, with an emphasis on its impact on the patient-provider relationship and social support more broadly. Results revealed an indirect relation of EA to ART non-adherence through poorer patient-provider relationships among HIV+ individuals. Moreover, recruitment site did not moderate these relations, suggesting that the results held across two geographically diverse samples. Accordingly, EA may be an important factor to target in interventions aimed at increasing adherence to ART prescription regimens and improving the quality of the patient-provider relationship.

Indeed, improvement of the patient-provider relationship has been a primary intervention target of treatment programs designed to increase ART adherence behavior [61]. Components of these programs often attempt to improve medical providers' communication skills [62] or increase patients' HIV and ART knowledge and adherence-supportive behaviors (e.g., lifestyle alterations, use of memory devices, goal setting) [63, 64], including their participation in health consultation meetings [60]. Yet, evidence regarding the efficacy of ART adherence interventions is mixed and the observed effect sizes of these interventions are moderate at best [62, 63, 65–69], suggesting that these interventions may not fully target all relevant risk factors for ART adherence.



Our results suggest that the use of behavioral treatment strategies that address EA may facilitate the development of more positive, supportive relationships with healthcare providers among HIV+ patients, which, in turn, may enhance ART adherence outcomes. For example, patients who have a tendency to avoid their emotional experiences may also share fewer relevant personal details about their lives and experiences with their medical provider. This behavior could limit a provider's ability to design an effective ART regimen and treatment plan for the patient (e.g., one that takes into account that individual's unique environmental and personal barriers to adherence). Specification of relationship-oriented behaviors that differ between emotionally avoidant and non-avoidant patients may increase our understanding of how EA impacts patient-provider relationships and, as such, aid in the development of effective adherence programs.

Evaluation of EA as part of the intake process through the use of brief self-report measures [30, 70] may assist in the identification of patients who may benefit from brief acceptance-based behavioral treatments designed to reduce EA. Acceptance and Commitment Therapy (ACT) [71] is one such empirically-supported treatment that may be beneficial for patients struggling with ART adherence and the formation of positive interpersonal relationships. ACT targets EA through various techniques designed to increase the acceptance of internal experiences in the service of better attending to present moment opportunities to engage in behaviors that are guided by personally-chosen life values. ACT has demonstrated efficacy in the treatment of physical health problems [72-74] and is amenable to medical settings [73]. Further, recent research suggests that ACT may also be useful for improving ART adherence [75]. Though research evaluating the effect of ACT on patient-provider relationships and ART adherence in primary care settings is lacking, development of such programs could offer providers a way to promote and support adherence behavior. Specifically, ACT may contribute to positive outcomes within this population by (a) modeling and rewarding acceptance of personal fears and concerns; (b) explicitly identifying the patient's personal values related to the patient-provider relationship and her or his own health care; and (c) developing behavioral goals (e.g., regular attendance at physician appointments) in-line with these values.

Adherence outcomes related to broader social support (i.e., beyond that received from medical providers) remain less clear. Contrary to our predictions, as well as past research linking EA with poorer social relationships [30] and social support with better adherence behavior [19], perceived support from family, friends, and significant others did not mediate the relation of EA to ART adherence. It is possible that the previously observed relation

between EA and social support may not hold in HIV+ populations, wherein other factors, such as contextual or other patient-level factors, may have a greater influence on the development and maintenance of supportive relationships. For example, findings that HIV-related stigma is inversely associated with perceived social support in African-American populations [76] highlight the need for future research examining the impact of such stigma on the relations among EA, social support, and adherence behavior. Likewise, research suggests that co-occurring psychiatric difficulties, such as depression, may also have an impact on perceived social support [77] and EA [35]. Evaluating the effect of depression on the relations examined herein may further clarify the importance of EA to adherence behavior within this population. In addition, use of available community resources that provide both emotional and instrumental support (e.g., peer support groups) [78, 79] could reduce the need for or reliance on social support from family, friends, and significant others, potentially decreasing the strength of the relations examined here. Future research examining the extent to which community resource availability and use influences the relations among EA, perceived social support, and adherence behavior is needed. Alternatively, our method of operationalizing social support as perceived social support may have influenced our findings. Though perceived social support buffers stressful experiences and is related to positive outcomes for HIV+ individuals more strongly than actual available support [80], the influence of EA on the relation between actual available support and relevant outcomes is unclear. Identifying the relations of EA to both perceived and actual social support, while also accounting for common HIV-related contextual and patient-level factors, may lead to a better understanding of the paths through which EA influences adherence behavior.

It is also important to note that efforts to avoid internal experiences may negatively influence adherence through multiple mechanisms. For example, both EA and a general tendency to avoid thoughts, feelings, and physical sensations have been found to be related to greater levels of depression, anxiety, and substance use [13, 14, 30, 32-34, 43, 44, 81-85], all of which have, in turn, been linked to poor ART adherence [61, 86-89]. Factors associated with psychiatric difficulties, such as difficulties communicating with others and understanding medical advice and cultural stigma surrounding mental health problems [90], may have a negative impact on patientprovider and other social relationships that could otherwise support adherence behavior. Furthermore, avoidance is correlated with dysfunctional health-related behaviors [91] and predicts negative health outcomes [92], including poor illness management in HIV+ populations [93], whereas acceptance of one's illness appears relevant to successful



coping and adjustment to disease [94, 95]. Accordingly, emotionally-avoidant patients may have greater treatment needs and be more difficult to treat than those who are more accepting of internal experiences, potentially increasing the risk for provider burnout [96] and related poor adherence outcomes [97]. Future studies examining the various paths through which EA may lead to poor adherence are needed to clarify the role of EA in adherence outcomes and to identify potential intervention targets to mitigate these negative outcomes (such as programs designed to help providers cope with and avoid professional burnout [98], including ACT-based burnout interventions [99]). Furthermore, research incorporating these additional pathways may help clarify the ways in which social support outside of the context of the patient-provider relationship may promote or interfere with adherence behaviors.

Results should be interpreted with consideration of limitations of the present study. First, we chose to use a single self-report item to measure adherence behavior. Although self-report is the most common method of assessing ART adherence [12] and correlates with objective assessment methods [100, 101], self-reported adherence may overestimate adherence behaviors relative to other response formats [102]. This shortcoming may be addressed by examining the relations of interest using multi-method assessments (e.g., unannounced pill counts or medication event monitoring systems). Second, we assessed EA as a general tendency to avoid all emotional experiences; the impact that the avoidance of specific emotions (e.g., shame, guilt, anxiety) may have on the relations among EA, supportive relationships, and ART adherence is unclear and in need of further study. Identification of commonly avoided emotions within this population may also facilitate the development of targeted interventions aimed at increasing the experience and expression of emotions most relevant to adherence behaviors. Third, our assessment did not capture the course of ART treatment. As such, we cannot elucidate differences in the observed relations between treatmentnaïve patients and those with extended use of ART [63]. Inclusion of such information in future studies may provide the specificity needed to develop EA-inclusive interventions that are better able to address the needs of patients who may be at different points of the "continuum of ART adherence needs" (p. 295) [63]. Finally, our use of a cross-sectional design prevents identification of the precise nature and direction of the observed relations. It is not possible to determine if non-adherence to ART undermines the patient-provider relationship, a poor patient-provider relationship leads to non-adherence (as hypothesized here), or the relation between ART adherence and the patient-provider relationship is bidirectional and reciprocal. Moreover, adherence is a fluid process, particularly in the context of chronic medical conditions such as HIV, and single time point assessments may falsely classify individuals as adherent [103]. Longitudinal research designs combined with timeline followback [88] or daily diary assessment methods may help clarify the time-dependent and/or reciprocal nature of the relations examined herein.

In sum, outcomes related to HIV infection may be favorably influenced by the elucidation of factors that:
(a) aid in the identification of patients at risk for poor adherence behaviors, and (b) are likely to be amenable to change through psychosocial interventions. The present results suggest that EA may be one easily assessed patient-level factor that increases the potential for poor ART adherence through its negative impact on the patient-provider relationship. As such, targeting EA directly by integrating acceptance-based behavioral treatments such as ACT [71] into pre-existing ART adherence programs that focus on improving patient—provider relationships may result in more positive patient health outcomes.

### **Compliance with Ethical Standards**

Conflict of interest The authors declare that they have no conflict of interest.

**Ethical Approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from all individual participants included in the study.

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