# A New Attitude Towards Treatment Measure Predicts Survival Over 17 Years



Gail Ironson, PhD, MD<sup>1,2</sup>, Emily Hylton, MPH<sup>1</sup>, and Rachel Verhagen, BA<sup>1</sup>

<sup>1</sup>Department of Psychology, University of Miami, 5665 Ponce de Leon Blvd, Coral Gables, FL, USA; <sup>2</sup>Department of Psychiatry, University of Miami, Coral Gables, USA.

**BACKGROUND:** For patients diagnosed with chronic illness, attitude towards treatment may play an important role in health and survival. For example, negative attitudes towards treatment have been related to poorer adherence to treatment recommendations and prescribed medication across a range of chronic illnesses. In addition, prior research has shown that attitude towards treatment assessed through a psychiatric interview predicted survival at 1 year after bone marrow transplantation with great accuracy (> 90%).

**OBJECTIVE:** The purpose of this study was to determine the relationship between a self-report attitude to a treatment measure that operationalized a psychiatric interview, and survival over 17 years in a sample of people living with HIV (PLWH).

**PARTICIPANTS AND DESIGN:** Participants (N=177) who were in the mid-range of HIV illness at baseline (CD4s 150 to 500, no prior AIDS-defining clinical symptom) were administered the Montreal-Miami Attitude to Treatment (MMAT-20/HIV) scale and followed longitudinally to determine survival at 17 years.

**MEASURES:** The Montreal-Miami Attitude to Treatment (MMAT-20/HIV) scale is a 20-item self-report questionnaire designed to survey multiple factors that contribute to an overall psychological construct of the treatment process.

**RESULTS:** The MMAT-20/HIV predicted survival over 17 years controlling for biomedical (baseline CD4, viral load, antiretroviral medications, age) and psychosocial (race, education, antiretroviral medications) variables. Those in the top half on the MMAT-20/HIV were almost twice as likely to survive than those in the lower half. Scores on the MMAT-20/HIV were significantly but modestly correlated with adherence (r=.20, p<.05), but adherence was not a mediator of the relationship between the MMAT-20/HIV and survival.

**CONCLUSIONS:** An individual's attitude towards the treatment process predicted survival, raising the possibility that optimal clinical management would include ways to probe these attitudes and intervene where possible. The ease of administering the MMAT-20 and adaptability to other illnesses could facilitate this endeavor.

 $\label{eq:KEYWORDS: Attitude; Treatment; HIV; Survival; Trust.}$ 

J Gen Intern Med 37(10):2351–7 DOI: 10.1007/s11606-021-07245-y

 $\ensuremath{{}^{\odot}}$  The Author(s) under exclusive licence to Society of General Internal Medicine 2021

#### INTRODUCTION

## Importance of Attitude Towards Treatment

For patients with chronic illnesses, attitude towards treatment may play an important role in predicting patient-related outcomes including survival. The literature supports several possible credible pathways: Negative attitudes towards treatment have been related to poorer adherence to treatment and prescribed medication across a range of chronic illnesses, including inflammatory bowel disease, 1 renal disease, 2 asthma,<sup>3, 4</sup> and HIV.<sup>5–9</sup> Non-adherence, in turn, has been linked to poor health and higher mortality in patients with chronic illness. 10-12 Optimism and hope may be linked to attitude towards treatment and have been associated with better health outcomes and survival in chronic disease. 13 Poor treatment appraisals and concern about medical care have been linked with higher levels of health anxiety, 14, 15 and anxiety is linked to morbidity and mortality in the context of chronic illness. 16, <sup>17</sup> Positive relationships with health care providers may serve as social support, 18 which has been associated with better treatment self-management and health status in the context of chronic illness. 19, 18 These potential pathways suggest that attitudes towards treatment may play an integral role in predicting health outcomes and even survival in people with chronic illnesses. In fact, a psychodynamically oriented psychiatric assessment of attitudes to treatment was shown to predict mortality over 1 year in bone marrow transplant patients<sup>20, 21</sup> with great (> 90%) accuracy.

While attitude towards treatment typically focuses on beliefs and feelings towards a specific medication or prescribed procedure (such as bone marrow transplant, chemotherapy, or physical therapy), we consider a broader construct incorporating not only the specific prescribed treatment, but also the process involved in arriving at treatment decisions (e.g., gathering information, expressing feelings with others, optimism about the illness, beliefs about self-efficacy, etc.) and thus including emotions, cognitions, and behaviors. The literature on attitudes towards treatment thus covers a wide variety of

constructs, including beliefs and knowledge about medications/treatments, emotions, physician trust and interactions, active patient involvement, and self-efficacy. We review each of these below.

# Attitude Towards Treatment and Relationship to Health/HIV Outcomes

Several studies have examined attitudes towards treatment in people living with HIV (PLWH). Illness appraisals of HIV were related to how people think and feel about available treatments and decisions regarding initiation of antiretroviral treatment (ART). Several researchers found that HIV-related knowledge, concerns about ART, and a realistic view of ART efficacy were associated with ART adherence. However, Kamal et al. did not find a significant association between ART adherence and the Beliefs about Medicine Questionnaire (Necessity & Concerns; 25) or the Illness Perception Questionnaire.

Another important aspect of attitudes towards treatment is the provider-patient relationship. Ironson et al.<sup>27</sup> found that active patient involvement in the doctor-patient relationship predicted increases in medication adherence over 12 months, and that participants' active engagement in their care was greater in long survivors than in normal HIV-course controls. Patient comfort with asking questions, provider trust, and clarity of provider were significantly related to undetectable viral load (VL) and retention in HIV care.<sup>28</sup> Connection, respectful communication, and professional partnering skills were negatively correlated with depression in PLWH.<sup>29</sup>.

We found two scales measuring patient treatment self-efficacy in PLWH. The HIV Treatment Adherence Self-Efficacy Scale subscales of adherence integration and adherence perseverance both significantly correlated with clinical status, psychosocial measures, ART adherence, and healthcare utilization.<sup>30</sup> Increases in scores on a self-efficacy inventory over a 3-month intervention period were related to decreases in viral load and increases in CD4 in a sample of women living with AIDS.<sup>31</sup>.

# Measures of Attitude Towards Treatment in Non-HIV Samples

In addition, a variety of validated measures capture constructs related to attitude towards treatment in populations with chronic illnesses. Only one of these scales specifically measures "attitudes towards treatment" as a distinct but multifaceted construct. The PRACTA Attitude Towards Treatment and Health Questionnaire has four factors: cognition, positive emotions, negative emotions, and motivation.<sup>32</sup>.

Several validated scales measure patient relationship with or trust in their healthcare provider. Examples are the Wake Forest Physician Trust Scale<sup>33, 34</sup> and The Stanford Trust in Physician Scale.<sup>35</sup> These have been correlated with physician continuity and patient satisfaction at 6 months' follow-up,<sup>35</sup> and medication adherence cross-sectionally<sup>34</sup> and at 6 months' follow-up.<sup>35</sup>.

In addition to Ironson and colleagues' scale, <sup>27</sup> we found one other scale measuring active patient involvement in treatment. Those with higher scores on the Patient Activation Measure<sup>36</sup> (believing active role is important, having confidence and knowledge to take action, taking action, and staying the course of treatment under stress) reported better health, fewer doctor and emergency room visits, and fewer hospital nights.<sup>36</sup>.

In addition, numerous other scales measure attitude towards specific types of treatments or medications. The Chemotherapy Side Effects Fear Scale<sup>37</sup> and the Attitude Towards Adjuvant Chemotherapy measure<sup>38</sup> measure attitudes towards chemotherapy. Attitudes towards treatment for diabetes include the Attitude Towards Diabetes and Its Treatment scale<sup>39</sup> and the Diabetes Attitudes Scale.<sup>40</sup> Attitudes towards medication include the Beliefs About Medicines Questionnaire<sup>35</sup> and Attitudes Towards Medications Questionnaire.<sup>41</sup>.

# The Present Study

Few studies have measured the impact of attitude towards treatment on survival, and none in PLWH. Given the impact of attitudes towards treatment on chronic illness, this study operationalizes an interview generated in a clinical setting into a self-report measure. It encompasses many dimensions of treatment attitudes. And the questions ask about actual patient experiences, which respondents may be able to report on more factually, rather than just guessing at hypotheticals or stating levels of agreement with poorly defined "attitudes." The interview was previously shown to predict survival in bone marrow transplant patients, and was based upon psychoanalytic principles of object relations.

## **METHODS**

This substudy took place within a larger longitudinal study that focused on disease progression, stress, and coping in PLWH. 42, 43.

# **Participants**

Participants were 177 PLWH with no prior AIDS-defining symptoms and between 150 and 500 CD4 cells/mm<sup>3</sup>. Subjects were recruited in South Florida through community events, flyers, newspaper advertisements, physician offices, community organizations, and word of mouth. Exclusion criteria included psychosis, active substance dependence (determined using the psychotic screen and substance use module from the Structured Clinical Interview for DSM-III-R Disorders, <sup>44</sup>), and/or dementia (determined using the Mini-Mental State Test <sup>45</sup>).

Descriptive statistics for medical and sociodemographic characteristics of the sample have been previously reported. The sample was diverse in terms of age (M [SD] 37.49 [8.88]), sex (70.1% male), race/ethnicity (36.2% African American, 30.5% White, 28.2% Hispanic, and 5.2% other), and sexual

orientation (54.8% gay or bisexual). Nearly three quarters of participants had achieved educational attainment beyond high school. Most participants (61.6%) reported annual income at or less than US \$10,000. Most participants (90%) reported taking antiretroviral medication for HIV during the study period.

## **Procedures**

Participants provided informed consent, completed psychosocial measures, and were given blood draws (for CD4 and VL) at the baseline visit (which occurred between 1997 and 1999) and at 6-month intervals until 2008. Subjects were given \$50 for attending study visits at each time point.

## **Measures**

The Montreal Miami Attitude to Treatment (MMAT-20/HIV) measure is a 20-item, multiple-choice, self-report measure. 46 Each item asks the patient to choose the option that best describes how they would think, feel, or respond in a particular situation. The questions are based on psychoanalytic concepts of object relations and attachment, and sought to address broad overlapping categories such as the following: (1) How do I hold the treatment in my conscious mind? (2) When I think about it, how do I tolerate the associated affects? (3) What kind of internal mental object does the treatment represent to me? (4) How do I represent my relationship with the treating team as a projection of the other? (5) What is my style of observing ego and psychological mindedness?

The content (determined by a factor analysis) includes aspects of the doctor-patient relationship such as whether the patient brings information to the doctor; whether the patient seeks or avoids information about complications and side effects; whether the patient has a positive/negative attitude; how they tolerate uncertainty and inexact information; expressing and discussing feelings; and how they feel about HIV. The six content areas above were identified by eigenvalues greater than one in a principal component factor analysis with a quartimax rotation.

Table 1 gives factor labels and sample items for each factor. A sample item with scoring is as follows: "If your doctor

cannot give you definite answers to your questions about your future health, what would best describe your reaction?" Response options are as follows: (a) I would understand because it is unrealistic to think that my doctor knows all the answers (scored 3); (b) I would be worried but would eventually accept that maybe my doctor can't have all the answers (scored 2); (c) I would be very scared and even possibly lose confidence in my doctor and the treatment (scored 1); and (d) I would be very disappointed because my doctor should know these answers (scored 1). Each item is scored on a scale from 1 to 3, where 3 represents a more psychodynamically mature response. Cronbach's alpha for the 20-item measure is 0.81.

Validation.

In a pilot study comparing the psychodynamic psychiatric interview and a longer version of the MMAT (65 items) with 35 bone marrow transplant patients, the correlation between the MMAT-65 score and the attitude to treatment semi-quantitative interview score was substantial (Pearson r = 0.64,  $p < 0.001^{47}$ ). The 20 items showing the strongest correlation with the psychiatric interview score were selected and wording was adapted for use with PLWH.

Background.

This scale was developed by a group of clinicians whose psychodynamically oriented assessment was shown to predict mortality over 1 year in bone marrow transplant patients.<sup>20, 21</sup> Since the "T" factor (attitude towards treatment) appeared to be the most promising predictor, the original study team (of two psychiatrists and a hematologist) added a psychometrically oriented psychiatrist (GI) in order to operationalize this approach into a self-report measure that could be more easily administered. Thus, it is based on clinical empirical experience driven by a theoretical orientation. Rather than starting from predetermined constructs (i.e., doctor-patient trust, emotional expression), the measure was developed to reflect the range of real-live interactions that occur between doctor and patient during the process of treatment. All four principals (Ironson, Hoffman, Sullivan, and Szrumelak, and an additional psychologist—Stivers) generated the 65 items and responses for the original MMAT while meeting over several days. A thorough description of the psychodynamic foundation of the measure can be found in Hoffman et al., 20 but briefly, the

Table 1 Factor Labels and Sample Items for Each Factor on the Montreal-Miami Attitude to Treatment Scale

	Factor label	Percent variance explained	Example item
1	Whether the patient brings information to the doctor	23.32	"What happens when you bring information regarding treatment for HIV disease to your doctor?"
2	Whether the patient wants information about complications and side effects or prefers avoiding it	8.84	"Do you have information concerning the possible complications for treatment for HIV?"
3	Whether the patient has a positive/negative attitude	7.15	"Is maintaining a positive attitude in the face of HIV important to you?"
4	How the patient tolerates uncertainty and inexact information	6.75	"Are you upset when your doctor is not able to give you exact information about what will happen to you?"
5	Expressing and discussing feelings	5.89	"Do you think it would be useful to discuss your true feelings about having HIV with someone?"
6	How the patient feels about HIV	5.37	"How do you feel when you think about being HIV positive?

psychodynamic approach includes the individual's capacity "to imagine him/herself undergoing the treatment, as well as a readiness to discuss his potential complications and consequences, including the positive and negative aspects."<sup>20</sup>, Psychodynamically, this is "what the treatment represents intrapsychicly to that individual; an opportunity to discover and grow, a repetition of past conflicts, or an unavoidable

Survival data was obtained from Social Security Administration (SSA) information.<sup>48</sup> The Death Master File (DMF) reflects all deaths reported to the SSA from 1935 to the present, is publicly available, and is updated weekly. We supplemented DMF data by searching for obituaries on the internet using participant names and birth dates. Present analyses include deaths occurring before April 30, 2014.

## **Statistical Analyses**

punishment and attack."20, 21.

All analyses were conducted using SPSS® version 26. We used Cox proportional hazard regression to determine whether attitude towards treatment (total score on the MMAT-20/HIV) predicted survival over 17 years. We controlled for biomedical variables in block 1 [including baseline CD4 cells/mm<sup>3</sup>, baseline VL (undetectable/detectable at baseline), age, and prescribed antiretroviral medication (no medication, combination therapy, or highly active antiretroviral therapy)]. Block 2 controlled for sociodemographic control measures [education (1 = less than high school, through 7 = some graduate school);sex (1 = male, 2 = female); and race (African American/ Black = 1; other = 0)]. The total score on the MMAT-20/HIV was entered in block 3 to examine the effect of attitude towards treatment. An additional control variable or potential mediator was adherence defined as the proportion of missed doses over the past 3 days (averaged over the entire study time<sup>49</sup>). We used the total score on the MMAT-20/HIV rather than the factors identified by the factor analysis because the factor analysis showed there was one large factor, the alpha for the 20-item scale was good (= 0.81), and many of the other factors had too few items to form reliable subscales.

## **RESULTS**

By 2004 (after 7 years), 15% of participants had died. By 2010 (after 13 years), 32% had died, and by 2014 (after 17 years), 34% had died. The mean MMAT-20 score was 45.06 (SD = 7.78).

Survival analyses results are presented in Table 2. Previous analyses have shown that higher CD4, lower VL, younger age, and antiretroviral medications have been related to survival; they comprise the biomedical covariates. Similarly, sex. race. and education each predict disease progression in HIV and comprise the sociodemographic covariate block. 42, 43 Table 2 shows that attitude towards treatment predicts significantly higher survival, first, with no covariates controlled (MMAT alone, HR(survival) = 1.041, p = 0.013). After controlling for biomedical and sociodemographic covariates, MMAT still significantly predicts survival (HR = 1.037, p = 0.037). Note the HR for survival from MMAT is only slightly reduced by the inclusion of covariates (from 1.041 to 1.037 or about a 10% (0.04/0.041) reduction). In fact, when controlling for biomedical variables only, the prediction from MMAT to survival is slightly stronger (p = 0.001). In an additional analysis, the relationship between attitude towards treatment and survival remained significant even after controlling for adherence. While adherence (proportion of missed doses) was correlated with MMAT-20/HIV (r = -0.204, p < 0.01), it was not a mediator as it was not significant when both MMAT-20/ HIV and adherence were included in the Cox regression together (p > 0.20). The inclusion of adherence in the Cox regression did not affect the MMAT prediction to survival (HR = 1.038), although it should be noted that because not everyone was taking medication, the sample was not the same as in the other analyses and thus cannot be directly compared.

In order to interpret the impact of these findings, hazard ratios for survival are presented for dichotomized MMAT as well. There is about twice the survival rate for those high on attitude towards treatment compared to those low on attitude towards treatment (divided at the median). Figure 1 depicts survival curves using Cox regression for those high and low

Table 2 Results of Cox Regression with Attitude Towards Treatment (MMAT). Predicting Survival in a Cohort of People (N=177) Living with HIV

Predictor (covariates)	HR (survival)	p value	95% CI
MMAT (no covariates)	1.041	.013	1.008-1.074
MMAT (dichotomized, no covariates)	2.014	.007	1.208-3.358
MMAT (biomedical covariates)*	1.056	.001	1.022-1.091
MMAT (all covariates) <sup>†</sup>	1.037	.037	1.002-1.074
MMAT (dichotomized, all covariates) <sup>‡</sup>	1.974	.018	1.126-3.458
MMAT (adherence added)§	1.038	.048	1.001-1.078

<sup>\*</sup>Controlling for biomedical variables (baseline CD4 count, baseline HIV viral load, age, and antiretroviral medication)

Controlling for biomedical variables (above) and sociodemographic variables (age, gender, race)

<sup>&</sup>lt;sup>‡</sup>Dichotomized at the median

<sup>§</sup>Controlling for biomedical variables, sociodemographic variables, and adherence. Note that the sample size is reduced because not everyone is taking medication

on attitude towards treatment, controlling for biomedical and sociodemographic variables.

#### DISCUSSION

Aspects of attitudes towards treatment have been related to health behaviors such as adherence to treatment and prescribed medication, <sup>5–9</sup> and morbidity and mortality in chronic illness. <sup>10–12</sup> Our study, which demonstrates that attitude towards treatment predicts greater survival over 17 years in PLWH, extends this to the sparse literature on attitudes towards treatment and survival and to PLWH. Those with more favorable attitudes towards treatment have almost twice the survival rate of those in the bottom half.

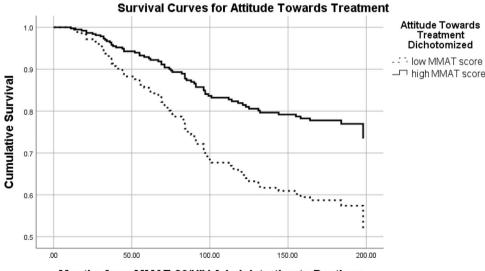
Prior literature identified aspects of attitude towards treatment that included self-efficacy,<sup>31</sup> beliefs and knowledge about medical treatment,<sup>25</sup> emotions,<sup>32</sup> physician trust and interactions, <sup>33–35, 29</sup> and active patient involvement.<sup>27</sup> The novel psychodynamic and experiential approach to the development of the current measure provides a broader explication of attitudes towards treatment that includes reactions, feelings, and thoughts in a particular situation. Included are these factors: aspects of the doctor-patient relationship such as whether the patient would bring information to the doctor; whether the patient seeks or avoids information about complications and side effects; whether the patient has a positive/negative attitude; how they tolerate uncertainty and inexact information; expressing and discussing feelings; and how they feel about HIV. From the data presented herein, concepts such as affect regulation and attachment style may be relevant to illness adjustment and impact social and biological parameters underlying survival. We hope that this clinically oriented research provides clinicians and future researchers with a wider base of relevant inquiry.

Limitations.

Although the attitudes towards the treatment measure used in the current study were developed with bone marrow transplant patients and operationalized and tested in PLWH, a key question is whether these results will generalize. Since the constructs used to develop the instrument showed prediction in these two chronic illnesses, and are based on general psychodynamic principles, it has potential for generalizing but needs to be tested in other illnesses as well as current-day HIV patients. Future studies might also determine whether this scale predicts survival better than other measures of related constructs. Additionally, other than adherence, we did not examine potential mediators of the survival effect. Most notably, physician trust may impact whether patients are honest with their physicians about medication adherence<sup>50</sup> or are willing to share concerns with the doctor-both of which may enhance decision-making.<sup>51</sup> Having a positive attitude towards treatment may also increase self-efficacy and motivation to follow treatment recommendations. Other psychosocial pathways include emotional factors, such as depression, that may impede decision-making,<sup>52</sup> or optimism and hope that may enhance decision-making and treatment engagement, or social support. 53 especially from the doctor and significant others. Other health behaviors such as diet and substance use should also be considered. Finally attitude towards treatment should be examined for its relationship to other patient-related outcomes, not just survival.

Clinical Implications.

We operationalized a psychiatric interview that predicted survival over a year in bone marrow transplant patients, and demonstrated that this self-report measure predicted survival in PLWH. Based on these studies, it has potential for use with other illnesses, but should be tested with other illnesses before it is ready for general use. This study demonstrates the poten-



Months from MMAT-20/HIV Administration to Death or 5/01/2014

Fig. 1 Survival curves using Cox regression for attitude towards treatment controlling for biomedical and demographic variables: baseline CD4 count, baseline HIV viral load, age, use of antiretroviral medication, gender, education, and race

tial importance of clinicians asking questions to ascertain a patient's attitude towards treatment, or giving the questionnaire to ascertain problem areas. Where resources are limited and a full psychiatric interview cannot be done, this 20-item self-report questionnaire may be a useful tool. Identifying the reasons for reluctance to follow recommendations in a supportive way may help increase the probability of better health outcomes.

**Supplementary Information** The online version contains supplementary material available at https://doi.org/10.1007/s11606-021-07245-v.

Acknowledgements We wish to thank the research participants for contributing valuable information. The parent study was funded by NIH: R01MH53791 and MH066697 (G. Ironson, PI). We also wish to thank Drs Lawrence Hoffman, Arthur Sullivan, Nadia Szkrumelak, and Margaret Stivers for their valuable contributions including discussions surrounding the development of items, choosing and modification of items and scoring for the MMAT20/HIV, and helpful suggestions for this paper.

**Corresponding Author:** MD, Department of Psychology, University of Miami, 5665 Ponce de Leon Blvd, Coral Gables, FL, USA (e-mail: g. ironson@miami.edu).

#### Declarations

**Conflict of Interest**The authors declare that they do not have a conflict of interest.

#### **REFERENCES**

- Horne R, Parham R, Driscoll R, Robinson A. Patients' attitudes to medicines and adherence to maintenance treatment in inflammatory bowel disease. Inflamm Bowel Dis. 2009;15:837-44.
- Horne R, Sumner S, Jubraj B, Weinman J, Frost S. Haemodialysis patients' beliefs about treatment: implications for adherence to medication and fluid-diet restrictions. Int J Pharm Pract. 2001;9:169–175.
- Horne R, Weinman J. Self-regulation and self-management in asthma: exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. Psychol Health. 2002;17:17–32.
- Menckeberg TT, Bouvy ML, Bracke M, et al. Beliefs about medicines predict refill adherence to inhaled corticosteroids. J Psychosom Res. 2008;64:47-54.
- Horne R, Buick D, Fisher M, Leake H, Cooper V, Weinman J. Doubts about necessity and concerns about adverse effects: identifying the types of beliefs that are associated with non-adherence to HAART. Int J STD AIDS. 2004:15:38-44.
- Horne R, Cooper V, Gellaitry G, Leake Date H, Fisher M. Patients' perceptions of highly active antiretroviral therapy in relation to treatment uptake and adherence: the utility of the necessity-concerns framework. JAIDS. 2007;45:334–41.
- Wrubel J, Moskowitz JT, Stephens E, Johnson MO. Illness and medication appraisals in people with HIV deciding to begin antiretroviral treatment. PLoS One, 2011;2:117–21.
- Batchelder AW, Gonzalez JS, Berg KM. Differential medication nonadherence and illness beliefs in co-morbid HIV and type 2 diabetes. J Behav Med. 2014;37:266-75.
- Weiss JJ, Konstantinidis I, Boueilh A, et al. Illness perceptions, medication beliefs, and adherence to antiretrovirals and medications for comorbidities in adults with HIV infection and hypertension or chronic kidney disease. J Acquir Immune Defic Syndr. 2016;73:403-10.

- Bangsberg DR, Perry S, Charlebois ED, et al. Non-adherence to highly active antiretroviral therapy predicts progression to AIDS. AIDS. 2001;15:1181-3.
- Hershman DL, Shao T, Kushi LH, et al. Early discontinuation and nonadherence to adjuvant hormonal therapy are associated with increased mortality in women with breast cancer. Breast Cancer Res Treat. 2011;126:529-37.
- Walsh CA, Cahir C, Tecklenborg S, Byrne C, Culbertson MA, Bennett KE.
   The association between medication non-adherence and adverse health outcomes in ageing populations: A systematic review and meta-analysis.
   Br J Clin Pharmacol. 2019:85:2464-78.
- Schiavon CC, Marchetti E, Gurgel LG, Busnello FM, Reppold CT.
   Optimism and hope in chronic disease: a systematic review. Front Psychol. 2017;7:2022
- Maguire R, Hanly P, Drummond FJ, Gavin A, Sharp L. Regret and fear in prostate cancer: The relationship between treatment appraisals and fear of recurrence in prostate cancer survivors. Psychooncology. 2017;26:1825-31.
- Hinz A, Mehnert A, Ernst J, Herschbach P, Schulte T. Fear of progression in patients 6 months after cancer rehabilitation-a-validation study of the fear of progression questionnaire FoP-Q-12. Support Care Cancer. 2015;23:1579-87.
- Székely A, Balog P, Benkö E, et al. Anxiety predicts mortality and morbidity after coronary artery and valve surgery

  –a 4-year follow-up study. Psychosom Med. 2007;69:625-31.
- Watkins LL, Koch GG, Sherwood A, et al. Association of anxiety and depression with all-cause mortality in individuals with coronary heart disease. J Am Heart Assoc. 2013;2:e000068.
- Kamp KJ, Luo Z, Holmstrom A, Given B, Wyatt G. Self-management through social support among emerging adults with inflammatory bowel disease. Nurs Res. 2019;68:285-95.
- Wang HH, Wu SZ, Liu YY. Association between social support and health outcomes: a meta-analysis. Kaohsiung J Med Sci. 2003;19(7):345-51.
- Hoffman LH, Szkrumelak N, Sullivan AK. Psychiatric assessment of candidates for bone marrow transplantation: a psychodynamicallyoriented approach. Int J Psychiatry Med. 1999;29:13-28
- Sullivan AK, Szkrumelak N, Hoffman LH. Psychological risk factors and early complications after bone marrow transplantation in adults. Bone Marrow Transplant. 1999;24:1109-20.
- Olley BO. The role of support group and duration of infection in HIV/ AIDS patients' knowledge and attitudes to their illness. Afr J Med Med Sci. 2007;36:11-6.
- Carey MP, Schroder KE. Development and psychometric evaluation of the brief HIV Knowledge Questionnaire. AIDS Educ Prev. 2002;14:172-82.
- Kamal, S, Bugnon, O, Cavassini, M, Schneider, MP. HIV-infected patients' beliefs about their chronic co-treatments in comparison with their combined antiretroviral therapy. HIV Med. 2018;19:49-58.
- Horne R, Weinman J, Hankins M. The Beliefs about Medicines Questionnaire: The development and evaluation of a new method for assessing the cognitive representation of medication. Psychol Health 1999;14:1–24.
- Moss-Morris R, Weinman J, Petrie K, Horne R, Cameron L, Buick D. The Revised Illness Perception Questionnaire (IPQ-R). Psychol Health. 2002;17:1-16.
- Ironson G, Lucette A, McIntosh R. Doctor-Patient Relationship: Active Patient Involvement (DPR:API) is related to long survival status and predicts adherence change in HIV. J AIDS Clin Res. 2015;6,2.
- Sauceda JA, Lisha NE, Dilworth SE, et al. Measuring engagement in HIV care: Measurement invariance in three racial/ethnic patient groups. Health Psychol. 2020;39:623-31.
- Bova C, Fennie KP, Watrous E, Dieckhaus K, Williams AB. The health care relationship (HCR) trust scale: development and psychometric evaluation. Res Nurs Health. 2006;29:477-88.
- Johnson MO, Neilands TB, Dilworth SE, Morin SF, Remien RH, Chesney MA. The role of self-efficacy in HIV treatment adherence: validation of the HIV Treatment Adherence Self-Efficacy Scale (HIV-ASES). J Behav Med. 2007;30:359-70.
- Ironson G, Weiss, S, Lydston, D, et al. The impact of improved self-efficacy on HIV viral load and distress in culturally diverse women living with AIDS: the SMART/EST women's project. AIDS Care. 2005;17:222-36.
- Lazarewicz MA, Włodarczyk D, Chylinska J, et al. Testing a New Tool
  Assessing Attitude Towards Treatment and Health in Primary Health
  Care Setting: Senior Patients and Doctors Perspectives. Scand J Public
  Health. 2019;47:61–9.
- Hall MA, Zheng B, Dugan E, et al. Measuring patients' trust in their primary care providers [published correction appears in Med Care Res Rev. 2003 Mar;60(1):118.]. Med Care Res Rev. 2002;59:293-318.

- Blackstock OJ, Addison DN, Brennan JS, Alao OA. Trust in primary care providers and antiretroviral adherence in an urban HIV clinic. J Health Care Poor Underserved. 2012;23:88-98.
- Thom DH, Ribisl KM, Stewart AL, Luke DA. Further validation and reliability testing of the Trust in Physician Scale. The Stanford Trust Study Physicians. Med Care. 1999;37:510–7.
- Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res. 2004;39(4 Pt 1):1005-26.
- Vasic I, Jankovic S, Jelic M. Psychometric development of Chemotherapy Side Effects Fear Scale. Acta Fac. Medicae Naissensis. 2017;34:55-64.
- Jansen SJT, Otten W, Baas-Thijssen MCM, van de Velde CJH, Nortier JWR, Stiggelbout AM. Explaining differences in attitude toward adjuvant chemotherapy between experienced and inexperienced breast cancer patients. J Clin Oncol. 2005; 23:6623-30.
- Wikblad KF, Wibell LB, Montin KR. The patient's experience of diabetes and its treatment: construction of an attitude scale by a semantic differential technique. J Adv Nurs. 1990;15:1083-91.
- Anderson RM, Fitzgerald JT, Funnell MM, Gruppen LD. The third version of the Diabetes Attitude Scale. Diabetes Care. 1998;21:1403-7.
- Hayward P. Medication self-management: a preliminary report on an intervention to improve medication compliance, J Ment Health. 1995:4:511–518.
- Ironson G, O'Cleirigh C, Fletcher MA, et al. Psychosocial factors predict CD4 and viral load change in men and women with human immunodeficiency virus in the era of highly active antiretroviral treatment. Psychosom Med. 2005;67:1013-21.
- Ironson G, O'Cleirigh C, Kumar M, et al. Psychosocial and Neurohormonal Predictors of HIV Disease Progression (CD4 Cells and Viral Load): A 4 Year Prospective Study. AIDS Beh. 2015;19:1388-97.
- Spitzer RL, Williams JBW, Gibbon M, First MB. The Structured Clinical Interview for DSM-III-R (SCID): I: History, Rationale, and Description. Arch Gen Psychiatry. 1992;49:624-9.

- Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res. 1975;12:189–98.
- Hoffman LH, Ironson GI, Skrumelak N, Stivers M, Sullivan AK. Montreal Miami Attitude To Treatment Scale: HIV. Unpublished scale, Copyright 1997
- Hoffman LH, Szkrumelak N, Lipton J, Sullivan AK. Thinking about my transplant: What does it matter? Presented at the Canadian Association of Psycho-oncology. Montreal, May 2006
- U.S., Social Security Death Index, 1935-Current [Internet]. Provo, UT, USA: Ancestry.com Operations Inc, 2014.
- Chesney MA, Ickovics JR, Chambers DB, et al. Self-reported adherence to antiretroviral medications among participants in HIV clinical trials: the ACTG adherence instruments. Patient Care Committee & Adherence Working Group of the Outcomes Committee of the Adult AIDS Clinical Trials Group (AACTG). AIDS Care. 2000;12::255–66.
- Kremer H, Ironson G. To tell or not to tell: why people with HIV share or don't share with their physicians whether they are taking their medications as prescribed. AIDS Care. 2006;18:520-8.
- Kremer H, Ironson G. Measuring the involvement of people with HIV in treatment decision making using the control preferences scale. Med Decis Making. 2008;28:899-908.
- Leykin Y, Roberts CS, Derubeis RJ. Decision-Making and Depressive Symptomatology. Cognit Ther Res. 2011;35:333-41.
- Brabers AE, de Jong JD, Groenewegen PP, van Dijk L. Social support plays a role in the attitude that people have towards taking an active role in medical decision-making. BMC Health Serv Res. 2016;16:502.

**Publisher's Note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.