Published in final edited form as:
Arthritis Rheum. 2007 October 15; 57(7): 1296–1302. doi:10.1002/art.23017.

Development and Initial Evaluation of a Measure of Self-Management for Adults With Antineutrophil Cytoplasmic Antibody–Associated Small-Vessel Vasculitis

CAROLYN T. THORPE, PhD, MPH[1], **ROBERT F. DEVELLIS, PhD**[2], **MEGAN A. LEWIS, PhD**[3], **SUSAN J. BLALOCK, PhD**[2], **SUSAN L. HOGAN, PhD**[2], and **BRENDA M. DEVELLIS, PhD**[2]

[1]Veteran's Affairs Medical Center, Durham, North Carolina

[2]University of North Carolina, Chapel Hill

[3]RTI International, Research Triangle Park, North Carolina

Abstract

Objective—To develop a measure of illness self-management for adults living with antineutrophil cytoplasmic antibody (ANCA)–associated small-vessel vasculitis (ANCA-SVV) and to gather evidence of its reliability and validity.

Methods—Development of the Vasculitis Self-Management Scale (VSMS) was guided by previous research on self-management in other chronically ill populations, a review of the current treatment literature for ANCA-SVV, interviews with patients, and consultation with experts. A total of 205 patients living with ANCA-SVV or a closely related condition then completed the VSMS, along with measures of sociodemographic and clinical variables, social desirability bias, and general adherence to medical recommendations, using a self-administered mailed questionnaire. A principal components analysis was conducted on the VSMS items. Internal consistency reliability and construct validity of the resulting subscales were assessed. Forty-four patients completed the VSMS a second time, for the purpose of assessing test-retest reliability.

Results—Analyses suggested an 8-factor solution. The final VSMS consisted of 43 items representing these 8 behavioral domains. Correlations among the 8 domains were null to modest in magnitude. The internal consistency reliability of the 8 subscales ranged from minimally acceptable ($\alpha = 0.67$) to excellent ($\alpha = 0.94$), and correlations between subscale scores at time 1 and time 2 suggested good temporal stability. Preliminary evidence for validity was mixed.

Address correspondence to Carolyn T. Thorpe, PhD, MPH, Center for Health Services Research in Primary Care, VA Medical Center, 2424 Erwin Road, Suite 1105, Durham, NC 27705. carolyn.thorpe@duke.edu..

AUTHOR CONTRIBUTIONS

Dr. Thorpe had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study design. Thorpe, Robert DeVellis, Lewis, Hogan, Brenda DeVellis.

Acquisition of data. Thorpe, Hogan.

Analysis and interpretation of data. Thorpe, Robert DeVellis, Lewis, Blalock, Hogan.

Manuscript preparation. Thorpe, Robert DeVellis, Lewis, Blalock, Hogan, Brenda DeVellis.

Statistical analysis. Thorpe, Robert DeVellis.

Development of Wording and Domains for the Measurement Tool. Thorpe, Hogan.

Conclusion—These findings suggest that the VSMS is a promising method for assessing illness self-management in adults with ANCA-SVV. More research exploring the validity of the measure is warranted.

Keywords

Systemic vasculitis; Illness self-management; Health behavior; Psychometrics

INTRODUCTION

Antineutrophil cytoplasmic antibody (ANCA)–associated small-vessel vasculitis (ANCA-SVV) is a group of rare autoimmune conditions characterized by inflammation and necrosis of blood vessels primarily in the respiratory tract and kidneys (1). Although often fatal without treatment (2), immunosuppressive therapy has transformed ANCA-SVV into a chronic condition characterized by periods of remission and relapse. Patients with ANCA-SVV face a daunting array of psychosocial and physical challenges (3,4); however, there is a paucity of research on the psychosocial aspects of living with this condition (4).

One central psychosocial issue in ANCA-SVV is illness self-management (5), defined as the "day-to-day tasks an individual must undertake to control or reduce the impact of disease on physical health status" (6). Self-management usually involves treatment adherence, or "the extent to which a person's behavior—taking medication, following a diet, and/or executing lifestyle changes—corresponds with agreed-upon recommendations from a health care provider" (7), as well as other self-care tasks not explicitly recommended by health care providers (8). ANCA-SVV self-management typically requires patients to take medications, obtain vaccinations, regularly use health services, monitor symptoms and treatment side effects, communicate with physicians, and make lifestyle changes (9). Self-management tasks vary based on disease activity and comorbidities (9), and patients usually remain on these regimens for many years, even after remission is attained (10).

Little is known about the extent to which patients with ANCA-SVV perform self-management tasks. However, up to 50% of patients across illnesses do not adhere to doctor-recommended behaviors (7). As in other illnesses (7,11), poor self-management in ANCA-SVV could lead to poor outcomes including renal failure (12), impaired quality of life, and death.

One barrier to the study of ANCA-SVV self-management and development of interventions is the lack of an existing self-report measure that can reliably, validly, and conveniently measure patients' performance of self-management tasks specific to this illness. Therefore, the first goal of the present study was to develop a self-report measure of ANCA-SVV self-management. We sought to develop a measure with multiple self-management domains given that nonadherence in chronic illness is known to vary across different behaviors (7,13-15). Based on prior research in other illnesses, we expected behavioral domains to be only modestly correlated with one another, if at all (13,14). Our second goal was to gather evidence of the measure's reliability and validity.

PATIENTS AND METHODS

The Vasculitis Self-Management Scale (VSMS) was developed in 4 steps: definition of the construct and identification of specific behaviors to be measured; item generation; pilot testing; and scale administration, item and dimensionality analysis, and reliability and validity testing.

Identification of behaviors and initial scale development

Potential domains of self-management behavior were first identified through a review of the ANCA-SVV literature (9,10,16). In subsequent telephone interviews, 18 adults with ANCA-SVV described whether and how these behaviors were relevant in managing their condition, and whether any additional behaviors were relevant. To increase the likelihood that all behaviors relevant to a majority of patients were identified, we interviewed patients representing a range of characteristics relevant to ANCA-SVV self-management (Table 1). Ten adherence behaviors were identified, including adherence to self-administered medications, medication administered by a health professional, appointments with health professionals, recommended medical tests and immunizations, infection avoidance behaviors, diet, exercise, symptom monitoring recommendations, mental health medication, and appointments with mental health professionals. Also, 3 general self-care behaviors were identified: adjusting activities based on symptoms and fatigue, prompt reporting of new or increased symptoms to a health professional, and prompt reporting of new treatment side effects to a health professional. Although smoking cessation, nasal irrigation, use of nonprescribed complementary therapies (e.g., herbal remedies), and attending support group meetings were also identified as potentially relevant, we excluded them from the measure because the interviews revealed them to be relevant for only a small subset of patients. Multiple items assessing performance of each behavior were then written, with guidance from phraseology in established measures of self-care behavior (14,17,18).

Pilot testing and measure revision

We obtained 2 rounds of feedback on the content, clarity, and specificity of the draft VSMS. First, 9 professional experts in illness self-management, scale development, and ANCA-SVV reviewed the draft VSMS, resulting in minor changes and additional instructions to increase its applicability to a broader range of patients. Eight additional patients, again representing a variety of characteristics relevant to ANCA-SVV self-management (Table 1), then completed the revised measure at home and provided feedback via telephone. Because these interviews revealed that mental health care providers were rarely utilized, we deleted items assessing this behavior. Also, patients typically included medications for depression, anxiety, and sleeplessness with other self-administered medications, so separate items assessing adherence to mental health medications were deleted.

After pilot testing, the VSMS consisted of 68 items assessing performance of the remaining 8 adherence behaviors and the 3 general self-care behaviors. Within the adherence sections, respondents were asked if a health professional currently recommended the behavior. If the behavior was not recommended, respondents skipped to the next section; otherwise, respondents completed items about how frequently, using a 5-point Likert scale, they

followed the recommendation. We followed the example of many well-validated health-related surveys (19) that use recall of the past 4 weeks to gain stable estimates of daily events (e.g., medication taking) and the past year for infrequent events (e.g., attending appointments). Several items were negatively worded and reverse scored, so that higher scores corresponded to higher levels of self-management. The 3 sections assessing general self-care behaviors were identical in format to the adherence sections, except that all patients completed these items unless they had not experienced any symptoms during the recall period.

Administration and analysis of the final measure

Participants and procedures—Participants had to be 18 years or older, able to read and write in English, and self-report a diagnosis of ANCA-SVV or a closely related condition (Goodpasture's disease: n = 2, temporal arteritis: n = 1). Because some patients who present with unambiguous forms of ANCA-SVV repeatedly test negative for ANCA (20), ANCA status was not an inclusion criterion. Participants were recruited via letters to patients enrolled in a vasculitis disease registry and announcements in ANCA-SVV newsletters, Web sites, and support group meetings. Through these methods, 275 eligible and interested patients were identified and mailed consent forms, 230 (84%) provided consent, and 205 (75%) completed the study questionnaire, including the VSMS and the measures described below. In addition, 44 of 48 (92%) randomly selected participants completed the VSMS a second time, a mean ± SD of 6.2 ± 2.7 weeks after time 1. Participants received $10 for each completed questionnaire.

Demographic and clinical variables—Patients provided information about their age, sex, race/ethnicity, education, marital status, specific diagnosis, history of dialysis and kidney transplant, and illness duration. Patients were asked to rate their current disease activity from 1 (not active at all/remission) to 10 (extremely active).

Validation measures—Social desirability bias was assessed using the short form of the Marlowe-Crowne Social Desirability Scale (21). This 20-item scale (Cronbach's $\alpha = 0.77$) is widely used to determine whether answers to self-reported questionnaires are influenced by respondents' desires to appear in socially desired ways. Patients' general tendency to adhere to medical recommendations in the past 4 weeks was measured using the 5-item General Adherence Scale (17) (Cronbach's $\alpha = 0.70$).

Statistical analysis—Analyses were conducted using SAS software, version 9.13 (SAS Institute, Cary, NC). Because respondents were instructed to skip VSMS items if a behavior was not relevant for managing their condition, we anticipated some missing data. We specified a priori that VSMS items must have been completed by at least 50% of patients to be included in the factor analysis and final measure. Although this is a relaxed standard, the variability in patients' self-management regimens required us to accept a higher level of missing data if we were to create a measure that assessed a range of domains of self-management relevant to a majority of patients, instead of a measure that only assessed 1 or 2 self-management behaviors. Because missing data were due to physicians not recommending a particular behavior rather than issues of item validity (e.g., poor item

wording), we chose to use this relaxed standard rather than discard useful information about self-management behaviors that apply to most, but not all, patients with vasculitis. Accordingly, items regarding adherence to medications administered by a health professional, which were completed by only 52 (25%) participants, were excluded from further analyses. The remaining 62 items were completed by a minimum of 123 (60%) participants.

To determine the factor structure of the VSMS, we conducted a principal components analysis (PCA) of the 62 items. To retain as many observations as possible, we analyzed the pairwise correlation matrix, which assumes that the correlation between any 2 items obtained from the reduced sample is an acceptable estimate of the true correlation between those items. Cattell's scree test (22) and parallel analysis (23) were used to determine the optimal number of factors to extract (24,25). The scree test involves plotting eigenvalues from highest to lowest and retaining factors that lie above the point at which the values become horizontal, or the "elbow" (26). Parallel analysis involves comparing eigenvalues from study data with eigenvalues produced by a PCA on multiple (n = 100 in this study) randomly generated data sets with the same characteristics as the study data set (25). The number of factors to retain is equal to the number of study eigenvalues that exceed the randomly produced eigenvalues. We also evaluated these results with regard to parsimony and plausibility. An oblique rotation, which allows factors to correlate with one another, was then performed to determine which items loaded most highly on which factor. Guidelines in factor analysis suggest deleting an item if it loads <0.30 on its primary factor (27,28). We conservatively chose to retain items only if they achieved rotated factor loadings >0.40 on their primary factor. We also discarded items that loaded >0.20 on any secondary factor.

Item sets, or subscales, were assessed for internal consistency reliability by computing Cronbach's alpha. Items with poor item-total correlations were eliminated from the subscales to optimize scale brevity while maintaining acceptable internal consistency reliability. An unweighted total score was computed for each subscale using the meanof all retained items within the subscale. Pearson's correlations between these final subscales were examined.

Using data from the 44 respondents who completed the VSMS twice, we calculated several measures of test–retest reliability for each subscale. Because the VSMS was designed to measure adherence as a continuous phenomenon using arbitrary units (i.e., a 5-point Likert scale), we examined relative consistency, rather than absolute agreement, of individuals' scores over time. Two measures of relative consistency for each subscale across the 2 administrations were evaluated (29): Pearson's product-moment correlation (r) and the (3,1) intraclass correlation coefficient (ICC) (30). Paired *t*-tests were used to detect systematic shifts in subscale scores between time 1 and time 2.

As a preliminary evaluation of validity (26), we examined Pearson's correlations between participants' scores on the VSMS subscales and their scores on the social desirability and general adherence measures. We expected that VSMS scores would be 1) minimally correlated with respondents' tendencies to report in socially desirable ways and 2) positively and significantly correlated with General Adherence Scale scores. Because reporting of

general adherence to medical recommendations likely reflects a combination of adherence to each individual behavioral recommendation, we expected the latter to be small to moderate in magnitude, such as has been described for adherence in diabetes (17). Multivariable linear regression was used to further explore the relationship between general adherence and VSMS scores, controlling for social desirability bias, a potential confounder.

RESULTS

Sample characteristics

Participant characteristics are shown in Table 2. Approximately half of the participants were women, and almost all were white. The mean age was 54.7 years (range 18–83), and the average education level was some college. The most common diagnosis was Wegener's granulomatosis (70.7%), and mean illness duration was 75.6 months (6.3 years). Thirty-one percent reported that their illness was currently in remission (either with or without medication). The characteristics of this sample are similar to those previously reported for US samples of adults with systemic vasculitis (10,31). Bivariable linear regression analyses failed to reveal significant differences between characteristics of the subsample who completed the VSMS twice versus the rest of the sample.

Factor structure

The scree test revealed 2 elbows, one indicating a 9-factor solution and another indicating a 7-factor solution. The parallel analysis indicated a 9-factor solution. Because of these ambiguous results, we examined solutions for 7, 8, and 9 factors. The 8-factor solution resulted in the fewest number of cross-loadings and distinct factors that were theoretically coherent, and accounted for 58.2% of the total variance. The 8 factors included 6 adherence domains: medication, recommended health services (including adherence to medical tests and immunizations and attending appointments with health professionals), infection avoidance, diet, exercise, and symptom monitoring adherence. The remaining factors consisted of 2 general self-care domains: prompt reporting of symptoms and side effects and adjusting activities in response to fatigue and symptoms.

To construct the final 8 subscales, we deleted 15 items that exhibited cross-loadings >0.20. We then deleted 1 item from the exercise adherence subscale that resulted in an improvement in Cronbach's alpha. Three of 10 remaining items from the reporting symptoms and side effects subscale were deleted to decrease its length while maintaining alpha >0.90. The final 8-factor VSMS consisted of 43 items (see Appendix A, available at the *Arthritis Care & Research* Web site at http://www.interscience.wiley.com/jpages/0004-3591:1/suppmat/index.html).

Correlations between subscales are shown in Table 3. As expected, correlations between these 8 factors were null to modest, ranging from $r = -0.003$ to $r = 0.37$.

Reliability

Descriptive and test–retest statistics for the 8 subscales at time 1 and time 2 are shown in Table 4. Internal consistency reliability (at time 1) ranged from minimally acceptable for the

adjusting activities subscale (α = 0.67) to excellent for the exercise adherence subscale (α = 0.94). Test–retest Pearson's correlations ranged from r = 0.56 for health services adherence to r = 0.79 for exercise adherence. ICCs were similar in magnitude to Pearson's correlations. Scores on the 8 subscales at time 2 did not differ from time 1, except for infection avoidance adherence, which was higher at time 2 (mean ± SD difference 0.22 ± 0.54, $t = 2.13$, df 26, $P < 0.05$).

Validity

As expected, participants' social desirability scores demonstrated nonsignificant correlations with exercise (r = 0.05), infection avoidance (r = 0.15), and diet (r = 0.14) adherence. Contrary to expectations, scores on the medication (r = 0.26, $P < 0.01$), health services (r = 0.15, $P < 0.05$), symptom monitoring (r = 0.22, $P < 0.05$), reporting symptoms and side effects (r = 0.19, $P < 0.05$), and adjusting activities (r = 0.17, $P < 0.05$) subscales were modestly but significantly associated with social desirability. As expected, general adherence was positively and significantly related to medication (r = 0.26, $P < 0.01$), diet (r = 0.31, $P < 0.01$), exercise (r = 0.39, $P < 0.01$), and symptom monitoring (r = 0.26, $P < 0.01$) adherence, and reporting symptoms and side effects (r = 0.20, $P < 0.01$). These relationships remained substantively unchanged after controlling for social desirability. Unexpectedly, general adherence was not related to health services adherence (r = 0.13), infection avoidance adherence (r = 0.10), or adjusting activities (r = 0.05).

DISCUSSION

To our knowledge, this is the first study of ANCA-SVV self-management. Our results indicate that 8 behaviors are relevant for a majority of patients, including medication, health services, infection avoidance, diet, exercise, and symptom monitoring adherence; prompt reporting of symptoms and side effects; and adjusting activities in response to symptoms. One hypothesized domain, adherence to medications administered by health professionals, only pertained to a minority of patients. This may have been due to the long illness duration reported by most of the study participants, because intravenous medication is often discontinued after achieving initial remission. Future studies should evaluate these items with a larger sample of patients currently taking such medication. In addition, although we initially thought that items assessing appointment keeping and obtaining tests and immunizations would factor separately, factor loadings suggested one factor representing both behaviors. However, the loadings for appointment-keeping items were somewhat lower and more ambiguous than those for medical tests and immunizations, leading to elimination of all but one of these items from the final subscale. Given this loading pattern and the ambiguous results of the scree test and parallel analysis, it may be prudent to retain and reexamine all appointment-keeping, test, and immunization items in future studies. Overall, however, the factor loadings for the items retained in the final subscales lend strong support for the 8-factor solution in this study. All final subscales include at least 3 items with very good (>0.63) or excellent (>0.70) (27) loadings on their primary factor, with no secondary loading greater than 0.20.

This study also confirmed that ANCA-SVV self-management behaviors are relatively independent of one another. All intersubscale correlations were well below the cutoff of r = 0.70 considered high enough to result in factor interpretation errors (32). These correlations are also consistent with prior research in other illness contexts (7), with previously reported correlations between diet and exercise adherence of r = 0.27–0.34 (14), comparable with the r = 0.35 found in this study.

All 8 subscales appear to have acceptable internal consistency reliability. Only the adjusting activities subscale had a Cronbach's alpha <0.70, but performed above this benchmark (26) at time 2. Also, all subscales demonstrated temporal stability, in terms of both relative consistency as measured by Pearson's r and the ICC, and a lack of systematic shift in mean scores over time. Although the increase in mean score for the infection avoidance adherence subscale across the 2 administrations was statistically significant, it represents only a 6% increase in scores on average. The observed temporal consistency is impressive, given that test–retest reliability estimates may be artificially reduced due to real changes in the construct across the administration interval (28), which is possible with regard to self-management behavior over a 6-week period.

Observed correlations between VSMS subscales and the measures of social desirability bias and general adherence demonstrated promising but mixed support for construct validity. The diet and exercise adherence subscales performed the best in relation to these measures, whereas the adherence to recommended health services and adjusting activities subscales performed the least well. The positive associations between scores on the social desirability scale and 5 of the 8 self-management subscales are, at first glance, concerning. However, these correlations tended to be modest (r < 0.30 for all) and similar to those found with other self-report measures of self-management with otherwise good evidence of validity (17). Future VSMS users should assess and control for social desirability bias, as was done in this study. It is also encouraging that scores on the General Adherence Scale, a measure that is positively associated with objective measures of disease control (e.g., blood glucose, blood pressure, body mass index) among patients with type II diabetes, hypertension, and heart disease (18), were significantly and positively correlated with the medication, diet, exercise, symptom monitoring, and reporting subscales, even after taking into account patients' social desirability bias. These observed correlations, which ranged from r = 0.20 to r = 0.39, are similar in magnitude to the modest correlations between behavior specific and general adherence observed in other illness populations (17,18).

Although our overall results demonstrate promising evidence of the VSMS's validity, our approach to assessing validity was limited due to feasibility issues. Ideally, we would have also examined correlations of VSMS scores with objective measures of self-management behavior (e.g., medication levels in blood, clinic appointment records). Exploring relationships between VSMS scores and measures of disease control (e.g., blood and protein levels in urine, scores on validated disease activity scales) or complications (e.g., incidence of infections) would also help evaluate the validity of the VSMS.

Several other limitations of this study should be noted. First, our sample was relatively small, especially taking into account missing data. However, we took advantage of all

available data by using the pairwise correlation matrix in the PCA, and a plausible factor solution did emerge. Also, we relied on patient recall for assessing which behaviors were explicitly recommended by a health professional; thus, the 6 adherence subscales actually measure perceived adherence. Future research should compare physician reports with patient recall of behavioral recommendations on the VSMS to determine rates of unintentional nonadherence.

Despite these limitations, this study presents a promising approach for measuring self-management in patients with ANCA-SVV. The measure offers a convenient, flexible way to assess a comprehensive set of self-management behaviors relevant for a majority of patients. Furthermore, its self-report format allows for assessment of behaviors not easily measured using objective measures (e.g., infection avoidance behavior). The multidimensionality of the measure conforms with what is known about self-management in other illnesses, and reliability of each subscale appears acceptable. Although evidence for validity is incomplete, future research can build on our results. If this evidence further supports the measure's validity, it will likely prove useful in both clinical and research settings.

Acknowledgments

We would like to thank the Glomerular Disease Collaborative Network and the University of North Carolina Kidney Center (especially Drs. Ron J. Falk and Patrick H. Nachman, Caroline E. Jennette, Clara Neyhart, RN, and Sheri Kramer), the PAIRS Study staff, the Vasculitis Foundation, and the Churg-Strauss Syndrome Association for their help with recruitment, and Joshua Thorpe, PhD, for his comments on an earlier draft of this manuscript.

Supported by a grant from the Vasculitis Foundation, a Doctoral Dissertation award from the Arthritis Foundation, and the William N. Reynolds Fellowship from the University of North Carolina Graduate School. Dr. Thorpe's work was supported by a postdoctoral fellowship from the VA Office of Academic Affairs.

REFERENCES

1. Watts RA, Scott DG. Classification and epidemiology of the vasculitides. Baillieres Clin Rheumatol. 1997; 11:191–217. [PubMed: 9220075]
2. Fauci AS, Haynes BF, Katz P, Wolff SM. Wegener's granulomatosis: prospective clinical and therapeutic experience with 85 patients for 21 years. Ann Intern Med. 1983; 98:76–85. [PubMed: 6336643]
3. Koutantji M, Harrold E, Lane SE, Pearce S, Watts RA, Scott DG. Investigation of quality of life, mood, pain, disability, and disease status in primary systemic vasculitis. Arthritis Rheum. 2003; 49:826–37. [PubMed: 14673970]
4. Koutantji M, Pearce S, Harrold E. Psychological aspects of vasculitis. Rheumatology (Oxford). 2000; 39:1173–9. [PubMed: 11085794]
5. Lewis MA, Kalinowski CT, Sterba KR, Barrett TM, DeVellis RF. Interpersonal processes and vasculitis management. Arthritis Rheum. 2006; 55:670–5. [PubMed: 16874771]
6. Clark NM, Becker MH, Janz NK, Lorig K, Rakowski W, Anderson L. Self-management of chronic disease by older adults: a review and questions for research. J Aging Health. 1991; 3:3–27.
7. World Health Organization. Adherence to long-term therapies: evidence for action. WHO Publications; Geneva: 2003.
8. Gallant MP. The influence of social support on chronic illness self-management: a review and directions for research. Health Educ Behav. 2003; 30:170–95. [PubMed: 12693522]
9. Vasculitis Foundation. Patient information packet: Web version. 2003. URL: http://www.vasculitisfoundation.org/

10. Hoffman GS, Drucker Y, Cotch MF, Locker GA, Easley K, Kwoh K. Wegener's granulomatosis: patient-reported effects of disease on health, function, and income. Arthritis Rheum. 1998; 41:2257–62. [PubMed: 9870883]
11. DiMatteo MR, Giordani PJ, Lepper HS, Croghan TW. Patient adherence and medical treatment outcomes: a meta-analysis. Med Care. 2002; 40:794–811. [PubMed: 12218770]
12. Andrassy K, Erb A, Koderisch J, Waldherr R, Ritz E. Wegener's granulomatosis with renal involvement: patient survival and correlations between initial renal function, renal histology, therapy and renal outcome. Clin Nephrol. 1991; 35:139–47. [PubMed: 1855316]
13. Johnson SB. Methodological issues in diabetes research: measuring adherence. Diabetes Care. 1992; 15:1658–67. [PubMed: 1468298]
14. Toobert, DJ.; Glasgow, RE. Assessing diabetes self-management: the summary of diabetes self-care activities questionnaire. In: Bradley, C., editor. Handbook of psychology and diabetes: a guide to psychological measurement in diabetes research and practice. Harwood Academic Publishers; Chur (Switzerland): 1994. p. 351-75.
15. Bosworth, HB.; Weinberger, M.; Oddone, EZ. Introduction. In: Bosworth, HB.; Oddone, EZ.; Weinberger, M., editors. Patient treatment adherence: concepts, interventions, and measurement. Lawrence Erlbaum Associates; Mahwah (NJ): 2006. p. 3-11.
16. Jayne DR. Conventional treatment and outcome of Wegener's granulomatosis and microscopic polyangiitis. Cleve Clin J Med. 2003; 69(Suppl 2):SII110–5. [PubMed: 12086249]
17. Hays, RD. The Medical Outcomes Study (MOS) measures of patient adherence [serial online]. 1993. URL: http://www.rand.org/health/surveys_tools/mos/mos_adherence_survey.pdf
18. Kravitz RL, Hays RD, Sherbourne CD, DiMatteo MR, Rogers WH, Ordway L, et al. Recall of recommendations and adherence to advice among patients with chronic medical conditions. Arch Intern Med. 1993; 153:1869–78. [PubMed: 8250648]
19. Keller SD, Bayliss MS, Ware JE Jr, Hsu M, Damiano AM, Goss TF. Comparison of responses to SF-36 Health Survey questions with one-week and four-week recall periods. Health Serv Res. 1997; 32:367–84. [PubMed: 9240286]
20. Hoffman GS, Langford CA. Are there different forms of life in the antineutrophil cytoplasmic antibody universe? Ann Intern Med. 2005; 143:683–5. [PubMed: 16263891]
21. Strahan R, Gerbasi K. Short, homogenous version of the Marlowe-Crowne Social Desirability Scale. J Clin Psychol. 1972; 28:191–3.
22. Cattell RB. The scree test for the number of factors. Multivariate Behav Res. 1966; 1:245–76.
23. Horn JL. A rationale and technique for estimating the number of factors in factor analysis. Psychometrika. 1965; 30:179–85. [PubMed: 14306381]
24. Fabrigar LR, Wegener DT, MacCallum RC, Strahan EJ. Evaluating the use of exploratory factor analysis in psychological research. Psychol Methods. 1999; 4:272–99.
25. Hayton JC, Allen DG, Scarpello V. Factor retention decisions in exploratory factor analysis: a tutorial on parallel analysis. Organ Res Methods. 2004; 7:191–205.
26. DeVellis, RF. Scale development: theory and applications. 2nd ed.. SAGE Publications; Thousand Oaks (CA): 2003.
27. Comrey, AL.; Lee, HB. A first course in factor analysis. Lawrence Erlbaum; Hillsdale (NJ): 1992.
28. Pett, MA.; Lackey, NR.; Sullivan, JJ. Making sense of factor analysis: the use of factor analysis for instrument development in health care research. SAGE Publications; Thousand Oaks (CA): 2003.
29. Weir JP. Quantifying test retest reliability using the intraclass correlation coefficient and the SEM. J Strength Cond Res. 2005; 19:231–40. [PubMed: 15705040]
30. Shrout PE, Fleiss JL. Intraclass correlations: uses in assessing rater reliability. Psychol Bull. 1979; 86:420–8. [PubMed: 18839484]
31. Hogan SL, Falk RJ, Chin H, Cai J, Jennette CE, Jennette JC, et al. Predictors of relapse and treatment resistance in antineutrophil cytoplasmic antibody-associated small-vessel vasculitis. Ann Intern Med. 2005; 143:621–31. [PubMed: 16263884]
32. Nunnally, JC. Psychometrictheory. 2nd ed.. McGraw-Hill; NewYork: 1978.

Table 1

Characteristics of patients participating in telephone interviews*

Characteristic	First round of telephone interviews (n = 18)	Second round of telephone interviews (n = 8)
Disease duration, years		
<1	2	1
≥1	16	7
Current disease activity		
No symptoms of active disease	5	4
Some symptoms of active disease	13	4
Medication regimen		
Taking medication for ANCA-SVV or its complications	18	8
Not taking any medication for ANCA-SVV or its complications	0	0
Dialysis		
Currently on dialysis	1	1
Not currently on dialysis	17	7
Transplant history		
History of kidney transplant	2	1
No history of kidney transplant	16	7
Comorbid conditions		
No other conditions unrelated to ANCA-SVV	11	4
At least one other condition unrelated to ANCA-SVV	7	4

*Values are the number of participants. ANCA-SVV = antineutrophil cytoplasmic antibody–associated small-vessel vasculitis.

Table 2

Characteristics of individuals completing the 68-item Vasculitis Self-Management Scale at time 1 and time 2*

	Full sample (n = 205)	Time 2 sample (n = 44)
Sociodemographics		
Sex		
Male	46.3	40.9
Female	53.7	59.1
Race/ethnicity		
White	93.6	93.0
American Indian/Alaskan Native	1.0	0
Asian	2.5	2.3
African American	1.0	2.3
Hispanic/Latino	2.0	2.3
Age, mean ± SD years (range 18–83)	54.7 ± 14.7	56.5 ± 14.8
Education, mean ± SD years	14.6 ± 2.4	15.1 ± 2.3
Marital status		
Married	74.2	75.0
Nonmarried	25.9	25.0
Clinical characteristics		
Diagnosed condition		
Wegener's granulomatosis	70.7	68.2
Microscopic polyangiitis	7.8	9.1
Churg-Strauss syndrome	4.9	4.6
ANCA-glomerulonephritis	15.1	18.2
Goodpasture's disease	1.0	0
Temporal arteritis	0.5	0
Time since diagnosis, mean ± SD months	75.7 ± 70.7	88.5 ± 88.3
Patient-perceived disease activity score, mean ± SD (range 1–10)	2.9 ± 2.1	2.2 ± 1.5
Ever on dialysis	15.8	16.3
Currently on dialysis	3.5	0
History of kidney transplant	7.5	11.4

*Values are the percentage unless otherwise indicated. ANCA = antineutrophil cytoplasmic antibody.

Table 3

Pearson's correlations between the 8 final subscales of the Vasculitis Self-Management Scale*

	Medication	Health services	Infection	Diet	Exercise	Symptom monitoring	Reporting	Adjusting activities
Medication	1.0 (191)	–	–	–	–	–	–	–
Health services	0.23 (188)†	1.0 (202)	–	–	–	–	–	–
Infection	0.17 (132)	−0.04 (141)	1.0 (142)	–	–	–	–	–
Diet	0.19 (145)‡	0.12 (152)	0.24 (120)†	1.0 (154)	–	–	–	–
Exercise	0.21 (121)‡	0.06 (125)	−0.03 (98)	0.35 (101)†	1.0 (125)	–	–	–
Symptom monitoring	0.19 (123)‡	0.08 (131)	0.37 (102)§	0.21 (117)‡	0.37 (93)§	1.0 (133)	–	–
Reporting	0.25 (167)†	0.26 (175)§	0.20 (128)‡	0.12 (141)	0.07 (110)	0.34 (118)§	1.0 (177)	–
Adjusting activities	0.15 (172)‡	−0.003 (182)	0.25 (131)†	0.33 (141)§	0.07 (118)	0.16 (124)	0.19 (163)‡	1.0 (185)

*Values are the correlation (sample size for each correlation).

†$P < 0.01$.

‡$P < 0.05$.

§$P < 0.001$.

Table 4

Descriptive and test–retest statistics for the 8 subscales of the Vasculitis Self-Management Scale at times 1 and 2*

	Time 1			Time 2			Test–retest statistics		
	n	Mean ± SD	α	n	Mean ± SD	α	Mean ± SD difference	Pearson's r	ICC (3,1)
Medication adherence	191	4.5 ± 0.54	0.77	43	4.6 ± 0.52	0.87	0.06 ± 0.44	0.60†	0.61
Health services adherence	202	4.6 ± 0.63	0.78	44	4.6 ± 0.58	0.73	−0.01 ± 0.51	0.56†	0.54
Infection avoidance adherence	142	3.7 ± 0.79	0.85	33	3.9 ± 0.73	0.84	0.22 ± 0.54‡	0.67†	0.69
Diet adherence	154	3.6 ± 0.76	0.76	34	3.6 ± 0.73	0.71	−0.16 ± 0.59	0.65†	0.60
Exercise adherence	125	3.2 ± 1.02	0.94	29	2.8 ± 0.94	0.96	−0.22 ± 0.67	0.79†	0.75
Symptom monitoring adherence	133	3.8 ± 0.97	0.91	29	3.5 ± 1.07	0.94	−0.20 ± 0.92	0.68†	0.63
Reporting symptoms and side effects	177	3.2 ± 1.08	0.90	40	3.1 ± 1.02	0.86	−0.11 ± 0.70	0.76†	0.76
Adjusting activities	185	3.4 ± 0.64	0.67	40	3.5 ± 0.62	0.71	0.10 ± 0.42	0.77†	0.76

*ICC = intraclass correlation coefficient.

†$P < 0.001$.

‡$P < 0.05$.