

RESEARCH ARTICLE

The positive and negative appraisals of caregiving (PANAC) scale: A new measure to examine the caregiving experience in Alzheimer's disease and related dementias

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Funding information

the National Institute on Aging of JEG, Grant/Award Numbers: R01 AG040211-01A1, R01 NS101483-01A1; the Harry T. Mangurian Foundation; the Leo and Anne Albert Charitable Trust

Abstract

Introduction: Dementia caregiving is often examined as a monolithic experience describing the challenges caregivers face, exploring one construct at a time, with little research on the positive experiences of caregiving. To address this, we developed the Positive and Negative Appraisals of Caregiving (PANAC) scale.

Methods: PANAC was validated in 253 patient-caregiver dyads. Factor analyses revealed a two-factor solution: Positive Appraisals (PAs) and Negative Appraisals (NAs). Psychometric properties were compared with patient and caregiver characteristics and outcomes, disease stage, and etiology.

Results: Internal consistency was good with Cronbach's alpha: 0.82 NA and 0.80 PA ($P < 0.001$). NA correlated with patient and caregiver characteristics, whereas PA correlated only with caregiver characteristics. The PA/NA ratio could be used to capture change due to an intervention.

Discussion: The PANAC scale is a useful measure of the overall caregiver experience accounting for negative and positive experiences and may be used to tailor support to individual caregivers.

KEYWORDS

Alzheimer's disease, caregiver burden, caregiver depression, caregiver preparedness, caregiving, dementia, mild cognitive impairment, self-efficacy

1 | BACKGROUND

The cognitive, functional, and behavioral decline experienced by individuals diagnosed with Alzheimer's disease and related dementias (ADRD) can be severe and debilitating, leading to a significant need of support from formal and informal caregivers beginning early in the course of the disease.¹ As such, there may be an increasing sense of strain, stress, and burden to family caregivers (FCG), as spouses and adult children often take on a multitude of new responsibilities

previously managed by the person living with dementia (PLWD), often beginning prior to a formal diagnosis and continuing through transitions to skilled nursing facilities.² In conjunction with increasing burden, there is often an accompanying sense of grief and loss as the disease progresses.³⁻⁵ There are a number of easy-to-use scales available that capture caregiver burden, strain, grief, preparedness, and depression that make up the basis for many caregiver studies, interventions, and as secondary outcomes in randomized clinical trials for new therapeutics.

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However, much of the caregiving literature assumes a view of the caregiving as a burden without consideration of the caregivers' expectations and experiences.⁶ Yet within the caregiving journey, individuals can experience a variety of emotions that are not solely negative.⁷ Although caregiving can be stressful, there can also be benefits and rewards.⁸ Caregivers can report positive feelings about caregiving (eg, family togetherness and the satisfaction of helping others).^{2,9,10} Other perceived benefits associated with caregiving may include the opportunity to give back; improved relationships; feeling good about the quality of care; serving as a role model for others; increased self-esteem; an enhanced sense of purpose; and feelings of pleasure and satisfaction.¹¹ Individuals with higher positive views of caregiving may report less burden and depression.⁹ However, despite a fair library of instruments that capture negative aspects of caregiving, there are few instruments that capture positive aspects, and to the best of our knowledge, there are no instruments specifically designed to capture both positive and negative aspects of caregiving.

Studies of caregiving commonly explore one construct at a time, limiting the full understanding of the caregiver experience. Alternatively, multiple scales need to be administered, increasing the burden to the respondent. In addition, there are few measures that examine the potential positive and rewarding experiences associated with caregiving. The absence of exploring these constructs may limit the investigation of how caregiver interventions may or may not succeed in meeting their primary outcomes. To address this, we developed a new scale: the Positive and Negative Appraisals of Caregiving (PANAC) (Table 1).

2 | METHODS

2.1 | Study participants

This study was conducted in 253 consecutive patient-caregiver dyads attending our center for clinical care or to participate in cognitive aging research who completed all questions in the PANAC. During the visit, the patient and caregiver underwent a comprehensive evaluation including the Quick Dementia Rating System (QDRS),¹² the Clinical Dementia Rating (CDR) and its sum of boxes (CDR-SB),¹³ mood, neuropsychological testing, caregiver ratings of patient behavior and function, and a caregiver psychosocial and needs assessment. All components of the assessment are part of standard of care at our center,¹⁴ and protocols in the clinic and research projects are identical. The sample (n = 253) includes 37 cognitively normal, 79 mild cognitive impairment (MCI), 38 Alzheimer's disease (AD), 81 Lewy body dementia (LBD), 12 vascular contribution to cognitive impairment and dementia (VCID), and 6 frontotemporal degeneration (FTD) cases. An additional 22 individuals were evaluated but did not complete all PANAC questions; they were excluded from these analyses as we were unable to determine the Positive Appraisals (PAs), Negative Appraisals (NAs), and/or PA/NA ratio for the PANAC scale. A waiver of consent was obtained from clinic patients and research participants provided written informed consent. This study was approved by the University of Miami Institutional Review Board.

RESEARCH IN CONTEXT

- 1. Systematic Review:** The authors reviewed the literature (eg, PubMed), focusing on papers describing negative and positive aspects of caregiving. Scales for caregiving burden, grief, strain, and other constructs covering the negative aspects of caregiving are commonly reported but papers generally study one construct at a time or require time-burdensome evaluation of caregivers with multiple scales. There are few scales available that capture positive aspects of caregiving.
- 2. Interpretation:** Our findings support that the Positive and Negative Appraisals of Caregiving (PANAC) scale may provide a brief, comprehensive assessment of both commonly studied negative aspects of caregiving, and the less frequently studied positive aspects. The PANAC scale works well across different caregiver and patient sociodemographic characteristics, dementia stages, and dementia etiologies.
- 3. Future Directions:** There will be a need for future studies of the longitudinal properties of the PANAC, its response to caregiver interventions, and performance in diverse community samples.

2.2 | Administration of PANAC

Prior to the office visit, a welcome packet was mailed to the patient and caregiver to collect demographics and medical history and included the PANAC scale. The family caregiver (FCG) also provided ratings of the patients physical, mental, and emotional health, and socialization using a 4-point Likert scale (Excellent, Good, Fair, Poor) used in previous studies.^{4,5} PLWDs provided self-ratings of cognitive and everyday functioning using the Cognitive Change Index (CCI).¹⁵ The FCG returned the packet prior to the appointment.

2.3 | Clinical assessment

The in-person clinical assessments are modeled on the Uniform Data Set (UDS) 3.0 from the National Institute on Aging (NIA) Alzheimer Disease Research Center (ADRC) program.^{16,17} The CDR¹³ was used to determine the presence or absence of dementia and to stage its severity; a global CDR 0 indicates no dementia and includes individuals with (44%) and without (56%) subjective cognitive complaints; CDR 0.5 represents MCI or very mild dementia; CDR 1, 2, or 3 corresponds to mild, moderate, or severe dementia. The Global Deterioration Scale (GDS)¹⁸ was determined to provide a global cognitive and function stage: a GDS 1 indicates no cognitive impairment; GDS 2 indicates subjective cognitive impairment (SCI); GDS 3 corresponds to mild cognitive impairment; GDS 4 to 7 corresponds to mild, moderate,

TABLE 1 The positive and negative appraisals of caregiver (PANAC) scale. The following statements reflect different opinions regarding the feelings different individuals have about providing care and assistance to individuals with memory disorders. For each question, please choose the one best answer that describes your agreement or disagreement with the statement

| When considering your role in providing care or assistance to the patient, please state how strongly you agree or disagree with the following statements: | Strongly disagree | Disagree | Neither agree or disagree | Agree | Strongly agree |
|---|-------------------|----------|---------------------------|-------|----------------|
| I feel stress, strain, or anger when dealing with my loved one | | | | | |
| I look at this as an opportunity to give back to my loved one | | | | | |
| I feel that my physical health has suffered | | | | | |
| I am the best person to care for my loved one | | | | | |
| I feel a great sense of burden placed on me to care for my loved one | | | | | |
| Caring for my loved one gives me a sense of purpose | | | | | |
| My social life and relationships have suffered | | | | | |
| Caring for my loved one has improved our relationship | | | | | |
| I feel obligated with the responsibility to care for my loved one | | | | | |
| Caring for my loved one makes me feel good about myself | | | | | |
| I feel depressed, sad, or hopeless | | | | | |
| I feel a sense of satisfaction in my efforts to care for my loved one | | | | | |
| I feel a sense of grief over my loved one's illness | | | | | |
| Caring for my loved one prepares me to handle other life problems | | | | | |
| I feel my quality of life is worse because of my caregiving responsibilities | | | | | |
| By caring for my loved one, I serve as role model for others | | | | | |
| TOTAL NEGATIVE APPRAISALS | | | | | |
| TOTAL POSITIVE APPRAISALS | | | | | |

moderate-severe, or severe dementia, respectively. Diagnoses were determined at consensus conference using standard criteria for SCI,¹⁹ MCI,²⁰ AD,²¹ LBD,²² VCI,²³ and FTD.²⁴ Extrapyramidal features were assessed with the Movement Disorders Society-Unified Parkinson's Disease Rating Scale, motor subscale part III (UPDRS).²⁵ Vascular risk factors were assessed using a modified version of the Cardiovascular Risk Factors, Aging, and Incidence of Dementia scale (mCAIDE).²⁶ The Charlson Comorbidity Index²⁷ was used to measure overall health and medical comorbidities. Physical functionality and the risk of frailty were assessed with the mini-Physical Performance Test (mPPT)^{28,29} and the Fried Frailty Scale.³⁰

2.4 | Cognitive assessment

Each patient was administered a 30-minute test battery at the time of the office visit to assess their cognitive status. The psychologist was unaware of the diagnosis, CDR, or PANAC scale scores. The Montreal Cognitive Assessment (MoCA)³¹ was used for a global screen. The rest of the battery was modeled after the UDS battery used in the NIA Alzheimer Disease Research Centers¹⁷ supplemented with additional measures: 15-item Multilingual Naming Test (naming)¹⁷; Animal naming and Letter fluency (verbal fluency)¹⁷; Hopkins Verbal Learning Task (episodic memory for word lists—immediate, delayed, and

recognition trials)³²; Number forward/backward and Months backwards tests (working memory)¹⁷; Trailmaking Test A and B (processing and visuospatial abilities)³³; a novel Number-Symbol Coding Test (executive function); Clock Drawing (construction); and the Noise-Pareidolia test (visual perception).³⁴ Mood was assessed with the Hospital Anxiety Depression Scale³⁵ providing subscale scores for depression (HADS-D) and anxiety (HADS-A).

2.5 | Caregiver ratings of patient cognition, function, and behavior

Activities of daily living were captured with the Functional Activities Questionnaire (FAQ).³⁶ Dementia-related behaviors and psychological features were measured with the Neuropsychiatric Inventory (NPI).³⁷ Health-related quality of life was measured with the Health Utilities Index-Mark 3 (HUI-3).³⁸ FCG ratings of global cognitive functioning was measured with the informant version of the Quick Dementia Rating Scale (QDRS).¹² Patient daytime sleepiness was assessed with the Epworth Sleepiness Scale,³⁹ whereas daytime alertness was rated on a 1-10 Likert scale ("Rate the patient's general level of alertness for the past 3 weeks on a scale from 0 to 10") anchored by "Fully and normally awake" (scored 10), and "Sleep all day" (scored 0).⁴⁰

2.6 | Ratings of caregiver characteristics

Caregivers completed ratings of mindfulness, self-efficacy, social support, care confidence, care preparedness, burden, mood, and sleep quality. Published scales were used when available. Other domains were captured with investigator-generated questionnaires. Global mindfulness level was assessed using the 15-item Applied Mindfulness Process Scale (AMPS),⁴¹ capturing three domains of mindfulness: decentering (*Factor 1*), positive emotional regulation (*Factor 2*), and negative emotional regulation (*Factor 3*). Care Confidence was adapted from the Dementia Care Confidence scale⁴² and used in prior studies¹⁴ consisting of four questions scored on a 0-4 Likert Scale (range 0-16, higher scores are better). Caregiver preparedness was assessed with the Preparedness for Caregiving Scale.⁴³ Caregiver burden was captured with the 12-item Zarit Burden Inventory (ZBI).⁴⁴ Caregiver mood was assessed using the Personal Health Questionnaire-4 (PHQ4).⁴⁵ Caregiver self-efficacy was measured with four investigator-generated questions scored on a 0-4 Likert scale (range 0-16, higher scores are better) used in previous studies.⁴⁶ A brief measure of social support was captured with two investigator-generated questions ("I can identify sources of support" and "I am comfortable discussing problems with family and friends") scored on a 0-4 Likert Scale (range 0-8, higher scores are better). To capture sleep quality, the caregiver was asked to give an overall self-rating of the quality of their sleep on a 0-4 Likert scale (Excellent, Very good, Good, Fair, Poor).

2.7 | Statistical analyses

Analyses were conducted with IBM SPSS Statistics v26 (Armonk, NY, USA). Descriptive statistics were used to examine demographic characteristics of PLWD and FCG, informant rating scales, dementia staging, and neuropsychological testing. One-way analysis of variance (ANOVA) with Tukey-Kramer post hoc tests were used for continuous data and chi-square analyses were used for categorical data. To assess item variability, the item frequency distributions, range, and standard deviations (SDs) were calculated. Item and subscale scores were examined for floor and ceiling effects. Factor analysis using principal components with a Varimax rotation was performed revealing a two-factor solution: Positive Appraisals (PAs) and Negative Appraisals (NAs). A ratio of Positive to Negative Appraisals was also calculated to give an overall experience of the FCG. Individual PANAC factor scores, and the PA/NA ratio were examined for their psychometric properties and compared with patient and caregiver characteristics and caregiver reports of burden, grief, preparedness, mood, mindfulness, self-efficacy, social support, and care confidence.

Concurrent (criterion) validity was assessed comparing the mean performance on each gold standard measure of cognition (e.g., CDR, CDR-SB, neuropsychological testing), function (ie, FAQ), behavior (eg, NPI, HADS), and caregiver ratings (eg, ZBI, PHQ4), with the PANAC using Pearson correlation coefficients^{12,47} with corrections for multiple comparisons with Bonferroni correction when appropriate.

Convergent and discriminative construct validity was assessed with Spearman correlation coefficients. For convergent validity, moderate correlations ($P > 0.35$) between items in each domain and between similar constructs in patient and caregiver characteristics were accepted as evidence. For divergent validity, low correlation ($P < 0.2$) between items in different domains and between non-similar patient and caregiver characteristics were accepted.^{12,47} Internal consistency was examined as the proportion of the variability in the responses that is the result of differences in the respondents, reported as the Cronbach alpha reliability coefficient. Coefficients >0.7 are good measures of internal consistency.^{12,47} Know-group validity was assessed by examining the PANAC scores by sociodemographic characteristics (sex, race, ethnicity, caregiver relationships), CDR and GDS staging, and dementia etiology.

3 | RESULTS

3.1 | Sample characteristics

The mean age of the patients was 77.7 ± 8.8 (SD) years and for the caregivers was 55.5 ± 15.1 years (Table 2). The patients had a mean CDR-SB of 4.5 ± 4.7 , a mean QDRS score of 6.4 ± 6.3 , and a mean MoCA score of 18.5 ± 7.1 . This covered a range of cognitively normal (CDR 0 = 37), MCI or very mild dementia (CDR 0.5 = 83), mild dementia (CDR 1 = 41), moderate dementia (CDR 2 = 22), and severe dementia (CDR 3 = 9). Dementia diagnoses at consensus included 38 AD, 81 LBD, 12 VCID, and 6 FTD cases. Caregivers were mostly spouses (68.6%) followed by adult children (18.8%) and others (12.6%), with 69.1% of caregivers living with the patient. Table 2 lists mean performances on all patient and caregiver rating scales used in this study. Because the correlations between the PANAC scale and each of the neuropsychological tests were similar, the MoCA score is used to represent overall cognitive performance in subsequent discussions.

3.2 | PANAC data quality

Table 3 demonstrates the properties of the PA and NA factors, with loading scores, Eigenvalues, inter-item correlations, and item-factor correlations. The PA factor had an Eigenvalue of 3.35, contributing 20.9% of the variance of the PANAC. Individual items for the PA factor were weakly to moderately correlated with each other, suggesting that they capture different positive aspects of caregiving within the same factor supported by strong item-total factor correlations. The NA factor had an Eigenvalue of 4.13, contributing 25.8% of the variance of the PANAC. Similarly to the PA factor, individual NA items were weakly to moderately correlated with each other, suggesting that they capture different negative aspects of caregiving within the same factor supported by strong item-total factor correlations with the exception of the question "I feel obligated with the responsibility to care for my loved one," which had only a moderate item-total factor correction

TABLE 2 Sample characteristics (n = 253)

| Patient characteristics | | Caregiver characteristics | |
|----------------------------|-------------|---------------------------|-------------|
| Age, y | 77.7 (8.8) | Age, y | 55.5 (15.1) |
| Sex, % F | 46.1 | Sex, % F | 62.7 |
| Education, y | 15.5 (2.7) | Education, y | 16.0 (2.6) |
| Race, % White | 97.4 | Race, % White | 92.9 |
| Ethnicity, % Hispanic | 6.4 | Ethnicity, % Hispanic | 8.0 |
| CDR-SB | 4.5 (4.7) | Relationship | |
| QDRS | 6.4 (6.3) | % Spouse | 68.6 |
| MoCA | 18.5 (7.1) | % Adult Child | 18.8 |
| HADS-D | 5.7 (3.7) | % Other | 12.6 |
| FAQ | 9.8 (10.2) | Lives with Patient, % Yes | 69.1 |
| NPI | 5.7 (5.4) | Caregiver burden | 12.5 (9.3) |
| HUI-3 | 0.5 (0.3) | PHQ-4 | 2.1 (2.5) |
| Epworth | 6.5 (5.3) | Caregiver preparedness | 21.1 (6.9) |
| Charlson Comorbidity Index | 2.4 (1.7) | AMPS total score | 38.8 (11.2) |
| mCAIDE | 7.8 (3.0) | Care Confidence | 11.5 (5.3) |
| Fried Frailty Score | 2.4 (1.5) | Care Self-Efficacy | 10.9 (2.9) |
| mPPT | 9.7 (3.6) | Social Support | 5.3 (1.7) |
| UPDRS | 11.3 (14.7) | | |

Data presented as mean (SD) or %.

Abbreviations: AMPS, Applied Mindfulness Process Scale; CDR-SB, Clinical Dementia Rating Sum of Boxes; FAQ, Functional Activities Questionnaire; HADS-D, Hospital Anxiety and Depression Scale-Depression Subscale; HUI-3, Health Utilities Index-Mark 3; mCAIDE, modified Cardiovascular Risk Factors, Aging, and Incidence of Dementia; MoCA, Montreal Cognitive Assessment; mPPT, Mini Physical Performance Test; NPI, Neuropsychiatric Inventory; PHQ4, Personal Health Questionnaire-4; QDRS, Quick Dementia Rating System; UPDRS, United Parkinson's Disease Rating Scale.

($R = 0.45$) and may be tapping into a unique domain, regarding the moral, religious, or filial responsibility and obligation of a family member to take care of their elders.

3.3 | Reliability and scale score feature of PANAC

The degree to which the PANAC scale was free from random error was assessed by its internal consistency with Cronbach alpha (Table 4). The internal consistency was excellent (0.84 for the PAs, and 0.82 for the NAs). The PANAC PA and NA factors and the ratio of PAs/NAs covered the entire range of possible scores, and the mean, median, and SD demonstrated a sufficient dispersion of scores for assessing the full caregiving experience with low percentage of missing data. There was very low floor (0.5% to 4.5%) and ceiling (0% to 2.5%) effects. The PA and NA factors were not correlated with each other supporting that they capture distinct aspects of the caregiving experience ($r = -0.07$). The PA/NA ratio was correlated

with both factors but was more strongly correlated with the NAs ($r = 0.71$ vs 0.44).

3.4 | Concurrent and construct validity of PANAC

Concurrent validity of the PANAC scale with patient characteristics is presented in Table 5. After correcting for multiple comparisons, NAs by caregivers were strongly correlated with worse patient cognitive staging (QDRS, CDR-SB, MoCA), higher subjective complaints by patient (Cognitive Change Index), worse behavior (NPI), worse function in everyday activities (FAQ), more daytime sleepiness (Epworth Sleepiness Scale), and lower alertness, lower health-related quality of life (HUI-3), worse mood (HADS depression), more parkinsonian symptoms (UPDRS), more vascular risk factors (mCAIDE), poor physical functionality (mPPT), and more frailty (Fried Frailty Score). Correlations with PA/NA ratio closely resemble the NAs. No patient characteristic was associated with PAs.

Concurrent validity of the PANAC scale with caregiver characteristics is presented in Table 5. PAs of caregiving were associated with higher mindfulness in the caregiver (AMPS), particularly decentering (AMPS factor 1), and enhancing positive emotional regulation (AMPS factor 2), higher caregiver preparedness and better social support. NAs of caregiving were associated with low positive emotional regulation (AMPS factor 2), lower self-efficacy, higher caregiver burden (ZBI), and greater caregiver depression (PHQ4). The PA/NA ratio was correlated with measures of mindfulness, self-efficacy, and burden (ZBI).

Construct validity of the PANAC refers to how well each individual item corresponds to a theorized trait (Table 3). For PAs, convergence suggested that these PANAC questions tapped into different aspects of Caregiver Preparedness and Care Confidence and were divergent from most patient characteristics. Three PANAC PAs (opportunity to give back, improving relationships, and serving as role model) tap into novel domains. For NAs, PANAC questions tapped into common caregiver themes of burden, depression, grief, and low self-efficacy, and global patient staging, health-related quality of life, function, and behavior. NAs generally diverged from Care Confidence, Caregiver Preparedness, Caregiver Mindfulness, and Social Support. One question (feel obligated to care) tapped into a novel negative appraisal not captured by other caregiving scales. This may be reflected by the item-total factor correlation ($R = 0.45$, Table 3). In general, neither PAs nor NAs were related to patient cognitive performance or mood.

3.5 | Know-groups validity of PANAC

The extent to which the PANAC factors and ratio perform based on sociodemographic characteristics, CDR and GDS staging, and different etiologies of dementia is shown in Table 6. The PA and NA factors and PA/NA ratio perform similarly between male and female caregivers. Although caregivers from minority backgrounds make up a small percentage of respondents, there appears to be notable differences

TABLE 3 PANAC item distributions, factor loading, inter-item and item-factor correlations, and convergent validity

| Positive appraisals | Mean (SD) | Inter-item correlations | | | | | | | | Factor loading | Item-factor R | Convergent validity |
|---|-------------|-------------------------|------------|------------|------------|------------|------------|------------|------------|----------------|---------------|---|
| | | PA1 | PA2 | PA3 | PA4 | PA5 | PA6 | PA7 | PA8 | | | |
| I look at this as an opportunity to give back to my loved one (PA1) | 2.84 (1.12) | 1 | | | | | | | | .798 | .631 | |
| I am the best person to care for my loved one (PA2) | 2.85 (1.16) | .281 | 1 | | | | | | | .756 | .583 | CP |
| Caring for my loved one gives me a sense of purpose (PA3) | 2.41(1.04) | .313 | .289 | 1 | | | | | | .748 | .780 | CP |
| Caring for my loved one has improved our relationship (PA4) | 2.19 (1.05) | .168 | .120 | .492 | 1 | | | | | .672 | .595 | |
| Caring for my loved one makes me feel good about myself (PA5) | 2.63 (1.01) | .223 | .270 | .490 | .393 | 1 | | | | .605 | .779 | CP |
| I feel a sense of satisfaction in my efforts to care for my loved one (PA6) | 2.67 (0.99) | .327 | .360 | .666 | .568 | .554 | 1 | | | .575 | .809 | CP |
| Caring for my loved one prepares me to handle other life problems (PA7) | 2.17 (1.04) | .327 | .280 | .394 | .312 | .386 | .405 | 1 | | .513 | .701 | CP, CC |
| By caring for my loved one, I serve as role model for others (PA8) | 2.28 (0.99) | .245 | .116 | .231 | .239 | .381 | .274 | .450 | 1 | .503 | .603 | |
| Eigenvalue | | | | | | | | | | 3.35 | | |
| % Variance Explained | | | | | | | | | | 20.94 | | |
| Negative Appraisals | | NA1 | NA2 | NA3 | NA4 | NA5 | NA6 | NA7 | NA8 | | | |
| I feel stress, strain, or anger when dealing with my loved one (NA1) | 1.42 (1.19) | 1 | | | | | | | | .778 | .708 | QDRS, NPI, HUI, SE, ZBI, PHQ4 |
| I feel that my physical health has suffered (NA2) | 1.16 (1.25) | .537 | 1 | | | | | | | .755 | .751 | QDRS, HUI, NPI, CDR, AMPS, SE, ZBI, PHQ4 |
| I feel a great sense of burden placed on me to care for my loved one (NA3) | 1.20 (1.17) | .518 | .411 | 1 | | | | | | .729 | .706 | HUI, SE, ZBI |
| My social life and relationships have suffered (NA4) | 1.49 (1.23) | .387 | .506 | .357 | 1 | | | | | .688 | .722 | MoCA, FAQ, NPI, HUI, QDRS, CDR, SE, ZBI, PHQ4 |

(Continues)

TABLE 3 (Continued)

| Negative Appraisals | | NA1 | NA2 | NA3 | NA4 | NA5 | NA6 | NA7 | NA8 | | | |
|--|-------------|------|------|------|------|------|------|------|-----|--------------|------|--|
| I feel obligated with the responsibility to care for my loved one (NA5) | 2.27 (1.35) | .252 | .268 | .390 | .323 | 1 | | | | .680 | .446 | |
| I feel depressed, sad, or hopeless (NA6) | 1.06 (1.15) | .418 | .398 | .317 | .219 | .105 | 1 | | | .573 | .635 | SE, PHQ4 |
| I feel a sense of grief over my loved one's illness (NA7) | 2.29 (1.24) | .384 | .251 | .240 | .282 | .253 | .272 | 1 | | .566 | .621 | QDRS, FAQ, HUI, CCI, NPI, CDR, SE, ZBI, PHQ4 |
| I feel my quality of life is worse because of my caregiving responsibilities (NA8) | 1.39 (1.15) | .470 | .494 | .505 | .538 | .369 | .440 | .375 | 1 | .534 | .783 | QDRS, HUI, NPI, CDR, SE, ZBI |
| Eigenvalue | | | | | | | | | | 4.13 | | |
| % Variance Explained | | | | | | | | | | 25.79 | | |

Abbreviations: AMPS, Applied Mindfulness Process Scale; CC, Care Confidence; CDR, Clinical Dementia Rating; CP, Caregiver Preparedness; HUI, Health Utilities Index; NPI, Neuropsychiatric Inventory; PHQ4, Personal Health Questionnaire-4; QDRS, Quick Dementia Rating System; SE, Self-Efficacy; ZBI, Zarit Burden Inventory.

TABLE 4 PANAC scale features: internal-consistency reliability, score distributions, and inter-scale correlations

| Domain | Reliability | | Score features and distribution | | | | | | Inter-scale correlation Spearman r | | |
|----------|-------------|-------------------------|---------------------------------|------|--------|-----|---------|-----------|------------------------------------|----------|-------|
| | Items | Cronbach alpha (95% CI) | Range | Mean | Median | SD | % Floor | % Ceiling | Positive | Negative | Ratio |
| Positive | 8 | .840 (.803-872) | 0-32 | 19.9 | 20.0 | 5.7 | 1.0 | 2.5 | 1 | | |
| Negative | 8 | .823 (.782-858) | 0-32 | 12.1 | 12.0 | 6.5 | 4.5 | 0 | -.074 | 1 | |
| Ratio | n/a | n/a | 0-n/d | 2.3 | 1.6 | 2.1 | 0.5 | 0 | .444 | -.706 | 1 |

Note : % Floor is the percentage of caregivers who reported the lowest possible score.

% Ceiling is the percentage of caregivers who reported the highest possible score.

n/a: not applicable.

n/d: not defined.

in NAs ($P = 0.002$). In post hoc analyses, Black caregivers report significantly fewer NAs compared with White ($P = 0.001$) or Hispanic caregivers ($P = 0.001$) and have higher PA/NA ratios compared with White ($P = 0.03$) or Hispanic caregivers ($P = 0.04$). There were no differences in PAs by caregiver relationship. In post hoc analyses, spouse caregivers reported more NAs than non-family caregivers ($P = 0.04$) and reported a lower PA/NA ratio than either adult child ($P = 0.03$) or non-family caregivers ($P = 0.03$).

We next explored PANAC scores by dementia severity measured by global CDR staging. There were no differences in PAs by dementia severity, suggesting that these appraisals are more likely to be affected by caregiver traits rather than patient characteristics. There was a significant increase in NAs ($P < 0.001$) and a significant decrease in the PA/NA ratio ($P = 0.003$), with increasing dementia severity as measured by the CDR.

Because the CDR does not capture subjective cognitive impairment, we also explored PANAC scores by dementia severity by GDS staging.

Unlike the CDR, although the overall P -value for PAs was not significant ($P = 0.76$), post hoc analyses demonstrated that caregivers of GDS 2 individuals showed a trend to report more PAs than GDS 1 ($P = 0.47$) and no differences compared to GDS 3 individuals ($P = 0.67$). There was a significant increase in NAs ($P < 0.001$) and a significant decrease in the PA/NA ratio ($P = 0.003$) with increasing dementia severity as measured by the GDS.

Finally, we examined differences in PANAC scores by dementia etiology. There was a trend in PAs by dementia etiology ($P = 0.08$), with post hoc analyses demonstrating cognitively normal being different from AD ($P = 0.006$) and LBD being different from AD ($P = 0.02$). NAs increased with the development of dementia ($P < 0.001$) but not MCI. Among the dementias, VCID caregivers reported the fewest NAs and were not different from MCI or cognitively normal individuals. Caregivers of AD, LBD, and FTD patients reported the highest NAs but were not different from each other. Caution should be taken, however, as there were fewer VCID and FTD patients. The PA/NA ratio was

TABLE 5 Concurrent validity of PANAC scale with patient and caregiver characteristics

| Patient characteristic | Positive appraisals | Negative appraisals | Positive/Negative ratio |
|----------------------------|-------------------------|--------------------------|--------------------------|
| Patient physical health | .150 (.111) | -.319 (.001) | .331 (< .001) |
| Patient mental health | .087 (.355) | -.315 (.001) | .270 (.004) |
| Patient emotional health | .178 (.057) | -.381 (< .001) | .280 (.003) |
| Patient socialization | .431 (.115) | -.292 (.002) | .188 (.050) |
| QDRS – caregiver version | -.100 (.280) | .447 (< .001) | -.321 (.001) |
| Cognitive Change Index | .016 (.827) | .301 (< .001) | -.227 (.002) |
| Health Utilities Index | .173 (.063) | -.423 (< .001) | .348 (< .001) |
| Neuropsychiatric Inventory | -.049 (.559) | .507 (< .001) | -.357 (< .001) |
| FAQ | .008 (.931) | .348 (< .001) | -.239 (.011) |
| Epworth Sleepiness Scale | -.040 (.599) | .213 (.005) | -.152 (.050) |
| Alertness Rating | .102 (.177) | -.384 (< .001) | .272 (< .001) |
| MoCA | .062 (.506) | -.309 (.001) | .276 (.003) |
| CDR-SB | -.116 (.212) | .369 (< .001) | -.293 (.002) |
| HADS-A | .008 (.929) | .050 (.599) | .050 (.606) |
| HADS-D | -.053 (.575) | .246 (.008) | -.148 (.125) |
| UPDRS | -.232 (.013) | .249 (.008) | -.199 (.038) |
| mCAIDE | .081 (.258) | .222 (.002) | -.131 (.072) |
| Charlson Comorbidity Index | -.108 (.248) | .127 (.173) | -.114 (.233) |
| mPPT | -.002 (.981) | -.284 (.001) | .188 (.011) |
| Fried Frailty Score | -.159 (.086) | .274 (.003) | -.319 (.001) |
| Caregiver Characteristic | Positive Appraisals | Negative Appraisals | Positive/Negative Ratio |
| AMPS – Factor 1 | .286 (.004) | -.138 (.174) | .263 (.011) |
| AMPS – Factor 2 | .337 (.001) | -.290 (.004) | .308 (.003) |
| AMPS – Factor 3 | .256 (.011) | -.247 (.014) | .353 (< .001) |
| AMPS – Total | .312 (.001) | -.246 (.013) | .329 (.001) |
| Caregiver Self-Efficacy | .073 (.315) | -.551 (< .001) | .431 (< .001) |
| Social Support | .324 (< .001) | .053 (.460) | .112 (.128) |
| Care Confidence | .090 (.539) | -.302 (.035) | .280 (.052) |
| Caregiver Preparedness | .470 (< .001) | -.176 (.111) | .422 (< .001) |
| Caregiver Burden | .014 (.887) | .516 (< .001) | -.303 (.002) |
| Caregiver Depression | .026 (.485) | .372 (< .001) | -.239 (.012) |
| Self-rated Sleep Quality | .103 (.190) | .170 (.029) | -.161 (.044) |

Data presented as R-value (P-value); **Bold** signifies significant correlations after correcting for multiple comparisons.

Abbreviations: AMPS, Applied Mindfulness Process Scale; CDR-SB, Clinical Dementia Rating Sum of Boxes; FAQ, Functional Activities Questionnaire; HADS-A, Hospital Anxiety and Depression Scale-Anxiety subscale; HADS-D, Hospital Anxiety and Depression Scale-Depression subscale; mCAIDE, modified Cardiovascular Risk Factors, Aging, and Incidence of Dementia; MoCA, Montreal Cognitive Assessment; mPPT, mini Physical Performance Test; QDRS, Quick Dementia Rating System; UPDRS, United Parkinson's Disease Rating Scale.

lower in dementia cases compared with cognitively normal and MCI ($P = 0.04$) individuals, but there were no differences between different dementia etiologies.

4 | DISCUSSION

The PANAC is a brief rating of the overall caregiving experience that captures both the PAs and NAs of caregivers for the PLWD. The PANAC provides an easy way to assess multiple domains important for

caregiving research and to provide FCG with the support needed to care for themselves and the PLWD while maintaining the brevity and simple format for clinical practice, clinical research, and psychosocial assessments. The PANAC exhibits excellent data quality and works across different FCG types, stages of dementia, and dementia etiologies. Because this study included spouses and adult children of cognitively normal individuals with and without subjective cognitive impairment, we were able to demonstrate the utility of the PANAC in the earliest detectable symptomatic individuals (subjective cognitive impairment).¹⁹

TABLE 6 PANAC scores by sociodemographic characteristics, CDR staging, and dementia etiology

| Domain | Sex | | | Race/ethnicity | | | | Caregiver relationship | | | | | |
|----------|------------------|------------|------------|----------------|------------|------------|--------------|------------------------|-------------|------------|------------------|--|------------------|
| | Male | Female | P-value | White | Black | Hispanic | P-value | Spouse | Child | Other | P-value | | |
| Positive | 20.5 (5.0) | 19.3 (6.3) | 0.19 | 20.2 (5.3) | 18.0 (9.5) | 22.3 (3.7) | 0.36 | 19.9 (5.4) | 20.3 (5.1) | 18.5 (7.5) | 0.42 | | |
| Negative | 10.9 (5.7) | 12.6 (6.9) | 0.09 | 12.2 (6.0) | 4.4 (3.9) | 15.1 (7.2) | 0.002 | 12.9 (5.9) | 11.4 (7.2) | 10.0 (7.3) | 0.06 | | |
| Ratio | 2.6 (2.5) | 2.1 (1.9) | 0.15 | 2.2 (1.7) | 4.0 (2.3) | 1.9 (1.2) | 0.07 | 1.9 (1.8) | 2.7 (2.3) | 2.9 (2.6) | 0.02 | | |
| Domain | CDR 0 | | CDR 0.5 | | CDR 1 | | CDR 2 | | CDR 3 | | P-value | | |
| Positive | 18.7 (6.7) | | 19.9 (5.4) | | 20.6 (5.2) | | 20.1 (6.9) | | 19.1 (4.6) | | 0.68 | | |
| Negative | 8.2 (5.3) | | 10.8 (6.3) | | 15.3 (5.4) | | 15.0 (6.5) | | 17.9 (4.7) | | <0.001 | | |
| Ratio | 3.1 (2.5) | | 2.6 (2.5) | | 1.6 (0.8) | | 1.6 (1.1) | | 1.1 (0.5) | | 0.003 | | |
| Domain | GDS 1 | | GDS 2 | | GDS 3 | | GDS 4 | | GDS 5 | | GDS 6 | | P-value |
| Positive | 17.6 (7.0) | | 21.3 (5.4) | | 20.6 (5.7) | | 19.7 (5.60) | | 21.7 (4.10) | | 18.0 (6.7) | | 0.76 |
| Negative | 8.5 (5.20) | | 8.7 (4.50) | | 10.4 (6.6) | | 13.0 (6.1) | | 14.9 (5.0) | | 17.0 (6.5) | | <.001 |
| Ratio | 2.7 (1.8) | | 3.3 (2.8) | | 2.9 (2.7) | | 1.9 (1.50) | | 1.8 (1.1) | | 1.2 (0.7) | | .003 |
| Domain | Cognitive Normal | | MCI | | AD | | LBD | | VCID | | FTD | | P-value |
| Positive | 18.1 (6.2) | | 20.3 (5.5) | | 22.3 (4.5) | | 18.8 (5.9) | | 19.0 (3.8) | | 21.4 (5.4) | | 0.08 |
| Negative | 8.9 (4.9) | | 10.8 (6.9) | | 14.0 (5.9) | | 14.8 (6.4) | | 13.6 (4.1) | | 16.0 (4.5) | | <0.001 |
| Ratio | 2.8 (2.2) | | 2.7 (2.7) | | 1.9 (1.7) | | 1.6 (1.2) | | 1.6 (0.8) | | 1.5 (0.8) | | 0.04 |

Mean (SD).

Abbreviations: AD, Alzheimer's disease; CDR, Clinical Dementia Rating; FTD, frontotemporal degeneration; MCI, mild cognitive impairment; LBD, Lewy body dementia; VCID, vascular contributions to cognitive impairment and dementia.

One of the great challenges in caregiving research is deciding *a priori* which construct will be measured as each scale adds increasing burden to complete. In addition, few scales are available to capture the potential positive aspects of caregiving.¹⁰ The PANAC offers the efficiency of capturing multiple domains (eg, burden, preparedness, depression, self-efficacy) in one brief instrument validated against gold standard measures in a clinical sample. The PA and NA factors capture different aspects of the caregiving experience, whereas the ratio of PA/NA may provide a measure to capture the overall caregiving experience. The NAs are related to both patient and caregiver characteristics, whereas the PAs are associated only with FCG traits. The PANAC constructs showed convergence with standardized measures of caregiver burden, depression, preparedness, care confidence, mindfulness, and self-efficacy while also capturing novel domains of giving back, being a role model, and moral, religious, or filial obligation of responsibility.

Although caregiver stress, strain, burden, depression, and grief have been studied extensively in FCGs of PLWD,^{2,48} little is known about how these constructs influence other psychological and emotional constructs in FCGs such as self-efficacy and psychological well-being.⁴⁹ Many extant studies capture only a few caregiving constructs at one time, often leaving unanswered questions about how other caregiving domains may be influenced or impacted by a proposed intervention. For example, although increasing social support and self-efficacy have been shown to decrease FCG depression⁵⁰ or burden,⁵¹ no information was available to assess how other constructs may change. In

a recent mediation analyses, we found that increasing self-efficacy mediated the association between caregiver burden and psychological well-being, whereas increasing social support mediated the association between caregiver grief and psychological well-being.⁴⁹ In another study, we found that spouse and adult children FCGs may experience caregiving differently⁵²; however, only through completion of multiple scales of grief, burden, social support, and quality of life can these experiences be captured (for example, in the two previous cited study reports, FCGs took 45 minutes to complete 230 questions). A second downside of using multiple surveys to capture multiple constructs is that statistical corrections for multiple comparison may cause loss of detection of small (but clinically relevant) effects.

The Positive Aspects of Caregiving (PAC) scale¹⁰ was developed to explore perceptions of the caregiver's mental or affective state in the context of caregiving. The PAC includes questions such as feeling useful, feeling appreciated, and learning new skills¹⁰ deriving two factors in analyses: outlook on life and self-affirmation. PAs of caregiving may serve as a moderator of treatment outcomes in caregiver interventions⁹ such as reducing depression, burden, and stress due to PLWD behaviors. The main limitation of the PAC is that an entirely separate set of measures would be needed to capture the NAs.

There are several limitations to this study. The PANAC was developed and validated in the context of a memory disorders clinic and research program, where the prevalence of MCI and dementia are high and the FCGs tend to be highly educated and predominantly

White. Validation of the PANAC in other settings where dementia prevalence is lower (ie, community samples) is needed. Although we did not find differences across racial and ethnic groups in this study, the percentage of racial and ethnic minorities was small. Validation of the PANAC in samples of more diverse PLWD and FCGs is needed. This is particularly true because different racial and ethnic backgrounds may have different attitudes and belief systems regarding caregiving. Our research projects and clinic focus on healthy aging, MCI and early stage AD/DRD so fewer moderate to severe patients are seen. Future studies may wish to include individuals with more advanced stages of AD/DRD. This might have skewed the minimal floor and ceiling effects detected. The PANAC is a self-report scale so there may be a bias to report more positive symptoms; however, the PANAC alternates PAs and NAs to limit this possibility and in this study separate measures of just PAs and NAs were collected to further limit this possibility. Because this is a cross-sectional study, the longitudinal properties of the PANAC still need to be elucidated. PAs were not associated with any patient characteristic in this present study; however, it is possible that other characteristics not collected as part of this study such as patient or caregiver personality traits could explain other aspects of PANAC responses.

The strengths of this study include the use of a comprehensive evaluation that is part of standard of care with measurement of multiple patient and caregiver constructs using gold standard instruments. Another advantage of the PANAC is its brevity consisting of 16 questions to be printed on one piece of paper or viewed in a single screenshot to maximize its clinical and research utility. Finally, as all the components of PANAC are collected at the same time and cover multiple domains, no correction for multiple comparisons is necessary for the PANAC compared to collecting multiple separate scales to measure multiple caregiving constructs.

There are several implications of our findings. First, no patient characteristic was associated with PAs. This suggests that treatment of patient symptoms is more likely to affect the FCG's NAs of caregiving. Second, the PA/NA ratio was correlated with both factors but was more strongly correlated with the NAs ($r = 0.71$ vs 0.44), suggesting that the ratio could be used as a measure to capture change due to caregiver interventions that lessen NA. Third, the relationships between the PAs and NAs, and PA/NA ratio with various caregiver and patient characteristics suggest potential interventional targets to improve the overall caregiving experience. Future studies of the PANAC could focus on developing cutoff scores for referral for social support or psychotherapy, or to establish a clinical threshold for significant caregiver distress.

The PANAC may serve as an effective clinical tool for providing referrals for services, support groups, and psychotherapy for FCGs, while also being useful in caregiving social-behavioral research projects. The PANAC could also be utilized as a caregiver outcome in randomized clinical trials to test new therapeutics, interventions, and devices. The PANAC performed reliably and validly in comparison to standardized scales of caregiving experience, but in a brief fashion that could facilitate its use in caregiver research.

CONFLICTS OF INTEREST

All authors report no conflicts of interest.

AUTHOR CONTRIBUTIONS

Dr James E. Galvin was involved in the conceptualization, data curation, formal analysis, funding acquisition, methodology, supervision, and writing of original draft, review and editing. He approves of the final version and ensures the accuracy and integrity of the work. **Dr Magdalena I. Tolea** was involved in the data curation, formal analysis, and writing review and editing. She approves of the final version and ensures the accuracy and integrity of the work. **Dr Stephanie Chrisphonte** was involved in the data curation, project administration, and writing review and editing. She approves of the final version and ensures the accuracy and integrity of the work.

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How to cite this article: Galvin JE, Tolea MI, Chrisphonte S. The positive and negative appraisals of caregiving (PANAC) scale: A new measure to examine the caregiving experience in Alzheimer's disease and related dementias. *Alzheimer's Dement*. 2020;6:e12104. <https://doi.org/10.1002/trc2.12104>