

| Reference | Sample | Measurement Instrument | | | Psychometric Characteristics | |
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| | | Name of the Scale | Domains and Constructs | Length and Format of Instrument | Validity | Reliability |
| Greene <i>et al.</i> (1982) ¹ Scotland | ADRD | Behavioral and Mood Disturbance Scale (BMDS) | Perception of care recipient's behavior/mood disturbance Three factors: (1) Apathetic/withdrawn; (2) Active/disturbed; (3) Mood disturbance | 34 items, 5-point Likert scale (0=Never, 1=Rarely, 2=Sometimes, 3=Frequently, 4=Always or 0=Not at all, 1=A little, 2=Moderately, 3=Quite a lot, 4=Considerably) | Although not formally introduced as " <u>content validity</u> ", authors culled items for both scales from the literature and appropriately worded items for use with non-professional persons. A number of items also were created by the authors. The <u>structural validity</u> for the BMDS was established through EFA with PAF extraction and Varimax rotation that found three factors accounting for 41% of the total variance. A scree plot confirmed three factors: apathetic-withdrawn behavior, active-disturbed behavior, and mood disturbance. | Test-retest reliability was assessed by retesting a subsample of 18 caretakers 3 weeks after the initial test and calculating a Pearson's correlation coefficient. <u>Test-retest reliability, full scale=0.84.</u> <u>Test-retest reliability by subscales:</u> Apathetic (r=0.90); Active (r=0.87); Mood disturbance (r=0.73) |
| | | Relatives' Stress Scale (RSS) | CG experience with stress and upset Three factors: (1) Personal distress; (2) Life upset; (3) Negative feelings toward patient | 15 items 5-point Likert scale (0=Never, 1=Rarely, 2=Sometimes, 3=Frequently, 4=Always or 0=Not at all, 1=A little, 2=Moderately, 3=Quite a lot, 4=Considerably) | The <u>structural validity</u> for the RSS was established through EFA with PAF extraction followed by a Varimax rotation that found three factors accounting for 51% of the total variance. Scree plots also confirmed three underlying factors: personal distress, life upset, and negative feelings toward patient. <u>Concurrent validity</u> was examined by Pearson correlations between RSS subscales with two measures of self-care: Physical Self Maintenance (PSM) and ADLs. Only the RSS "life upset" factor (subscale) was significantly correlated with the PSM (r=0.34, $p<0.05$), that is, caretakers experienced "life upset" with poor physical self-maintenance of the patient. | Test-retest reliability was assessed by retesting a subsample of 18 caretakers 3 weeks after the initial test. <u>Test-retest reliability, full scale=0.85</u> <u>Test-retest reliability by subscales:</u> Personal distress (r=0.72); Domestic upset (r=0.80); Negative feelings (r=0.88) |
| Novak & Guest (1989) ⁴ Canada | ADRD | Caregiver Burden Inventory (CBI) | CG burden Five factors: (1) Time-dependence; (2) Developmental burden; (3) Physical burden; (4) Social burden; (5) Emotional burden | 24 items, 5-point Likert scale (ranging from 0=Not at all descriptive to 4=Very descriptive) | The <u>structural validity</u> of a 24-item scale (containing sixteen questions from a previous study and eight new questions added by the authors from the CG burden literature) was established by PCA with Varimax rotation identifying 5 components/factors accounting for 66% of the variance. | <u>Cronbach's α by subscales:</u> Time-dependence ($\alpha=0.85$) Developmental burden ($\alpha=0.85$) Physical burden ($\alpha=0.86$) Social burden ($\alpha=0.73$) Emotional burden ($\alpha=0.77$) |
| | | Social Conflict (SC) | Social conflict One factor: Lack or inadequacy of social support (or help) | 3 items, 5-point Likert scale (ranging from 1=Not at all to 5=Extremely) | <u>Structural validity.</u> A PCA with Varimax rotation yielded the SC factor/component explaining 18% of the variance. <u>Concurrent validity</u> was established by a significant positive Pearson correlation between the total scores on the SC and the ZBI item "Do you feel that your relative currently affects your relationship with other family members or friends in a negative way" (r=0.34, $p=0.001$). | <u>Cronbach's α, full scale =0.72</u> |
| Gerritsen <i>et al.</i> (1994) ¹⁴ The Netherlands | ADRD | Care-Giving Burden Scale (C-GBS) | Subjective burden Two factors: (1) Personal consequences (subjective impact of care-giving on the lives of the carers) (2) Relationship (evaluation/opinions of the care relationship) | 13 items, 5-point Likert scale (1=Disagree very much, 2=Disagree, 3=Agree on the one hand, disagree on the other, 4=Agree, 5=Agree very much) <u>Note:</u> Items were recoded to binary, 2-point scale (1,2=0; 3,4,5=1) | <u>Content validity</u> was appraised by researchers and colleagues screening items for caregiving burden from previous scales, in particular, the Vernooij-Dassen's Sense of Competence Questionnaire. The screening process reduced the original 27-item Sense of Competence scale, as well as additional author-developed items, to a final pool of 20 items. <u>Structural validity</u> was established through a PCA with Varimax rotation. The analysis yielded a two-factor/component solution that explained 34.4% of the variance. (A replication of the PCA at a second time point (after 3 months) produced similar results explaining 37.6% of the variance.) Based on these results and an inspection of item loadings, authors further reduced the 20-item scale to a 13-item scale. The <u>concurrent validity</u> was established by statistically significant ($p<0.001$) positive Pearson correlations between the C-GBS scores and CG depression measured by the Zung Self-Rating Depression Scale (r=0.53). C-GBS scores were significantly associated with both, patient deviant behavior and memory/orientation subscales from the RMBPC (r=0.53 and 0.31, respectively). | <u>Cronbach's α, full scale =0.84.</u> <u>Cronbach's α by subscales:</u> Personal consequences ($\alpha=0.74$) Relationship ($\alpha=0.77$) <u>Note:</u> Reliability estimates from an independent sample of CGs (N=42) were similar (full scale $\alpha=0.84$; Subscales: Relationship $\alpha=0.77$, Personal Consequences $\alpha=0.75$) |
| Gilleard <i>et al.</i> (1994) ¹⁵ United Kingdom | ADRD | Dementia Quiz (DQ) | Dementia knowledge Three domains: (1) Biomedical knowledge; (2) Services knowledge; (3) Coping knowledge | 25 items, 5-point, multiple-choice scale (including a fifth "don't know" option) | <u>Content validity.</u> Thirty-six items were gathered from unpublished questionnaires, the original Alzheimer's Disease Knowledge Test (ADK), and experience working with health care staff and families of those with dementia. Several "experts" experienced in aging and mental health guided the rewording and reduction of the item pool to 34 items. To provide evidence of face validity, a panel of 10 experts pilot tested the 34-item scale, and all items were scored 'correct' by at least eight out of 10. <u>Structural validity.</u> No formal analysis to study the underlying structure (dimensionality) of the 34-item scale is conducted. Authors reported further reducing the scale to 25 items due to low item-subscale (domain) correlations ($r's < 0.25$). <u>Concurrent validity</u> was established by correlating Dementia Quiz (DQ) scores with the Alzheimer's Disease Knowledge Test (ADK). The results indicated highly significant associations between the ADK score and the three DQ subscale scores: Biomedical Knowledge subscale (r= 0.59, $p < .001$); Services Knowledge subscale (r= 0.37, $p < .001$); and Coping Knowledge subscale (r= 0.52, $p < .001$). | <u>Cronbach's α, full scale =0.88</u> <u>Spearman-Brown (SB) split-half reliability estimate for subscales:</u> Biomedical Knowledge (SB=0.78) Services Knowledge (SB=0.71) Coping Knowledge (SB=0.71) |

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| Keady & Nolan (1996) ¹⁹ United Kingdom | ADRD | Behavioral and instrumental stressors in Dementia (BISID) | CG stress Three domains: (1) Behavior of patient (2) Activities of daily living (ADL) (3) Continence | 22 items, (Each item is rated using the scale below and <u>also</u> according to "Way of coping" and "Perceived stress level") <u>Ratings for Behavior and Continence domains:</u> 5-point Likert scale (from 0=Never, to 4=Very frequently (> once a day)) <u>Ratings for the ADL domain:</u> 4-point Likert scale (from 0=No help needed to 3=Totally unable to complete the activity) <u>Ratings for "Perceived stress level"</u> 4-point Likert scale (from 0=Not stressful to 3=Very stressful) | <u>Content validity</u> . Items were drawn from a comprehensive review of the literature on CGs needs and stressors, existing measures, and experiences of local dementia professionals. A pilot study of the 22 items with 38 dementia CGs confirmed the scale's content acceptability to CGs. <u>Structural validity</u> . No formal examination of the underlying factor structure of the scale using factor analysis is presented. | Cronbach's α estimates from the BISID subscales were obtained from <i>two independent samples</i> . The first sample comprised 205 caretakers and the second independent sample included 264 caretakers. <u>Cronbach's α by subscales</u> (N=205): Behavioral (α =0.89). ADL (α =0.90) Continence (α =0.92) <u>Cronbach's α by subscales</u> in the <i>second independent sample</i> (N=264) were very close and also within acceptable ranges: Behavioral (α =0.92) ADL (α =0.92) Continence (α =0.94) |
| Vernooij-Dassen <i>et al.</i> (1996) ²⁰ The Netherlands | ADRD | Sense of Competence Questionnaire (SCQ) | Feelings of competence Three factors: (1) Satisfaction with the demented patient; (2) Satisfaction with one's CG performance; (3) Consequences of caregiving for one's personal life | 27 items, 4-point Likert scale (1=Disagree Very Much, 2=Disagree, 3=Agree, 4=Agree Very Much) | <u>Content validity</u> was determined through classification of items by a 39-person panel of experts. <u>Structural validity</u> was established through EFA. Authors reported conducting an EFA that yielded the same 3-factor structure that the panel of experts had previously predicted. No further details of the EFA extraction procedures were provided. <u>Note</u> : The 7-item abbreviated version of the SCQ scale (S-SCQ) developed later by Vernooij-Dassen <i>et al.</i> (1999) ²¹ also produced the same 3-factor structure through an EFA. Using the same sample of CGs, authors found significant Pearson's correlation between the S-SCQ and the original SCQ (r =0.88). | Cronbach's α , full scale =0.79 <u>Cronbach's α by subscales</u> : Satisfaction with the demented patient (α =0.55); Satisfaction with one's CG performance (α =0.63); Consequences of caregiving for one's personal life (α = 0.50) (Cronbach's α for the abbreviated 7-item S-SCQ scale=0.76.) |
| Schoefield <i>et al.</i> (1997) ²⁴ Australia | Mixed | Comprehensive instrument to assess the experience of caregiving: A battery of scales <u>Scale 1: Social Support</u> | Social Support Three factors/components: (1) Family support; (2) Friends support; (3) Esteemed by family and friends | 7 items, 5-point Likert scale (ranging from 1=Strongly disagree to 5=Strongly agree) | <u>Content validity</u> was demonstrated by reviewing literature and instruments and conducting interviews with CGs to generate key domains and a preliminary bank of items. A pilot test with 98 CGs that included a comparison group of 78 non-CGs was also conducted that further refined the initial item pool. Items were organized into five main domains for analysis. The <u>structural validity</u> of the seven-item scale administered to CGs was determined through a PCA with Varimax rotation yielding a three-factor structure accounting for 66% of the variance. (All the scales in the battery were analyzed using the same sample, N=976). | Cronbach's α by subscales: Family support (α =0.64) Friend's support (α =0.57) Esteemed by family and friends (α =0.56) |
| | | <u>Scale 2: Family environment</u> | Family environment Two factors/components: (1) Closeness; (2) Conflict | 6 items, 3-point Likert scale (1=Less, to 3=More) | The <u>structural validity</u> for the 6-item scale administered to CGs was determined through a PCA with Varimax rotation yielding a 2-factor/component model explaining 63% of the variance. | <u>Cronbach's α by subscales</u> : Closeness (α =0.68) Conflict (α =0.70) |
| | | Scale 3: Caring role | Caring role Three factors/components: (1) Satisfaction/Love; (2) Resentment; (3) Anger | 16 items, 5-point Likert scale (1=Strongly disagree to 5=Strongly agree) | The <u>structural validity</u> for the 16-item scale administered to CGs was assessed through a PCA with Varimax rotation that produced a 3-factor/component structure explaining 44.2% of the variance. | <u>Cronbach's α by subscales</u> : Satisfaction (α =0.71) Resentment (α =0.69) Anger (α =0.71) |
| | | Scale 4: Help Needed by Recipient | Help needs by care recipient Two factors/components: (1) ADLs; (2) IADLs | 11 items, 3-point Likert scale (from 1=No help, 2=Some help, 3=A lot of help) | The <u>structural validity</u> of the 11-item scale administered to CGs was evaluated through a PCA with Varimax rotation that resulted in a 2-factor/component solution accounting for 57.1% of the variance. | <u>Cronbach's α by subscales</u> : ADL (α =0.82) IADL(α =0.68) |
| | | Scale 5: Behavior Problem | Behavior problems Three factors/components: (1) Aggressive; (2) Depressive; (3) Forgetfulness/confusion | 18 items, 4-point scale (0=Never, 1=Rarely, 2=Sometimes, 3=Often) | Finally, the <u>structural validity</u> for the 18-item scale administered to CGs was determined through a PCA, also with Varimax rotation that produced a 3-factor/component solution accounting for 41% of the variance. | <u>Cronbach's α by subscales</u> : Aggressive (α =0.84) Depressive (α =0.60) Forgetfulness/Confusion (α =0.73) |
| Matsuda (1999) ²⁸ | ADRD | Subjective Burden Scale (SBS) | Subjective burden Three domains: (1) Wellbeing of CG | 14 items, 5-point Likert scale (0=No, 1=Yes, a little bit, | The <u>content validity</u> of the SBS scale is not formally addressed by the author. However, a prior publication by the same author ²⁹ described the development of items for the tool based on literature reviews on stress and coping theories as well as clinical experiences. Development of items also | <u>Cronbach's α, full scale</u> =0.87 <u>Split-half reliability</u> of the full scale was estimated using the Spearman-Brown |

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| Japan | | | (emotional, physical, social, and financial); (2) Wellbeing of CG's family; (3) Interpersonal stress among relatives | 2=Yes, to some degree, 3=Yes, to much degree, 4=Yes, very much) | addressed differences in family context unique to Japan. For example, there is a higher proportion of three-generation households and daughter-in-law CGs in Japan with CG stressors unique to family members and relationships. No examination of the underlying factorial structure or dimensionality of the 14-item scale is presented. <u>Concurrent validity</u> was assessed by calculating a Pearson's correlation coefficient between the SBS total scores and a mental health criterion measured by the General Health Questionnaire (GHQ) ($r=0.41$, $p<0.001$). <u>Group discriminant validity</u> was established by comparing SBS scores for CGs with high scores in the GHQ (17 or higher-MU group) vs CGs with low GHQ scores (16 or under-MH group) using a t-test. The MU group showed significantly higher SBC scores than the MH group ($t=5.45$, $p < 0.001$). | formula ($r=0.80$). <u>Rest-retest reliability</u> (6-month interval) was calculated in a subsample ($N=50$) using a Pearson's correlation coefficient ($r=0.72$). |
| Hebert <i>et al.</i> (2000) ³⁰ Canada | ADRD | Zarit Burden Interview (ZBI) | Burden Two factors: (1) Personal strain; (2) Role strain | 12 items; 5-point Likert scale (0=Never to 4=Nearly always) | The <u>structural validity</u> of ZBI was assessed through a stepwise process that began with an exploratory analysis of the original 22-item ZBI scale followed by CFA. After comparing several CFA competing models, authors went back and ran an EFA model producing a 2-factor solution ("personal strain" and "role strain") with a reduced 12-item ZBI scale that was further tested for goodness of fit with a CFA model. Compared to previous competing CFA models, the 2-factor solution produced the best goodness-of-fit indexes (e.g., AGFI=0.98, RMR=0.10). <u>Concurrent validity</u> was established by significant Spearman's correlations (p -values < 0.001) between scores on the 12-item ZBI and a) CG depression as measured by the CES-D ($\rho=0.57$), b) behavior problems, measured by the Dementia Behavior Disturbance scale ($\rho=0.58$). | <u>Cronbach's α, full scale</u> =0.91 <u>Guttman's split-half reliability</u> estimate for the full 12-item scale=0.91 |
| Guberman <i>et al.</i> (2001) ³¹ Canada | Mixed | The Caregiver Risk Screen (CRS) | Risk to CG mental and physical wellbeing Two domains: (1) Level of risk to CG mental wellbeing; (2) Level of risk to CG physical wellbeing | 12 items, 4-point Likert scale (0=Totally disagree, 1=Somewhat disagree, 2=Somewhat agree, 3=Totally agree) | <u>Content validity</u> was established through several scale development stages. First, a literature review of validated tools on caregiving psycho-social scales measuring burden, depression, social support, etc. was conducted. Second, non-validated CG assessment tools were also collected from key informers representing public, private, and non-profit agencies as well as research on non-validated tools which described what key CG risk elements should contain. Third, nine focus groups were conducted with family CGs, administrators, and community care practitioners to identify the key elements to be included in a measure of risks to caregiving mental and physical wellbeing. Informal pretests were also conducted to assess the relevance of preliminary items. No formal tests were conducted to study the dimensionality of the scale. <u>Concurrent validity</u> was assessed by calculating a Pearson's correlation coefficient between the total scores on the 12-item Caregiver Risk Screen (CRS) and the Caregiver Burden Screen (Rankin et al, 1994), as the external criterion. The correlation was statistically significant ($r=0.83$, $p<0.005$). <u>Note</u> : The Caregiver Burden Screen was chosen as the external criterion to establish the CRS validity because it was short, validated in English and French, and contained two relevant dimensions: CG depression and patient level of care/demands. | <u>Cronbach's α, full scale</u> =0.88 |
| Suwa (2003) ³⁶ Japan | ADRD | Assessment Scale for Caregiver's Experience with Dementia (ASCED) | Stages in caregiving experience Three factors (subscales): (1) Empathetic caregiving experience; (2) Disciplinary caregiving experience; (3) Resigned caregiving experience | 24 items, 5-point Likert scale (1=Never, 2=Very infrequently, 3=Sometimes, 4=Frequently, 5=Continually) | <u>Content validity</u> was established by using prior qualitative research results that included CG interviews to develop a pool of items. The draft of the ASCED scale was guided by a 7-stage CG experience model. Ten items were written for each stage resulting in an initial 70-item measure. A panel of experts judged the appropriateness of the items for each caregiving stage, and another panel of CGs judged the legibility of items. After administering the 70-item ASCED tool to the sample ($N=90$), the correlation coefficients were computed for each of the 10 items at all seven stages. Using item-total correlation coefficients greater than 0.40 as item selection criterion, a final pool of 35 items were retained (5 items per the seven stages). <u>Structural validity</u> . An EFA with Varimax rotation was conducted on the 35-item tool to identify underlying patterns or "factors". EFA yielded a 3-factor model, but 11 items were dropped due to low factor loadings. The final EFA using the 24-item ASCED tool also showed a 3-factor structure accounting for 51.4% of the variance. <u>Concurrent validity</u> was demonstrated by "moderate" Pearson's correlations between scores on the ZBI and (a) scores on the "Disciplinary caregiving experience" subscale ($r=0.38$, $p < 0.01$) and (b) the "Resigned caregiving experience" subscale ($r=0.41$, $p < 0.01$). The correlation between the "Empathetic caregiving experience" and ZBI scores, however, was insignificant ($r=0.08$, $p=0.45$). | <u>Cronbach's α by subscales</u> : Empathetic caregiving experience ($\alpha=0.89$); Disciplinary caregiving experience ($\alpha=0.78$); Resigned caregiving experience ($\alpha=0.81$) Test-retest (temporal) reliability was evaluated with Pearson's correlations between scores in the ACED scale obtained in two administrations (1 to 4 weeks apart) using a subsample of respondents ($N=30$). <u>Test-retest reliability for subscales</u> : Empathetic caregiving experience ($r=0.34^*$); Disciplinary caregiving experience ($r=0.75$); Resigned caregiving experience ($r=0.71$) |
| Goolieb & Rooney (2003) ³⁸ Canada | ADRD | RIS Eldercare Self-efficacy Scale | Caregiver Self-Efficacy Beliefs Three factors: (1) Relational self-efficacy; (2) Instrumental self-efficacy; (3) Self-soothing efficacy | 10 items, 5-point Likert scale (1='I'm certain I can't do this, 2='I probably can't do this, 3='Maybe I can and maybe I can't do this, 4='I probably can do this, | <u>Content validity</u> was shown by developing 13 items from a review of the perceived self-efficacy literature. Among the many dimensions of perceived self-efficacy in the literature, authors focused on three dimensions they believed were universally experienced by CGs: CG beliefs about their ability to manage caregiving, to maintain a cooperative relationship with a care recipient, and to sustain personal wellbeing in demanding situations. Prior to the inspection of the underlying <u>structure of the scale</u> , inter-item correlations were calculated and separate internal consistency analyses were performed for each of the hypothesized subscales to | <u>Cronbach's α by subscales</u> : Relational self-efficacy ($\alpha=0.72$) Instrumental self-efficacy ($\alpha=0.74$) Self-soothing efficacy ($\alpha=0.79$) Test-retest reliability was calculated with Pearson's correlations between RIS scores obtained at baseline and 4-6 |

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| | | | | 5=I'm certain I can do this) | identify items that may reduce reliability estimates. This analysis reduced the item pool to 12 items. Iterative PCAs with oblique rotations were subsequently conducted to determine the factorial structure of the scale. A scree plot and eigenvalues inspection suggested a three-component/factor solution. Factor loadings led to removing two additional items. The final PCA applied to the 10-item scale also yielded a 3-component solution (subscales) that accounted for 66% of the total variance in items. <u>Concurrent validity</u> was demonstrated by expected significant positive Pearson's correlations between Perceived social support and the three RIS subscales a) Relational self-efficacy ($r=0.20, p < 0.05$), b) Instrumental self-efficacy ($r=0.23, p < 0.01$), and c) Self-soothing efficacy ($r=0.30, p < 0.001$). All three subscales (<i>Relational, Instrumental, and Self-soothing</i>) were (as expected) significantly (p -values < 0.05) associated with CG personality traits such as: a) Optimism ($r=0.28; r=0.41; r=0.36$, respectively), b) Agreeableness ($r=0.31; r=0.22; r=0.25$, respectively), and Conscientiousness ($r=0.33; r=0.40; r=0.29$, respectively). The RIS Relational and Instrumental subscales correlated significantly (p -values < 0.01) with a "Coping" measure ($r=0.32$ and $r=0.31$, respectively). Finally, the RIS Relational subscale correlated (as expected) negatively with "anger expression" ($r=-0.26$). | months later for a subsample of respondents ($N=105$). <u>Rest-retest reliability for subscales:</u> Relational self-efficacy ($r=0.48, p < 0.001$) Instrumental self-efficacy ($r=0.69, p < 0.001$) Self-soothing efficacy ($r=0.60, p < 0.001$) |
| Grässel <i>et al.</i> (2003) ³⁹ Canada | ADRD | Burden Scale for Family Caregivers (BSFC) | Subjective burden One factor: Subjective burden | 28 items, 4-point Likert scale (0=No, definitely not, 1=No, not really, 2=Yes, generally, 3=Yes, definitely) | <u>Content validity</u> was demonstrated through a multi-step item-development process. Statements recorded from CG discussion groups and interviews were developed into items and a prototype or preliminary scale. The preliminary scale was compared to published CG burden scales and reviewed by an expert panel prior to pilot testing. The scale was pilot tested and items were revised for comprehensibility and acceptability. Finally, the scales were translated from German into English before further psychometric testing. To study the <u>structural validity</u> of the 28-item BSFC scale, the authors conducted PCAs without rotation on two independent samples: one of dementia CGs ($N=1143$) and a second of non-dementia CGs ($N=548$). (Forty-five percent of the non-dementia CGs were caring for elderly people with relatively unimpaired cognition and the remaining 55% were carers of individuals with neurological disorders.) The PCA of the dementia CG responses yielded a one-component/factor solution explaining 29.1% of the variance. (The PCA of the non-dementia sample yielded a similar one-factor structure explaining 31.5% of the variance.) Using the dementia CG sample, the <u>concurrent validity</u> was established by a significant ($p < 0.001$) positive Pearson's correlation between the BSFC scores and patient behavioral disturbances ($r=0.39$) measured by the Sandoz Clinical Assessment-Geriatric. (The non-dementia CG BSFC scores produced a similarly significant positive Pearson's correlation with SCAG scores ($r=0.44, p < 0.001$).) | Sample 1 (Dementia CGs) <u>Cronbach's α, full scale</u> =0.90 <u>Split-half reliability</u> was calculated with the Spearman-Brown correlation coefficient=0.88 <u>Note:</u> Reliability calculations for the second independent sample of non-dementia CGs yielded similar results: Cronbach's $\alpha=0.91$ and the split-half reliability coefficient=0.90. |
| Andrén & Elmståhl (2005) ⁴⁸ Sweden | ADRD | Carers' Assessment of Satisfaction Index (CASI) | Subjective experience of satisfaction Four factors: (1) Purpose; (2) Pleasure (3) Appreciation; (4) Reverse | 20 items, 4-point Likert scale (1=Does not apply, 2=Applies, but does not provide a source of satisfaction, 3=Applies and provides quite a lot of satisfaction, 4=Applies and provides a great deal of satisfaction) | This study explores an existing 30-item CASI scale developed by Nolan <i>et al.</i> (1996) ⁴⁹ for CGs of relatives with common geriatric diseases and not specifically dementia. The current study validates CASI in a sample of dementia carers. The <u>structural validity</u> of the initial 30-item scale was established by factor analysis with Varimax rotation reducing the measure to 20 items, yielding four factors, and explaining 64% of the variance. According to the authors, this reduction of items resulted in a scale that was more specific to conditions of dementia. <u>Concurrent validity</u> was examined by Spearman's rank correlations between the CASI subscales and several criterion measures for assessing (a) patient dementia syndromes such as intellectual, emotional and motor performance, measured by the Gottfries-Brane-Steen (GBS) scale), (b) social dependency, measured by the Berger Scale), (c) CG stress management (measured by the Sense of Coherence Scale), d) burden, as measured by the Caregiver Burden Scale, and perceived health, assessed by the Nottingham Health Profile scale. Only the CASI Purpose subscale was associated with the patients' social dependency scores ($\rho=0.17, p < 0.05$) and intellectual syndrome (cognitive symptoms) scores ($\rho=0.168, p < 0.05$). <u>Group discriminant validity.</u> "Satisfaction", as measured by the CASI-Purpose subscale, was influenced by the patient's severity of disease. For the care recipient group with high independence (defined as low Berger score) CGs had higher mean scores in the Purpose subscale compared to the group of CGs caring for individuals with high dependence (23.4 vs. 20.4, $p = 0.023$). | <u>Cronbach's α, full scale</u> =0.78. <u>Cronbach's α by subscales:</u> Purpose ($\alpha=0.77$) Pleasure ($\alpha=0.80$) Appreciation ($\alpha=0.70$) Reverse ($\alpha=0.83$) |
| Charlesworth <i>et al.</i> (2007) ⁵³ United Kingdom | ADRD | Carers Assessment of Difficulties Index (CADI) | Objective burden Eight factors: (1) Carer's reaction to caring; (2) Degree of physical help; (3) CG-patient relationship; (4) Restrictions | 30-item, 3-point Likert scale (1=Never applies, 2=Sometimes applies, 3=Always applies) | The CADI scale was originally developed by Nolan and Grant (1989) to assess multiple dimensions of carer burden. The original 30 items were identified from theoretical and empirical literature on caring representing aspects of social life, economic situation, relationship with the patient and wider family, professional and family support, dependency factors and the carer's reaction to the demands of caregiving. However, its psychometric properties had not been examined with dementia CGs. The current study validates the scale in a sample of $N=232$ dementia CGs. | <u>Cronbach's α by subscales:</u> Carer's reaction to caring ($\alpha=0.77$) Degree of physical help ($\alpha=0.67$)* CG-patient relationship ($\alpha=0.67$)* Restrictions on social life ($\alpha=0.76$) Professional support ($\alpha=0.68$)* |

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| | | | on social life; (5) Professional support; (6) Family support; (7) Interpersonal demands; (8) Financial consequences | | The <u>structural validity</u> of the 30-item scale was established by PCA with oblique (direct Oblimin) rotation. It yielded an eight-component/factor structure accounting for 59% of the variance. Evidence of <u>group discriminant validity</u> was shown by the sensitivity of the CADI scale to differentiate carers' age groups and gender. The overall 'objective burden' score (as measured by CADI total scores) was significantly higher for females than male's $t(187) = -3.40, p < 0.001$. A significant negative Pearson correlation was found with age ($r = -0.25, p < 0.01$) and a positive correlation was found with duration of caring ($r = 0.273, p < 0.001$). | Family support ($\alpha = 0.64$)* Interpersonal demands ($\alpha = 0.71$) Financial consequences ($\alpha = 0.69$)* |
| Losada <i>et al.</i> (2008) ⁵⁴ Spain | ADRD | Revised Familism Scale (R-FS) | Familism Three factors: (1) Familial obligations; (2) Perceived support from the family; (3) Family as referents | 9 items, 5-point Likert scale (ranging from 1=Strongly disagree to 5=Strongly agree) | This study validates the previously developed Familism Scale (FS) in a sample of dementia CGs and confirms its original 3-factor structure. (The <u>factor/component structure of the scale</u> was originally assessed in a <u>non-CG</u> sample of 679 adults (452 Hispanics and 227 non-Hispanics) using a PCA. The current study used CFA techniques to examine the underlying dimensionality (<u>structural validity</u>) of the previous 14-item FS scale. After deleting five items due to low loadings, the CFA analysis confirmed the original 3-factor structure. The model fit indexes for the final 9-item Revised FS scale (R-FS) were within recommended thresholds (e.g., $\chi^2 = 40.17, df = 26, p = 0.04$; $\chi^2/df = 1.55$; GFI = 0.94; CFI = 0.96; and RMSEA = 0.06). No further validity estimates for the R-FS scale were provided. | Cronbach's α , full scale = 0.75. <u>Cronbach's α by subscales</u> : Familial obligations ($\alpha = 0.59$) Support from the family ($\alpha = 0.75$) Family as referents ($\alpha = 0.75$) |
| Cooper <i>et al.</i> (2008) ⁵⁵ United Kingdom | ADRD | The Brief-Coping Orientation to Problems Experienced (Brief-COPE) | Coping strategies Fourteen domains/subscales organized by three "composite subscales": <u>A. Problem-focused</u> (1) Active coping; (2) Use of informational support; (3) Positive reframing (4) Planning <u>B. Emotion-focused</u> (5) Emotional support; (6) Venting; (7) Humor; (8) Acceptance; (9) Religion; (10) Self-blame <u>C. Dysfunctional coping</u> (11) Self-distraction; (12) Denial; (13) Substance abuse; (14) Behavioral disengagement | 28 items, (2 items per subscale) 4-point Likert scale (1=Not doing it at all, 2=A little bit, 3=A medium amount, 4=Doing it a lot) | The original 60-item COPE scale was developed by Carver <i>et al.</i> (1989) ⁵⁶ and later simplified to a 28-item Brief COPE scale by Carver (1997) ⁵⁷ . However, the scales were validated in non-CG samples (undergraduate students and other adults). The current study validates and further simplified the Brief COPE scale with a sample of dementia CGs. No study of the underlying factorial structure of the scale is conducted to establish structural validity. <u>Concurrent validity</u> was established by calculating Pearson's correlations between the Brief COPE composite scores and existing measures of a) patient functional impairment (assessed by the AD Co-Operative Study Inventory-Activities of Daily Living-ADL), b) relationship quality (number of confidants), and c) subjective attachment style (secure, avoidant, and anxious/ambivalent) measured by the "Attachment questionnaire". As predicted, scores on the Brief-COPE Dysfunctional composite subscale were significantly associated with avoidant attachment ($r = 0.40, p < 0.001$). The Brief-COPE Emotion-focused composite scores correlated with number of confidants ($r = 0.29, p < 0.001$). Finally, the COPE Problem-focused composite scores correlated with ADL scores ($r = -0.22, p < 0.05$). <u>Note</u> : The Psychometric properties of the Brief-COPE scale are studied both using total scores on the three separate composite subscales and using total scores on the Brief-COPE scale. | Cronbach's α by "composite" subscale: Emotion-focused ($\alpha = 0.72$) Problem-focused ($\alpha = 0.84$) Dysfunctional ($\alpha = 0.75$) <u>Test-retest reliability</u> was established by calculating Pearson's correlations between <u>total</u> Brief COPE scores at one-year after ($r = 0.67$) and two-years after ($r = 0.54$) the first administration. In CGs whose ZBI scores remained "stable" between baseline and two-years after (change within 1 SD), <u>total</u> baseline COPE scores were associated with total scores at one and two-years after ($r = 0.72, 0.57$). Test-retest reliability over a year was also demonstrated for emotion-focused ($r = 0.51$), problem-focused ($r = 0.71$), and dysfunctional ($r = 0.64$) subscales.) |
| Montorio <i>et al.</i> (2009) ⁶⁸ Spain | ADRD | Dysfunctional Thoughts about Caregiving Questionnaire (DTCQ) | Dysfunctional thoughts about caregiving Two factors: (1) Perception of sole responsibility; (2) Perfectionism | 16-item, 5 point Likert scale (ranging from 0=Totally disagree to 4=Totally agree) | The Dysfunctional Thoughts about Caregiving Questionnaire (DTCQ) was originally developed by Losada (2005) ⁶⁹ to assess specific dysfunctional thoughts and provide a single summary score indicating a "maladaptive approach" to caregiving. The present study examined the psychometric properties of the scale in a sample of dementia CGs. The <u>structural validity</u> of the 16-item DTCQ was established by PCA with oblique rotation that produced a two component/factor solution accounting for 47.7% of the variance in items. (The two factors/components labeled: Perception of sole responsibility and Perfectionism, explained 39.3% and 8.6% of the variance, respectively.) <u>Concurrent validity</u> was demonstrated by a significant positive Pearson's correlation between total DTCQ scores and scores in the Dysfunctional Attitudes Scale ($r = 0.58, p < 0.001$). DTCQ scores also were, as expected, significantly and negatively correlated with a) social support, measured by the Psychosocial Support Questionnaire ($r = -0.21, p < 0.01$), b) the "amount of help received" question from socio-demographic variables ($r = -0.25, p < 0.001$), and c) seeking emotional support ($r = -0.23, p < 0.001$) and seeking instrumental support ($r = -0.26, p < 0.001$) both measured by items from the Coping Orientation to Problems Experienced (COPE) scale. The <u>discriminant validity</u> of the DTCQ was analyzed by computing a correlation between total scores on DTCQ and the Frequency of Behavioral Problems subscale from the RMBPC. As expected, the correlation was not significant ($r = -0.08, p = 0.23$). | Cronbach's α , full scale = 0.89. <u>Test-retest reliability</u> for a subsample (N=31) at an interval of four weeks between tests was calculated using a Pearson's correlation ($r = 0.60, p < 0.01$). |
| Losada <i>et al.</i> (2010) ⁷⁴ Spain | ADRD | Caregiver Guilt Questionnaire (CGQ) | Guilt Five factors: (1) Guilt about doing wrong by the care recipient; (2) Guilt about not rising to the | 22 item, 5-point Likert scale (0=Never, 1=Rarely, 2=Sometimes, 3=Several times, 4=Always or | <u>Content validity</u> was established by a literature review on guilt-related constructs and expert panel review of items resulting in an initial pool of 34 items. The structural validity was established by PCA using Varimax rotation that yielded a five-factor/component solution in a final 22-item tool that explained 59.25% of the total variability present in the total data set. | Cronbach's α , full scale = 0.88. <u>Cronbach's α by subscales</u> : Guilt about doing wrong by the care recipient ($\alpha = 0.89$) Guilt about not rising to the occasion |

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| | | | occasion as CGs; (3) Guilt about self-care; (4) Guilt about neglecting other relatives; (5) Guilt about having negative feelings towards other people | almost always) | Concurrent validity was demonstrated by significant positive correlations (p -values <0.01) between CGQ scores and a) guilt (r =0.46), measured by the ZBI Guilt factor, b) depression (r =0.46), measured by the CES-D, c) anxiety (r =0.46) measured by the Profile of Mood States Tension-Anxiety subscale, and d) both behavioral problem appraisal (r =0.51) and frequency (r =0.42) measured by the Revised Memory and Behavior Problems Checklist. In addition, there was a significant negative correlation (p <0.01) between CGQ scores and social support (r =-0.19, p <0.01), as measured by the Psychosocial Support Questionnaire. | as CGs (α =0.76) Guilt about self-care (α =0.69) Guilt about neglecting other relatives (α =0.86) Guilt about having negative feelings towards other people (α =0.61) |
| Wimo <i>et al.</i> (2010) ⁷⁵ Sweden | ADRD | Resource Utilization in Dementia (RUD) | Informal caregiving time Three domains: (1) Basic Activities of Daily Living (ADL; e.g., eating, dressing, bathing) (2) Instrumental Activities of Daily Living (IADL; e.g., cooking, cleaning, budgeting) (3) Supervision/Surveillance (e.g., preventing dangerous episodes and managing behavioral problems) | 3 "items" or domains, <u>Note</u> : Scoring in RUD consists of CG recollections of time (e.g., minutes) spent on activities in each the 3 "items" or domains: ADL, IADL, and Supervision. | The <u>content validity</u> of RUD has been previously established in an institutional care setting. ⁷⁶ The current study validates the accuracy of the caregiver time estimates provided with the RUD and tests its validity and reliability in a community care setting with dementia caregivers. <u>Concurrent validity</u> was shown by expected significant (p -values < 0.001) positive Pearson's correlations between CG estimates (recall) of time spent on caregiving activities (i.e., RUD scores) and <i>the time observed by a nurse</i> . Correlations between recalled and observed times were reported for the total scale (r =0.69) and each subscale: ADL (r =0.81), IADL (r =0.68), and Supervision (r =0.67). <u>Note</u> : Time spent caregiving was recorded in three ways: diary, observation, and recall. The CG recorded activities and their duration (in minutes) in a 24-hour diary period. CG recollections of activities and their duration were estimated after each diary period. <i>Nurse observations</i> were made in four-hour sessions. CG recollections of activities and their duration (recall using RUD) were estimated after each observation session. | <u>Inter-rater reliability</u> was calculated with the ICC for all recalled times (i.e., the full RUD) compared to diary was ICC=0.91 and compared to observation was ICC=0.80. <u>Inter-rater reliability by subscales</u> : ADL: Recalled versus diary (ICC=0.93) and versus observation (ICC=0.81) IADL: Recalled versus diary (ICC=0.85) and versus observation (ICC=0.74) Supervision: Recalled versus diary (ICC=0.87) and versus observation (ICC=0.78) |
| Yap <i>et al.</i> (2010) ⁷⁷ Singapore | ADRD | Gain in Alzheimer Care INstrument (GAIN) | Positive outcomes from caregiving; One factor: Gain, personal growth | 10 items, 5-point Likert scale (ranging from 0=Disagree a lot to 4=Agree a lot) | <u>Content validity</u> established by deriving items and themes from a qualitative study of CGs and from focus groups of CGs confirming the preliminary pool of identified items. The <u>structural validity</u> was assessed by a PCA that yielded one component accounting for 52.8% of the total variability present within the original dataset. <u>Concurrent validity</u> was demonstrated by significant positive correlations between the GAIN scale scores and a) Positive Aspects of Caregiving (r =0.68, p <0.001) and b) both active/engaged management (r =0.42, p <0.001) and encouragement (r =0.35, p <0.001) subscales of the Dementia Management Strategies Scale (DMSS). GAIN scores were significantly and negatively correlated with scores on the criticism subscale (r =-0.14, p <0.05) of the DMSS and the ZBI scores (r =-0.15, p <0.05). | <u>Cronbach's α, full scale</u> =0.89. <u>Test-retest reliability</u> (2-week interval) was assessed with the ICC using a subsample (N=149) of participants. (ICC=0.70) |
| Werner <i>et al.</i> (2011) ⁸⁰ Israel | ADRD | Family Stigma in Alzheimer's Disease Scale (FS-ADS): Scale 1: Family Stigma | CG's stigma Eight factors/components: (1) Esthetics; (2) Shame; (3) Pity; (4) Fear; (5) Concealment from professionals; (6) Concealment from friends; (7) Helping with ADL/IADL; (8) Concealment from family | 18 items, 5-point scale (ranging from 1=Lowest to 5=Highest) | <u>Content validity</u> . Authors report identifying an initial pool of 100 items from the literature and an earlier qualitative study including three dimensions representing/defining the scales (CGs' stigma, lay persons' stigma, and structural stigma). The <u>structural validity</u> of the FS-ADS was established with PCA and Varimax rotations to increase interpretability. Using the same sample of participants (N=185), the PCA analysis was conducted <u>separately</u> (and iteratively) in each of the three scales. For the Caregiver's Stigma scale, the final PCA yielded an 8-factor structure of an 18-item scale that explained 88% of the variance. <u>Concurrent validity</u> was demonstrated by significant positive Pearson's correlations (p -values < 0.05) between the ZBI and the following factors of the Caregiver's stigma scale: a) Esthetics (r =0.27), b) Shame (r =0.41), c) Fear (r =0.31), d) Pity (r =0.18), and e) ADL/IADL (r =0.38). Further evidence was shown by significant positive correlations between the Problematic Behavior Scale and the factors of Esthetics (r =0.30), Share (r =0.24), and ADL/IADL (r =0.27). | <u>Cronbach's α by subscales</u> : Esthetics (α =0.97) Shame (α =0.97) Pity (α =0.80) Fear (α =0.95) Concealment from professional (α =0.81) Concealment from friends (α =0.66) Helping with ADL/IADL (α =0.70) Concealment from family (α =0.41) |
| | | Family Stigma in Alzheimer's Disease Scale (FS-ADS): Scale 2: Lay persons stigma | Lay persons stigma Nine factors/components: (1) Esthetics; (2) Cognitive functioning; (3) Distancing; (4) Willingness to help; (5) Pity/uneasiness; (6) Physical functioning; (7) Fear; (8) Shame; (9) Disgust | 28 items, 5-point scale (ranging from 1=Lowest to 5=Highest) | <u>Structural validity</u> . A PCA approach yielded a 9-component/factor solution of the 28-item scale that explained 88% of the variance. <u>Concurrent validity</u> was demonstrated by significant positive Pearson's correlations coefficients between the ZBI and the following factors of the Lay person stigma scale a) Cognitive functioning (r =0.16, p <0.05), b) Physical functioning (r =0.19, p <0.05), c) Esthetics (r =0.25, p <0.01), d) Fear (r =0.25, p <0.01), e) Disgust (r =0.27, p <0.001), and f) Distancing (r =0.31, p <0.001). Further evidence was shown by the significant positive correlations between the Problematic Behavior Scale and a) Cognitive functioning (r =0.15, p <0.05), b) Physical functioning (r =0.35, p <0.001), c) Esthetics (r =0.30, p <0.001), d) Fear (r =0.15, p <0.05), e) Disgust (r =0.19, p <0.01), and f) Distancing (r =0.28, p <0.001). | <u>Cronbach's α by subscales</u> : Cognitive functioning (α =0.98); Disgust (α =0.95); Distancing (α =0.98); Esthetics (α =0.99); Fear (α =0.93); Physical functioning α =0.88); Pity/Uneasiness (α =0.81); Shame (α =0.97); Willingness to help (α =0.98) |
| | | Family Stigma in Alzheimer's Disease Scale (FS-ADS): Scale 3: Structural stigma | Structural stigma Two factors/components: (1) Structural stigma; (2) Professionals' relationship | 16 items 5-point scale (ranging from 1=Lowest to 5=Highest) | <u>Structural validity</u> . A PCA approach to factor extraction yielded a 2-factor/component solution of a 16-item scale that explained 72% of the variance. <u>Concurrent validity</u> was demonstrated by significant Pearson's correlation coefficients between the ZBI and the Structural stigma (r =-0.33, p <0.001) and Professionals' relationship (r =0.22, p <0.002) factors. Significant Pearson's correlations were also obtained between the Problematic Behavior Scale and a) Structural stigma factor (r =-0.25, p <0.001) and b) Professionals' relationship factor (r =0.24, p <0.001). | <u>Cronbach's α by subscales</u> : Structural stigma (α =0.96) Professionals' relationship (α =0.88) |

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| | | Caregiver-Perceived Burden Questionnaire (CPBQ): Scale 2: Caregivers' Assessment of Themselves (CAT) | Caregivers' Assessment of Themselves (CAT) (Caregiver-perceived burden in relation to the patient's engagement) Two "factors" from the EFA analysis (not labeled) (Rasch analysis suggested a unidimensional (one-factor) construct.) | 10 items, Likert scale (cut-points or thresholds not provided) | The <u>structural validity</u> for CAT was established by EFA with on a split-half sample yielding a 2-factor structure. After deleting items with low loadings, 10-items were retained for CAT. A CFA was conducted on the second split-half sample. The model produced a satisfactory fit (e.g., CFI=0.918, RMSEA=0.084, and SRMR=0.056) yet again "items were judged by the experts as the most plausible and meaningful". Also, the Rasch analysis of the 10-item CAT scale showed good overall fit suggesting a single (unidimensional) construct. <u>Concurrent validity</u> was demonstrated by significant Spearman's rank correlations ($p<0.001$) between the CAT and the NPI ($\rho=0.35$), the Severe Impairment Battery ($\rho=-0.19$), the Alzheimer's Disease Cooperative Study-ADL Scale ($\rho=-0.24$), the Clinician's Interview-Based Impression of Change-Plus Caregiver Input ($\rho=0.23$), and the Functional Assessment Staging Tool ($\rho=0.14$). | Cronbach's α , full scale =0.83. <u>Test-retest reliability</u> after a 4-week interval was calculated with the ICC=0.58. <u>PSI</u> (internal consistency under the Rasch model) estimate for the full scale=0.83.) |
| Quirk <i>et al.</i> (2012) ⁸² | Mixed | The Carer Well-being and Support (CWS) questionnaire | Quality of life/sense of meaning Two Factors: (1) Wellbeing; (2) Social support | 49 items, 4-point scale (0=Very dissatisfied, 1=Somewhat dissatisfied, 2=Somewhat satisfied, 3=Very satisfied) or 5-point scale (0=Poor, 1=Fair, 2=Good, 3=Very good, 4=Excellent) | <u>Content validity</u> was demonstrated by conducting workshops with carers for people with psychosis (N=5), common mental health problems (N=10) and dementia (N=8) and collecting feedback on how to improve a preliminary bank of items. As a result, a 74-item CWS measure was developed. After a "preliminary" pilot field test with a sample of 210 participants and an EFA, the CWS measure was further reduced to 49 items. The CWS was field tested using an independent sample of 361 carers. The <u>structural validity</u> was established through an EFA of the 49-item scale that produced a 2-factor structure (a 32-item well-being and a 17-item social support) accounting for 50.8% of the variance. <u>Concurrent validity</u> . The wellbeing subscale showed a "large" Pearson's correlation with the General health questionnaire, GHQ-12 ($r=-0.66$, $p < 0.001$) and the Involvement evaluation questionnaire, IEQ-EU ($r=-0.70$, $p < 0.001$). Discriminant validity. Wellbeing and support subscales were, as expected, uncorrelated with the age of the carer ($r=0.14$, ns). | Cronbach's α by subscales: Wellbeing ($\alpha=0.96$) Social support ($\alpha=0.97$) <u>Test-retest reliability</u> (2-week interval) was calculated with the ICC using a subsample (N=92). ICC by subscales: Wellbeing (ICC=0.92) Social support (ICC=0.88) |
| Riley <i>et al.</i> (2013) ⁸³ | ADRD | Birmingham Relationship Continuity Measure (BRCM) | Relationship continuity One factor: (Items cover the following domains: Relationship redefinition, Same/different person, Same/different feelings, Couplehood, loss of relationship) | 23 items, 5-point Likert scale (1=Disagree a lot, 2=Disagree a little, 3=Neither, 4=Agree a little, 5=Agree a lot) | <u>Content validity</u> was established by qualitative research on relationship continuity leading to a 42-item measure pilot tested on a sample of 51 spousal CGs. The <u>structural validity</u> of the BRCM was established through an EFA with PAF for factor extraction and Oblimin rotation producing a single-factor structure accounting for 46% of the variance in scores. A scree plot confirmed a one-factor structure. <u>Concurrent validity</u> was demonstrated by a significant positive Pearson's correlation coefficient between BRCM scores and the Closeness and Conflict Scale ($r=0.411$, $p=0.002$) and a significant negative correlation with the Heartfelt Sadness and Longing subscale of the Marwit-Meuser Caregiver Grief Inventory ($r=-0.641$, $p<0.001$). | Cronbach's α , full scale =0.947. <u>Test-retest reliability</u> was calculated (at one to three-week interval) using the ICC in a subsample (N=34) of participants (ICC=0.932). |
| Tebb <i>et al.</i> (2013) ⁸⁵ | Mixed | The Caregiver Well-Being Scale: Short Form Rapid Assessment: Basic Needs Scale | Basic Needs Three factors: (1) Emotional Needs; (2) Physical Needs (3) Self-Security | 8 items, 5-point Likert scale (from 1=Rarely to 5=Usually) | <u>Content validity</u> was established by a review of the initial 43-item pool of the Caregiver Well-Being Scale (CWBS) by an expert panel (5 psychometricians and 1 social worker) and a lay panel (10 family CGs of people with Alzheimer's disease). As a result of the review, the original 43-item scale was further reduced to a 16-item scale. The current study reports on the validation of two subscales identified in the original CWBS measure using a mixed sample that included dementia CGs. The <u>structural validity</u> by subscale was estimated with a CFA. Using the same sample of CGs (N=486), the two subscales ("Basic Needs" and "Activities of Living") from the full 16-item Caregiver Well-Being Scale (CWBS) were analyzed using two separate CFAs to test whether each subscale was conceptually distinct and psychometrically valid as a stand-alone scale, and whether it reliably measured the specific construct it was intended to capture within the larger CWBS scale. For the Basic Needs scale, the model fit the data well (e.g., RMSEA=0.05; CFI=0.97, and TLI=0.95). | Cronbach's α estimate for the Basic Needs scale=0.73. <u>Note</u> : Cronbach's α estimate for the full CWBS scale=0.83. |
| | | Activities of Daily Living Scale | ADLs Three factors: (1) Self-Care; (2) Connectedness; (3) Time for Self | 8 items, 5-point Likert scale (from 1=Rarely to 5=Usually) | <u>Structural validity</u> . For the Activities of Daily Living scale, the CFA analysis revealed that the hypothesized model fit the data. Fit indexes were acceptable (e.g., RMSEA=0.07, CFI=0.95, and TLI=0.92). | Cronbach's α estimate for the Activities of Daily Living scale=0.74. <u>Note</u> : Cronbach's α estimate for the full CWBS scale=0.83. |
| Orgeta <i>et al.</i> (2013) ⁸⁸ | ADRD | Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) | Mental wellbeing One factor: (Items cover the following domains: affective-emotional aspects, cognitive-evaluative dimensions, and psychological functioning.) | 14 items, 5-point Likert-type scale (1=None of the time to 5=All of the time) | The <u>structural validity</u> was shown by a PCA that yielded a single-factor structure explaining 57% of the variance. <u>Concurrent validity</u> was established by significant negative correlations between WEMWBS scores and (a) anxiety ($r=-0.053$, $p<0.001$) and depression ($r=-0.50$, $p<0.001$) measured by the HADS (b) dysfunctional coping strategies ($r=-0.51$, $p<0.001$) measured by the Coping Orientations to Problems Experienced Scale, and (c) stress ($r=-0.63$, $p<0.001$) measured by the Relative's Stress Scale. Further proof of concurrent validity was provided by significant positive correlations with physical health ($r=0.63$, $p<0.001$), measured by the EuroQoL-Visual Analogue Scale, and social support ($r=0.39$, $p<0.01$), measured by the Multidimensional Scale of Perceived Social Support. | Cronbach's α , full scale =0.83. |
| Crellin <i>et al.</i> | ADRD | Caregiver | CG efficacy for managing | 12-items, | <u>Content validity</u> . Based on a literature review on the link between self-efficacy and experiences of CGs | Cronbach's α , full scale =0.79. |

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| (2014) ⁹⁰ United Kingdom | | Efficacy Scale (CES) | behavioral and psychological symptoms in dementia Three factors/components: (1) Mood and hyperactivity; (2) Psychosis and nighttime disturbance; (3) Euphoria | 4-point Likert scale (ranging from 4=Not at all confident to 1=Very confident) | of individuals with dementia and their ability to cope with behavioral and psychological symptoms of dementia (BPSD), the CES was developed by the addition of a single item to <u>each of the 12</u> domains of BPSD in the Neuropsychiatric Inventory (NPI). ⁹¹ CGs reporting the presence of a behavioral disturbance also reported their <u>self-efficacy</u> in dealing with the problem. The <u>structural validity</u> was established through PCA with Oblimin rotation to improve components interpretability and a scree plot examination to determine the number of components/factors. The PCA yielded a 3-factor/component solution accounting for 49.85% of the variance. <u>Concurrent validity</u> was evaluated using Spearman's rank correlations between the CES scores and the subscales of the Revised Scale for Caregiving Self-Efficacy: "obtaining respite" ($\rho=-0.268, p<0.001$), "responding to disruptive behavior" ($\rho=-0.386, p<0.001$), and "controlling upsetting thoughts" ($\rho=-0.384, p<0.001$). Highly significant correlations were also obtained between CES scores and the NPI subscales. | |
| Gillanders <i>et al.</i> (2014) ⁹³ United Kingdom | ADRD | Cognitive Fusion Questionnaire (CFQ) | Cognitive fusion One factor (Items cover the following domains: Dominance of cognitive events in a person's experience, emotional reactions to thoughts and beliefs, and ability to view cognitive events from a different perspective | 7 items, 7-point Likert scale (1=Never true, 2=Very seldom true, 3=Seldom true, 4=Sometimes true, 5=Frequently true, 6=Almost always true, 7=Always true) | <u>Content validity</u> . Experts from the British Association for Behavioral & Cognitive Psychotherapy acceptance and commitment therapy Special Interest Group were asked to comment on item clarity and rate how well the initial pool of 44 items (developed by the authors) represented cognitive fusion and defusion. The final revised scale had 42 items. <u>Structural validity</u> was first examined through iterative EFA with oblique rotations and Horn's parallel analyses to determine the number of underlying factors using a sample (N=592) of younger adults (not dementia CGs). After removing items with low loadings, only 7 items were retained in a final one-factor scale. Independent CFA models were subsequently estimated using five different samples of CGs. The results for the sample of dementia CGs presented here yielded acceptable goodness-of-fit indexes for the one-factor structure (e.g., RMSEA=0.101; CFI=0.962; and IFI=0.963). A <u>measurement invariance</u> test across the five samples supported metric invariance making it possible to meaningfully compare mean CFQ scores between the five groups of CGs on the underlying construct. <u>Concurrent validity</u> in the sample of dementia CGs: CFQ scores were significantly associated with scores on the CES-D ($r=0.66, p<0.001$) | Cronbach's α , full scale =0.88. |
| Liu <i>et al.</i> (2014) ⁹⁴ Taiwan | ADRD | Finding a Balance Scale (FBS) | Balance between the demands of caregiving and other competing needs One factor (A single factor is assumed; no analyses are conducted to determine the underlying structure of the scale.) | 17 items, Items 1-17 (competing needs) 4-point Likert scale (0=Unable to handle either, 1=Able to handle only one, 2=Able to handle both, but not well, 3=Usually able to handle both well). | <u>Content validity</u> . Evidence of content validity is reported in a previous study while developing the scale for CGs of frail elders. The original scale was reviewed by a clinician, two sociologists, and three nurses who reported acceptable content validity. <u>Structural validity</u> . No formal analysis to assess the underlying structure of the 17 items in the FBS scale is presented with the current sample of dementia CGs. A unidimensional structure seems to be assumed. <u>Concurrent validity</u> was assessed by calculating Pearson's correlation coefficients between FBS total scores and (a) the Role Strain Scale ($r=-0.48, p<0.01$), (b) SF-36-Physical health, SF-36-Physical Component ($r=0.20, p<0.01$), and (c) the SF-36-Mental health ($r=0.44, p<0.01$). <u>Discriminant validity</u> was supported by the expected absence of a significant correlation between FBS total scores and total scores on the Mutuality Scale ($r=0.04, p=.61$). (The Mutuality scale measures the quality of the CG-care receiver relationship.) Group discriminant validity was shown by comparing a "well-balanced group" (FBS scores >2) with a "poor balance group" (FBS ≤2) on role strain and mental health scores. As expected, an independent samples t-test showed that the well-balanced group had significantly lower Role Strain ($t=-5.72, p<0.01$) and better SF-36-Mental health ($t=7.07, p<0.01$) than those in the poorly balanced group. | Cronbach's α , full scale =0.92. |
| Losada <i>et al.</i> (2014) ⁹⁵ Spain | ADRD | Experiential Avoidance in Caregiving Questionnaire (EACQ) | Experiential avoidance Three factors: (1) Active avoidant behaviors; (2) Intolerance of negative thoughts/emotions toward care recipient; (3) Apprehension concerning negative internal experiences related to caregiving | 15 items, 5-point Likert scale (1=Not at all, 2= A little, 3=Somewhat, 4=Often 5=A lot) | <u>Content validity</u> . Based on a literature review and a previously developed scale measuring experiential avoidance, a pool of 15 items was developed and tested in a sample of 44 dementia CGs. As a result, changes were made to both item content and response options. <u>Structural validity</u> was established via PCA with Oblimin rotation and a scree plot to determine the optimal number of components. The PCA yielded a 3-factor solution explaining 44.5% of the total variance. <u>Concurrent validity</u> was assessed through Pearson's correlations between the total EACQ scores and (a) the Acceptance and the Action Questionnaire (AAQ) ($r=0.14, p<0.05$) (b) the dysfunctional thoughts about caregiving questionnaire (DTCQ) ($r=0.22, p<0.01$) and (c) the POMS-Tension-Anxiety subscale ($r=0.14, p<0.01$) <u>Discriminant validity</u> of the EACQ subscales is shown by fitting a series of a hierarchical regression models entering the factors one at a time and determining whether there was a significant incremental change in percentage of explained variance indicating a unique/distinct factor-specific contribution to the scale. A significant incremental change in percentage of explained variance was found for each of the EACQ factors, indicating an estimate of the unique, construct-specific contribution of each factor. | Cronbach's α , full scale =0.70. Cronbach's α by subscales: Active avoidant behaviors ($\alpha=0.63$)* Intolerance of negative thoughts/emotions toward care recipient ($\alpha=0.71$) Apprehension concerning negative experiences ($\alpha=0.60$). |

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| Toye et al. (2014) ⁹⁷ Australia | Mixed | Dementia Knowledge Assessment Tool (DKAT2) | Dementia knowledge Two domains: (1) Knowledge of dementia and its progress; (2) Knowledge of dementia support and care (No factors are derived; the items are organized by the two domains above) | 21 items, Binary response options: Yes/No (with a "Don't Know" option) | Content validity was established by four experts with experience in supporting families of people with dementia and prior research in dementia and tool development. The panel examined items for clarity and consistency. After the review, the original pool of 25 items was reduced to 21 final items. The 21-item scale was pilot tested and further refined with 30 family carers (daughters, spouses, and other) and trained staff members (nurses and care workers). No further studies on the structural validity were conducted. <u>Note:</u> Although authors acknowledge the need to conduct validity studies with larger samples. They state that the results provide initial support for the tool's "validity" in that the care workers (who had formal education in dementia) obtained marginally higher scores than family CGs. No further studies on validity are provided. | Family CGs: <u>Cronbach's α, full scale</u> = 0.79 Care workers: <u>Cronbach's α, full scale</u> = 0.79 |
| Kraijo et al. (2014) ⁹⁸ The Netherlands | ADRD | The Perseverance Time (PT) | Perceived burden with capacity of CG to cope (The tool consists of a single question/item) <u>Note:</u> The single question states: "If the informal care situation stays as it is now, how long will you be able to cope with the care?" | One question, 6 ordered categories: < than one week; > than one week, but < than one month; > than one month, but < than six months; > six months, but < one year; > one year, but < two years; > two years | <u>Content validity</u> was evaluated by performing binary logistic regression analyses between Perseverance Time (PT) scores (dichotomized at three levels: >6 months: Yes/No; >1 year: Yes/No; and >2 years: Yes/No) and characteristics of dementia patients, informal carers, and care situations. Results showed that different categories of PT were associated with different sets of characteristics. <u>Concurrent validity</u> was assessed by estimating Spearman's rank correlations between PT scores and (a) measures of subjective burden (Caregiver Strain Index [CSI], Self-Rated Burden [SRB], and Care-related Quality of Life [CarerQoL-7 D]) and (b) happiness (CarerQoL-Visual Analogue). The convergent validity of PT was "moderate" with CSI ($\rho=-0.46$, $p < 0.001$) and care-related quality of life ($\rho=0.33$, $p < 0.001$), good with SRB ($\rho=-0.63$, $p < 0.001$), but poor with happiness ($\rho=0.22$, $p < 0.01$). | Not reported <u>Note:</u> Richters et al. (2016) ⁹⁹ reports a study on the test-retest reliability of the Perseverance time instrument. |
| Chang et al. (2016) ¹⁰¹ Taiwan | ADRD | Affiliate Stigma Scale | Self-stigma Three factors (components): (1) Cognitive; (2) Affective; (3) Behavioral (Each factor is tested independently to demonstrate unidimensionality of the separate scales.) (Authors also estimate scores for the full Affiliate Stigma Scale.) | 22 items, 4-point Likert scale (ranging from 1=Strongly disagree to 4=Strongly agree) | <u>Content validity</u> of the 22-item scale is reported in Mak et al. (2008). ¹⁰² The scale was previously tested in a sample of CGs of individuals with mental illness or intellectual disability. The current study validates the scale in dementia CGs. <u>Structural validity.</u> PCA revealed a 3-factor structure of the 22-item Affiliate Stigma Scale. The PCA showed that the first component's eigenvalue for the entire Affiliate Stigma Scale was > 2. Next, the PCA was conducted <i>separately</i> for each subset of items defining the 3 domains (cognitive, affective and behavioral) measured by the full scale. Since each separate domain produced eigenvalues <2, the three scales were each considered "unidimensional." Therefore, instead of conducting a CFA using the full 22-item scale, the authors conducted three separate CFAs followed by Rasch models to establish the psychometric properties for each scale: Cognitive, Affective, and Behavioral. All fit indices produced by the CFA indicated satisfactory fit: CFI and TLI were > 0.95, and RMSEA <0.06. Finally, Rasch models confirmed the unidimensionality of the three scales, suggesting <u>their use as separate scales</u> . Most Infit and Outfit statistics obtained through the Rasch model were within the acceptable ranges. <u>Concurrent validity</u> was demonstrated through significant (p -values < 0.05) positive Pearson's correlations between both the <u>total Affiliate Stigma Scale scores</u> (including each domain score and the entire scale score) with criterion measures such as the Caregiver Burden Inventory ($r=0.290$ to $r=0.628$), the Taiwanese Depression Questionnaire ($r=0.391$ to $r=0.612$), and the Beck Anxiety Inventory ($r=0.367$ to $r=0.467$). Concurrent validity was also shown via expected negative correlations with the World Health Organization Quality of Life questionnaire ($r=-0.59$ to -0.365). | <u>Cronbach's α, full scale</u> =0.93. <u>Note:</u> Using the same sample, authors conduct <u>three separate</u> CFAs for the cluster of items defining the following domains: (1) Cognitive (Cronbach's $\alpha=0.855$) (2) Affective (Cronbach's $\alpha=0.849$) (3) Behavioral (Cronbach's $\alpha=0.822$) |
| Kiriake & Moriyama (2016) ¹⁰⁷ Japan | ADRD | The Partnership Scale (PS) | Ability of family CGs to build partnerships inside and outside of the family while providing care for a family member with dementia. Three factors: (1) Ability for Receptive Coping; (2) Proactive Consultation and Information-Seeking; (3) Trust Formation and Role Coordination | 13 items, 5-point Likert scale (ranging from 0=Not at all to 4=Extremely so) | <u>Content validity</u> was established through cognitive interviewing with five family CGs who provided information on the ability of the CG to build collaborative relationships with the patients and with others involved in providing care. Interview results and further literature review were used to create an initial 39-item pool. Next, a team of nine dementia care experts ranked the appropriateness of each item using a 4-point Likert scale from 1 (not appropriate) to 4 (concise and appropriate). The item-content validity index ranged from 78 to 100%. All items were deemed appropriate. <u>Structural validity.</u> To analyze the underlying structure and dimensions of the scale, the sample was randomly split into two groups. The first group (N=130) was used to conduct an EFA using PAF for factor extraction and Varimax rotation, followed by a Horn parallel test to examine the number of factors to retain. After eliminating items with low factor loadings, the scale was reduced from 39 to 14 items. Alternative CFAs with MLE were conducted in the second group ($n = 131$) for cross-validation purposes. The best fitting model retained 13 items confirming a 3-factor structure. Goodness-of-fit indices for the final CFA model were acceptable (e.g., RMSEA=0.033; CFI=0.977; and TLI =0.971). <u>Concurrent validity.</u> The total score of the PS was confirmed to have a positive Spearman's rank correlation with the Scale of Social Support score ($r=0.488$, $p < 0.01$), a negative correlation with the ZBI score ($\rho=-0.334$, $p < 0.01$), and a positive correlation with the Caregiver Positive Appraisal score ($\rho=0.370$, $p < 0.01$). | <u>Cronbach's α, full scale</u> =0.78 <u>Cronbach's α by subscales:</u> Ability for Receptive Coping ($\alpha=0.84$) Proactive Consultation and Information-Seeking ($\alpha=0.71$) Trust Formation and Role Coordination ($\alpha=0.67$) <u>Test-retest reliability</u> (stability) (one week interval) was assessed with N=50 participants calculating the ICC. ICC for the full scale=0.80. ICC by subscales: Ability for Receptive Coping (ICC=0.83); Proactive Consultation / Information-Seeking (ICC=0.61); Trust Formation and Role Coordination (ICC=0.68). |
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| Maneewat et al. (2016) ¹⁰⁸ | ADRD | Caregiver Resilience Scale (CRS) | Resilience Six factors: (1) Physical competence; (2) Relationship competence; (3) Emotional competence; (4) Moral competence; (5) Cognitive competence; (6) Spiritual competence | 30 items, 4-point Likert scale (ranging from 0=Not true to 3=Mostly true) | Content identification began with a literature review of the concept of resilience and interviews with ten CGs of older persons with dementia. <u>Content validity</u> was established by a three-person expert panel review of an initial 36-item pool on relevancy and clarity. Six item were considered redundant and were omitted resulting in a final 30-item scale. The CVI of the final scale was 0.84. The <u>structural validity</u> or underlying factorial structure of the CRS scale was established via PCA with a Varimax rotation to maximize the variance of squared factor loadings and increase factor structure interpretability. The PCA produced a 6-component/factor solution explaining 63.67% of the variance of the items in the scale. | Cronbach's α , full scale = 0.87. <u>Cronbach's α by subscales</u> : ranged from 0.52 to 0.87. |
| Sullivan et al. (2016) ¹⁰⁹ | ADRD | The Thoughts Questionnaire (TQ) | Dysfunctional thoughts Seven "themes" represented in the measure: (1) Perfectionism; (2) Overinvestment and embarrassment; (3) Personal vulnerability and fatality; (4) Interpretation of behavior; (5) Self-neglect; (6) Sole responsibility; (7) Perceived social support | 25 items, 5-point Likert scale (0=Totally disagree, 1=Disagree, 2=Neither agree nor disagree, 3=Agree, 4= Totally agree) | <u>Content validity</u> was determined by an expert panel of project team members and both professional and nonprofessional family CGs who reviewed and evaluated an initial 55-item bank for face validity, usability, theoretical coverage, and overall perceived utility. A final 25-item scale was also assessed for item readability level using the Flesch Kincaid grade level score. <u>Concurrent validity</u> was established with Pearson's correlations between the TQ scale and: The Dysfunctional Thoughts about Caregiving Questionnaire (DTCQ); the geriatric depression (GDS); and Pearling's Stress and Coping (PSC) scales. TQ scores were not significantly associated with GDS ($r=0.319$, $p=0.183$) or DTCQ scores ($r=0.29$, $p=0.10$). However, as expected, TQ was significantly associated with all stress risk factors from Pearling's scales except for "conflict over attitudes toward the person with dementia." (Pearson's correlation estimates ranged from $r=0.359$ to $r=0.620$, $p < 0.05$). The expectation that the TQ would be negatively associated with a measure of coping was not supported. | Cronbach's α , full scale =0.85 |
| Romero-Moreno et al. (2017) ¹¹³ | ADRD | Valued Living Questionnaire Adapted to Caregiving (VLQAC) | Personal values in the CG stress process Two factors: (1) Commitment to own values; (2) Commitment to family values | 12 items, 10-point Likert scale (ranging from 1=Not at all important to 10=Extremely important) | <u>Content validity</u> was established in the original version of the scale developed by Wilson et al., 2010. ¹¹⁴ Authors added <u>two</u> caregiving-related items and validated the expanded scale in a sample of ADRD CGs. <u>Structural validity</u> was evaluated through EFA applying Oblimin rotation and followed by a Horn's parallel analysis to determine the optimal number of underlying factors. EFA identified two factors explaining 43.42% of variance between scale items. <u>Concurrent validity</u> . Pearson's correlation coefficients were used to study associations between scale factors (subscales) and criterion measures. Higher scores in "Commitment to Own Values" and "Commitment to Family Values" factors were significantly associated with lower scores in depression (measured by CES-D) ($r=-0.31$, $p < 0.01$; $r=-0.18$, $p < 0.01$, respectively) and anxiety, measured by POMS ($r=-0.27$, $p < 0.01$; $r=-0.31$, $p < 0.01$, respectively), as well as with a higher score in the Satisfaction with life scale ($r=0.35$, $p < 0.01$; $r=0.40$, $p < 0.01$, respectively). In addition, higher scores in the "Commitment to Own Values" factor were associated with higher scores in emotional acceptance, measured by the "Difficulties in Emotion Regulation Scale" ($r=0.14$, $p < 0.05$). | Cronbach's α , full scale =0.75. <u>Cronbach's α by subscales</u> : Commitment to Own Values ($\alpha=0.71$) Commitment to Family Values ($\alpha=0.61$) |
| Stott et al. (2017) ¹¹⁵ | ADRD | Hospital Anxiety and Depression Scale (HADS) | Anxiety and depression Three factors: (1) Anxiety; (2) Depression; (3) Negative affectivity | 13 items, 4-point Likert scale with several labels per scale: (1) 0=not at all to 3=most of the time (2) 0=hardly at all to 3=as much as I ever did (3) 0=very seldom to 3=often | <u>Content validity</u> . Previously established by Zigmond & Snaith (1983). ¹¹⁶ The current study validates HADS in a sample of AD CGs. <u>Structural validity</u> . CFA with robust MLE was used to test the fit of three previously proposed factor structures (one-, two-, and three-factors) using HADS data from the sample of dementia CGs. After eliminating one item and re-fitting the model, a 3-factor structure produced acceptable goodness-of-fit indexes (e.g., RMSEA=0.06; GFI=0.96; and TLI =0.95). Cross-validation in an independent sample confirmed initial results. <u>Concurrent validity</u> was examined using bivariate correlations between the Positive and Negative Affect Schedule (PANAS) and HADS subscales. Correlations were large, significant (p -values < 0.001), and in the expected direction ranging from -0.65 to -0.37 between scores on all HADS scales and those on PANAS-PA and from 0.57 to 0.69 for those in PANAS-NA. <u>Measurement invariance</u> tests across subgroups revealed possible systematic response bias between older (≥ 65) and younger (< 65) adults that may render latent variable mean group comparisons uninterpretable due to measurement bias rather than true group differences. | Cronbach's α estimates by subscales (factors): Anxiety ($\alpha=0.87$) Depression ($\alpha=0.85$) Negative affectivity ($\alpha=0.77$) |
| Losada et al. (2017) ¹¹⁷ | ADRD | The Caregiving Ambivalence Scale (CAS) | Ambivalence attitudes or feelings (The scale measures the degree in which CGs' attitudes and feelings toward their relatives afflicted with dementia are mixed or conflicted.) One factor: (1) Ambivalence | 6 items, 4-point Likert scale (0=Never, 1=Sometimes, 2=Frequently, 3=Always) | Although <u>content validity</u> is not formally addressed in the study, authors conduct a literature review and present research linking the caregiving experience to heightened ambivalence and conflicting emotions as a rationale for developing a caregiving ambivalence measure. Drawing upon a previous scale ¹¹⁸ and clinical experience, authors developed 6 items measuring ambivalent feelings in dementia CGs associated with caregiving. <u>Structural validity</u> . To analyze the underlying structure of the scale, the sample was randomly split into two groups. The first group (N=200) was used to conduct an EFA using MLE for factor extraction, followed by a Horn's parallel analysis to determine dimensionality. A CFA was conducted in the second group (N = 201) confirming a unidimensional scale structure. Goodness-of-fit indices for the CFA model were acceptable (e.g., RMSEA=0.058; GFI=0.91; and TLI =0.987). <u>Concurrent validity</u> was demonstrated by high Pearson's correlations between CAS scores and measures | Cronbach's α , full scale =0.86. |

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| | | | | | of disruptive behavior using the RMBPC ($r=0.42$, $p<0.01$); depression using the CES-D ($r=0.32$, $p<0.01$), and anxiety using POMS- tension subscale ($r=0.46$, $p<0.01$). | |
| Abdollahpour et al. (2017) ¹¹⁹ Iran | ADRD | Positive Aspects of Caregiving (PAC) Questionnaire | Gains in positive aspects of caregiving Two factors: (1) Patient and CG relationship; (2) CG's psychological wellbeing | 10 items, 5-point Likert scale (ranging from 0=Strongly disagree to 4=Strongly agree) | Content validity was assessed using a panel of five content experts (four neurologists and one psychologist), five CGs as lay experts, as well as one methodologist for the content validation process. Items were evaluated for relevancy and clarity using "item and scale content validity indexes" (I-CVI and S-CVI, respectively) resulting in acceptable ranges. I-CVI for relevancy and clarity were 0.90 to 1 and 0.80 to 1, respectively. S-CVI for relevancy and clarity indices were 0.97 and 0.93, respectively. The <u>structural validity</u> was evaluated via an EFA with Varimax rotation identifying a two-factor structure that explained 47% of total variance in PAC. <u>Concurrent validity</u> -The Pearson's correlation of <i>Self-reported health</i> (SRH) and PAC scores was examined for establishing "concurrent" validity ($r=0.343$, $p=0.01$). Divergent validity was assessed by correlating PAC scores with a measure of CG burden (<i>The Iranian caregiver questionnaire</i>) ($r=-0.291$, $p=0.001$). Rather than showing lack of association between the two measures, authors contrasted the two measures. | Cronbach's α , full scale =0.79. <u>Cronbach's α by subscales:</u> Patient and CG relationship ($\alpha=0.711$); CG's psychological wellbeing ($\alpha=0.707$) <u>Test-retest reliability</u> (3-week interval) was evaluated with 20 randomly selected CGs calculating the ICC. The ICC for the full scale=0.95. <u>ICC by subscales:</u> Patient and CG relationship (ICC=0.80) and Caregiver's psychological wellbeing (ICC=0.87) |
| Fabà & Villar (2017) ¹²⁰ Spain | ADRD | Gains Associated with Caregiving (GAC) scale | Gains associated with caregiving for a person with dementia One factor: Gains | 22 items, 4-point Likert scale (0=Not at all; 1=Yes, slightly; 2=Yes, quite a lot; 3=Yes, very much so) | Content validity was established by three external expert judges in the field of psychogerontology and developmental psychology. The judges evaluated the semantic definition of the five key domains (Industry, Identity, Intimacy, Generativity, and Ego Integrity) identified by the authors from the literature and included in an initial 62-item GAC scale. Two of the three judges were also asked to indicate the domain to which they considered each item belonged. Judges' agreement was high (Cohen's kappa coefficients ranged from 0.77 to 0.90, $p<0.001$) <u>Structural validity</u> was established by iterative EFA starting with a reduced 32-item scale using an independent sample of 152 participants. After eliminating items with low loadings and item-rest score correlations, the final EFA model produced a unidimensional (one-factor) 22-item scale. A scree plot confirmed the solution. Using the same initial protocol, an independent sample of 260 participants was selected to conduct a CFA on the resulting 22-items confirming a unidimensional GAC scale. With the exception of the SRMR=0.07, goodness-of-fit statistics, however, were below recommended thresholds (e.g., CFI=0.71). <u>Concurrent validity</u> was assessed by calculating Pearson's correlations between GAC scores and the ZBI ($r=-0.229$, $p<0.01$), the Geriatric Depression Scale-Short Form ($r=-0.237$, $p<0.01$), and the Satisfaction With Life Scale, SWLS ($r=0.257$, $p<0.001$). | Cronbach's α , full scale =0.95 |
| Moholt et al. (2018) ¹²³ Norway | ADRD | Carers of Older People in Europe (COPE) Index (Scale validation with family carers of people with dementia-Norway) | Support needs Three factors: (1) Negative impact of caregiving; (2) Quality of support; (3) Positive values of caregiving | 15 items, 4-point Likert scale (ranging from 1=Never to 4=Always) | Content validity was established in the original version of the scale developed by McKee et al., 2003. ¹²⁴ The original version targeted informal caregivers of older adults in general. The current study validates COPE in a sample of dementia caregivers. <u>Structural validity.</u> To analyze the underlying structure and dimensions of the scale items, the sample was randomly split into two groups. The first group (N=215) was used to conduct an EFA using PAF method to extract factors followed by an examination of a scree plot of eigenvalues to examine the number of factors to retain. A CFA with robust MLE was conducted in the second group (N=215) for cross-validation purposes confirming a 3-factor structure. Goodness-of-fit indices for the CFA model were acceptable (e.g., RMSEA=0.050; CFI=0.951; and TLI =0.939). (A second order model also provided a good fit supporting the use of a global COPE Index score.) <u>Concurrent validity.</u> The Pearson's correlation between COPE-Index and the World Health Organization-5 Well-being Index (WHO-5) was=0.62, $p<0.001$; the correlation of COPE-I and demands of caregiving item was=0.49, $p<0.001$. As expected, negative and statistically significant correlations were obtained between Cope-Index scores and a) a general status item ($r=-0.37$, $p<0.001$) and b) scores on a social restriction scale ($r=-0.33$, $p<0.001$). | Cronbach's α estimates per subscale: Negative impact of caregiving ($\alpha=0.86$) Quality of support ($\alpha=0.76$) Positive values of caregiving ($\alpha=0.64$) <u>Test-retest reliability</u> (4-week interval) was examined using Spearman's rank order correlation with a small subsample (N=32). Negative impact of caregiving ($r=0.91$) Quality of support ($r=0.76$) Positive values of caregiving ($r=0.92$) |
| Oliveira & Aubeeluck (2018) ¹²⁵ United Kingdom | ADRD | Dementia Quality of Life Scale for Older Family Carers (DQoL-OC) | Quality-of-life of older family carers One factor: Quality of life | 22 items, 5-point Likert scale (1=Always, 2=Frequently, 3=Occasionally, 4=Rarely, 5=Never) | Content validity and "practicality" were determined by a panel of six experts (four researchers and two older family carers) who assessed the relevance, length, clarity of language, and levels of difficulty of an initial item bank of 89 items that was further reduced to 81 items. The <u>structural validity</u> of the 81-item scale was determined by iterative EFAs using PAF for factor extraction and Promax rotations to account for factor correlations. Each iteration was followed up by a re-evaluation of parallel analyses and scree plots. The final EFA iteration produced a satisfactory 22-item unidimensional scale explaining 43.83% of the total variance. <u>Concurrent validity.</u> The total scores of the DQoL-OC showed significant Pearson correlations (p -values <0.001) with (1) the World Health Organization Quality of Life Scale ($r=0.74$), (2) the Satisfaction with Life Scale ($r=0.65$), (3) the Perceived Health Status Visual Analogue Scale ($r=0.39$), and (4) the Overall Perceived Health-Related Quality of Life Visual Analogue Scale ($r=0.44$). | Cronbach's α , full scale = 0.936. <u>Test-retest reliability</u> (two-week interval) was established through the calculation of the ICC using a small subsample of 18 participants. (ICC=0.835; $p<0.001$). |
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| Stansfeld et al. (2019) ¹²⁷ United Kingdom | ADRD | Sense of Coherence Scale-13 (SOC-13) | Sense of coherence Three factors: (1) Meaningfulness; (2) Comprehensibility; (3) Manageability | 13 items, 7-point Likert-type scales with labels that vary per cluster of items. | The <u>content validity</u> of the scale was established by Antonovki (1993). ¹²⁸ The scale has been used but its psychometric properties have not been established. This study, evaluates the measurement properties of the scale in a sample of dementia CGs. The <u>structural validity</u> of the scale was assessed with a CFA. However, the solution did not confirm the originally proposed 3-factor structure. The proposed model did not produce an adequate fit; with indices falling below or above acceptable thresholds. Factor loadings, however, were significant and ranged from 0.419–2.124. <u>Concurrent validity</u> . SOC-13 scores were a) strongly and positively correlated with scores on the Resilience Scale-14 ($r=0.56$, $p < 0.001$), b) moderately and positively correlated with scores on the 7-item Sense of Competence Scale ($r=0.42$, $p < 0.001$), and d) scores of the Self-efficacy for managing dementia scale ($r=0.46$, $p < 0.001$). SOC-13 was also moderately and negatively correlated with <i>health-related quality of life</i> , measured by the EuroQol 5-Dimension 5-level questionnaire ($r = -0.38$, $p < 0.001$). | Cronbach's α , full scale =0.88. <u>Cronbach's α by subscales</u> : Meaningfulness ($\alpha=0.72$) Comprehensibility ($\alpha=0.76$) Manageability ($\alpha=0.705$) |
| Ying et al. (2019) ¹³⁰ Singapore | ADRD | Center for Epidemiological Studies Depression Scale (CES-D) | Depression in CGs of persons with dementia Four factors: (1) Depressed affect; (2) Somatic symptoms; (3) Positive affect; (4) Interpersonal problems | 20 items, 4-point Likert scale (0=Rarely or none of the time, 1=Some or little of the time, 2=Moderately or much of the time, 3=Most or almost all the time) | The scale's <u>structural validity</u> was assessed with alternative CFA models varying in dimensionality (from a one-factor to the original 4-factor model). The 4-factor model produce the best fit (e.g., RMSEA=0.077; CFI=0.909; and TLI=0.895). (TLI was marginal; values above 0.90 are recommended.) <u>Concurrent validity</u> was evaluated by examining the correlations among the CES-D, the Gain in Alzheimer care instrument (GAIN), the ZBI, and their respective subscales, using the Pearson's correlation coefficient (all p-values < 0.01). CES-D correlated strongly with ZBI scores ($r = 0.71$) and most of the subscales of ZBI ($r=0.60$ to 0.70). Correlations were <i>weaker</i> between total CES-D and the Finances subscale of ZBI ($r = 0.46$) or the Caregiving gains scale (GAIN) ($r = -0.16$). The Positive affect subscale of CES-D was negatively associated with ZBI subscales ($r = -0.18$ to -0.34). | Cronbach's α , full scale =0.92. <u>Cronbach's α by subscales</u> : Depressed affect ($\alpha=0.91$) Somatic symptoms ($\alpha=0.85$) Positive affect ($\alpha=0.74$) Interpersonal problems ($\alpha=0.69$) |
| Barello et al. (2019) ¹³¹ Italy | Mixed | Caregiving Health Engagement Scale (CHE-s) | CG engagement in healthcare One-factor: Engagement in healthcare | 7 items, 4 types of "ordered" narrative/storylines in the process of family CG engagement: 1=denial, 2=hyper-activation, 3=drowning and 4=balance | <u>Content validity</u> . An initial item pool was generated based on literature reviews and interviews with a sample of 22 CGs about feelings and experiences in their caring roles and feeling of engagement. The item pool was reviewed for content and face validity by the project steering committee, and by CGs who participated in the interview, to check the relevance and comprehensiveness of items, response options, and instructions. This resulted in a refined 7-item scale. The <u>structural validity</u> of the CHE scale was evaluated using different approaches. Given the ordinal nature of the 7-item scale, the authors first conducted a CATPCA that yielded a one-dimensional (one-component) structure explaining 67.0% of the total variability. A CFA also yielded a one-factor structure producing adequate GFI's (e.g., CFI=0.96, SRMR=0.03, and RMSEA=0.05). Finally, a Rasch analysis, confirmed the unidimensionality of the scale. All Infit and Outfit statistics were within the acceptable range (0.66 to 1.27). <u>Concurrent validity</u> was established through Pearson's correlations between CHE's factor scores and scores from (a) the Caregiver Burden Inventory; (Pearson's r coefficients ranged from -0.62- -0.40, all p-values < 0.001) and (b) the two subscales of Caregiving Self-Efficacy (SE); SE-Obtaining respite ($r=0.25$, $p < 0.001$) and SE-Responding to Disruptive Patient Behaviors ($r=0.48$, $p < 0.001$). | Ordinal Cronbach's α =0.88 (Using a polychoric correlations matrix) PSI (reliability) produced by the Rasch analysis=0.907 |
| Brown et al. (2019) ¹³² United Kingdom | ADRD | Carer Dementia Quality-of-Life (C-DEMQOL) | Quality-of-Life applicable across the range of caring situations and severity in dementia. Five domains: (1) Carer-patient relationship; (2) Carer wellbeing; (3) Meeting personal needs; (4) Confidence in the future; (5) Feeling supported | 30 items, 5-point Likert scale (ranging from 5=Best to 1=Worst) | <u>Content validity</u> . Qualitative interviews with 32 family carers and 9 support staff, and two focus groups with 6 carers and 5 staff were conducted to generate measurable domains and indicators (items) of dementia carer quality of life. Pilot testing further refined the questionnaire items. The scale's <u>structural validity</u> was assessed by EFA with ordinal variables using a polychoric correlation and oblique rotation. A Horn's parallel analysis confirmed a 5-factor structure underlying the original 40-item pool. Given the high correlation of factors, an exploratory bifactor model was also tested. An independent sample was used to fit a graded response model with an underlying bifactor model to establish the final underlying structure of the scale and its psychometric properties. This resulted in a final 30-item scale with a bifactor structure (one general and five orthogonal specific factors). The fit of the model was within acceptable ranges (e.g., RMSEA=0.066; CFI=0.968; and SRMR = 0.072). <u>Concurrent validity</u> was established via positive, significant (p -values < 0.001) correlations between C-DEMQOL total (overall) scores and similar constructs: e.g., short form health survey, SF 12-mental ($r=0.70$); Personal Wellbeing Scale ($r=0.63$); World Health Organization (WHO) QOL: physical health ($r=0.61$) and psychological ($r=0.63$). <u>Divergent validity</u> was determined via "lower" (although not necessarily insignificant) correlations with conceptually unrelated constructs (e.g., correlations between C-DEMQOL scores and SF-12 physical ($r=0.34$, $p < 0.001$)). The average convergent correlation between C-DEMQOL and carer-focused external scales was 0.58, and the average divergent correlation with unrelated constructs was 0.40. | McDonald's ω , full scale=0.97. <u>McDonald's ω estimates by subscales</u> : Meeting personal needs ($\omega = 0.95$) Carer wellbeing ($\omega = 0.91$) Carer-patient relationship ($\omega = 0.82$) Confidence in the future ($\omega = 0.90$) Feeling supported ($\omega = 0.85$) |
| Cheng et al. (2019) ¹³³ | ADRD | Caregiver Grief Questionnaire (CGQ) | Pre-death grief Two factors: (1) Relational deprivation | 11 items, 5-point scale (ranging from 1=Strongly disagree | The current scale was assembled from existing measures of CG grief: 15 items from the Meuser-Marwit CG Grief Inventory ³⁴ and 3 items from Pearlín's et al. ¹³⁴ measure of "relational deprivation." After a content inspection by the team, 7-items were eliminated and the 11-item scale was validated in a | Cronbach's α , full scale = 0.90 <u>Test-retest reliability</u> (two-week interval) was evaluated with Pearson |

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| China | | | (RD); (2) Emotional pain (EP) | to 5=Strongly agree) | sample of AD CGs. <u>Structural validity.</u> A hypothesized two-factor model was evaluated against the one-factor model using a CFA. A two-factor model (RD & EP) provided a modest fit to the data (e.g., RMSEA=0.14; CFI=0.94; and non-normed fit index, NNFI=0.92). <u>Concurrent validity</u> was shown by significant (p -values < 0.001) positive Pearson's correlations of CGQ scores with ZBI (r =0.47), HAM-D Scale (0.31), and the Neuropsychiatric Symptoms scale (0.26). <u>Discriminant validity.</u> As expected, neither total CGQ scores nor RD or EP subscales were associated with "social network size." | correlation in a sample $N=46$, $r = 0.95$. |
| McCaffrey et al. (2020) ¹³⁵ Australia | Mixed | Carer Experience Scale (CES) | Caregiving experience Six domains: (1) Activities outside caring; (2) Social support (family and friends); (3) Institutional support (public and private organizations); (4) Fulfillment from caring; (5) Control over the caring; (6) Relationship with patient | 6 items, 3-point Likert scale by "amount" (1=A little/few, 2=Some, 3=A lot/most) or by "frequency" (1=Rarely, 2=Sometimes, 3=Mostly) | <u>Content validity.</u> The resulting CES scale was developed in a previous study (Al-Janabi et al, 2008) ¹³⁶ using a meta-ethnography of existing qualitative data to determine key conceptual attributes of caring. Sixteen semi-structured interviews with carers of older people were conducted to refine attributes and develop them into the CES measure. In this study, <u>concurrent validity</u> was established through Spearman rank correlations between CES scores and (a) the Adult Social Care Outcomes Toolkit for Carers (ρ =0.71, $p<0.001$) and (b) the Care-Related Quality of Life (ρ =0.45, $p<0.001$). <u>Group discriminant validity</u> was established by a Kruskal-Wallis one-way analysis of variance. Higher carer-related scores were associated with lower hours of care provided per week for CES (Kruskal-Wallis 53.41, $p < 0.001$). There was a significant difference in mean CES scores between informal carers who provided <20 hours and ≥ 40 hours ($p < 0.001$), 20-29 hours and ≥ 40 hours ($p < 0.001$) and 30-39 hours and ≥ 40 hours ($p < 0.05$). | <u>Cronbach's α, full scale</u> =0.59. <u>Test-retest reliability</u> was estimated via the ICC=0.81. The follow-up survey was administered 2 weeks after the baseline survey to a sample $N=104$. |
| Doherty et al. (2020) ¹³⁹ Australia | ADRD | Consumer Access, Appraisal and Application of Services and Information for Dementia (CAAASI-Dem) | Dementia-specific health literacy (ability to locate, navigate and use dementia services and information-either for oneself or in providing care for others) Five factors: (1) Evaluation and engagement; (2) Readiness (3) Social Supports; (4) Specific Dementia Services; (5) Practical Aspects | 26 items, Mixed format items: 5-point Likert scale: (ranging from "Not at all confident" to "Extremely confident" or "Strongly agree" to "Strongly disagree" or a binary scale: Yes/No) | The <u>content validity</u> of an initial pool of 70 items was assessed by three experts in the field with extensive experience and expertise in both scale development & dementia subject matter. The reviewers also checked content relevance, comprehensiveness, comprehensibility, and technical quality. The item pool was reduced to 65 items as a result of the content validity assessment. Using an independent sample of 1412 participants, items were pilot tested and data was used to make further revisions based on item-total and inter-item correlations and Cronbach's α -if-item-deleted. This revision resulted in the removal of 34 items. The underlying factorial structure of the scale was studied with an initial 31-item pool. The <u>structural validity</u> of the reduced 31-item scale was established by EFA with a PAF extraction method using response data from an independent sample of 3146 participants. After eliminating items with low loadings and item-rest score correlations, and re-running the EFA with an Oblimin rotation, the final EFA model produced a five-dimensional 26-item scale that explained 69.7% of the total variance. | <u>Cronbach's α estimates by subscales:</u> Evaluation and engagement (α =0.953) Readiness (α =0.911) Social Supports (α =0.887) Specific Dementia Services (α =0.926) Practical Aspects (α =0.888) |
| Furukawa & Greiner (2020) ¹⁴⁰ Japan | ADRD | Social Capital Scale for Caregivers of People with Dementia | Social capital: social networks, reciprocity, and trust Three factors: (1) Support for people with dementia and their CGs; (2) Trust in providing dementia care; (3) Support from neighbors | 17 items, 5-point Likert scale (ranging from 1=Strongly disagree to 5=Strongly agree) | <u>Content validity</u> was established by five experts using a scale to rate the relevance of 41 items. The ratings returned a content validity index, CVI= 0.94. Based on the CVI, 35 of original 41 items were retained. After further refinement, a final pool of 27 items were submitted to factor analysis. The <u>structural validity</u> of the scale was established by EFA using a ML likelihood factor extraction and oblique rotation. EFA produced a 3-factor solution and a final set of 17 scale items explaining 46.5 % of the total variance. <u>Concurrent validity</u> was demonstrated by a positive and significant Pearson correlation between the total scale scores and the Positive Aspects of Caring (PAC) scale (r =0.62, $p<0.01$). Each factor on the scale was also significantly correlated with the PAC scale (<i>Factor 1</i> : $r = 0.42$; <i>Factor 2</i> : $r = 0.58$, and <i>Factor 3</i> : $r = 0.40$). | <u>Cronbach's α, full scale</u> =0.85. <u>Cronbach's αs by subscales:</u> Support for people with dementia and their CGs (α =0.86); Trust in providing dementia care (α =0.74); Support from neighbors (α =0.78) <u>Test-retest reliability</u> (4-week interval) was estimated with the ICC in a sample of 50 respondents. (ICC=0.71) |
| Sakanashi & Fujita (2020) ¹⁴¹ Japan | ADRD | The Empowerment Scale for Family Caregivers of Community-dwelling People with Dementia (EFCD) | Empowerment Four factors: (1) Excellent Practice in Dementia Care (2) Understanding the Essence of Dementia Care (3) Caring for Oneself as well as for the Person with Dementia (4) Having Peers with Shared Support Activities | 16-items, 4-point Likert scale (0=Disagree, 1=Somewhat disagree, 2=Somewhat agree, 3=Strongly agree) | <u>Face/content validity</u> was examined by asking five administrators from the Alzheimer's Association of Japan to evaluate an initial pool of 44 items for appropriateness. This review and further item analyses resulted in the reduction of the scale to 31 items. <u>Structural validity</u> was assessed by EFA using PAF as factor extraction and Promax rotation to account for factor correlations. Sixteen items remained after deleting item factor loadings less than 0.40. A scree plot indicated a 4-factor solution. A CFA supported a 4-factor structure. Goodness-of-fit indices for the CFA model were, overall, satisfactory (e.g., RMSEA=0.08; CFI=0.91; and GFI=0.898). (The GFI was "marginally acceptable".) <u>Concurrent validity</u> was established estimating Spearman's rank correlations between EFCD and known measures of self-efficacy and general health. For example, statistically significant correlations were obtained between the EFCD and the Japanese versions of (a) the revised scale for caregiving self-efficacy, RSCSE (ρ =0.52, $p<0.01$) and (b) the general health questionnaire-12, GHQ12 (ρ =-0.27, $p<0.01$). | <u>Cronbach's α, full scale</u> =0.90. <u>Cronbach's α by subscales:</u> Excellent Practice in Dementia Care (α =0.86); Caring for Oneself as well as for the Person with Dementia (α =0.72); Having Peers with Shared Support Activities (α =0.70). <u>Test-retest reliability</u> (7-28 days interval) for the full scale was estimated with the ICC in a sample of 101 respondents. (The ICC=0.51; "moderate" test-retest reliability). |
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| Losada et al. (2020) ¹⁴³ Spain | ADRD | Revised Familism Scale (RFS) | Familism is dementia Three factors: (1) Familial interconnectedness; (2) Familial obligations; (3) Extended family support | 21 items, 5-point Likert scale (ranging from 0=Very much in disagreement to 4=Very much in agreement) | To enhance <u>content validity</u> , the authors combined 25 items from two existing scales: 14 items from the Familism Scale ¹⁴⁴ and 11 items from the Attitudinal Familism Scale. ¹⁴⁵ The <u>structural validity</u> of the initial 25-item scale was determined by EFA employing a polychoric correlation matrix and a weighted least square method for factor extraction and Oblique rotation to account for factor correlations. After eliminating four items and repeating EFA and a Horn's parallel analysis, a 3-factor model accounted for 53.22% of variance of the assessed construct. Goodness-of-fit indices for the EFA model were acceptable (e.g., RMSEA=0.06; CFI=0.97, SRMR=0.05; and TLI=-0.95). <u>Divergent validity</u> was established through a hierarchical regression model using the RFS total scores as outcomes through a series of hierarchical regression analyses. One "Familism" factor was entered in each of the regressions in a first step. In a second step, a "Familism" factor different from that entered in the first step was entered. A significant incremental change in percentage of explained variance (R^2) provided an estimate of the <i>unique, construct-specific</i> component for each factor. | Cronbach's α , full scale =0.85 <u>Cronbach's α by subscales</u> : Familial interconnectedness (α =0.82) Familial obligations (α =0.74) Extended family support (α =0.74) |
| Maltby et al. (2020) ¹⁴⁶ United Kingdom | Mixed | Adult Carers for Older Adults Quality-of-Life Questionnaire | Quality-of-life (including both the traditional and nontraditional roles of caregiving). Six factors: (1) Feelings of exhaustion; (2) Adoption of a traditional role; (3) Ability to care; (4) Personal growth; (5) Caring support; (6) Financial matters | 24 items, 4-point Likert scale (1=Never, 2=Some of the time, 3=A lot of the time, 4=Always) | Authors <i>combined items from two previous scales</i> : 40 items from the original version of Adult Carers Quality of Life ¹⁴⁷ Questionnaire and 21 items developed by Lawrence et al. (2008). ¹⁴⁸ <u>Content validity</u> was assessed through the examination of item wording by authors until they reached consensus on clarity and content relevance. The <u>structural validity</u> of the initial 61-item scale was established through EFA using a <u>mixed sample of CGs</u> from the United Kingdom (N=308). PAF extraction followed by a Promax rotation resulted in a 6-factor solution that was confirmed by a Horn parallel analysis. <i>Two replication studies</i> using competing model formulations (CFA and a bifactor model) were conducted using two independent samples from the United States (N=164) and China (N=131) using a reduced 24-item scale and the same 6-factor structure. The <i>bifactor model</i> was the best fitting model producing satisfactory goodness-of-fit indices per sample: United States (RMSEA=0.06; CFI=0.947; and non-normed fit index, NNFI=0.93). China (RMSEA=0.04; CFI=0.94; and non-normed fit index, NNFI=0.92). | <u>Cronbach's α estimates by subscales and country</u> (USA, China): Feelings of exhaustion (α =0.83; α =0.77) Adoption of a traditional role (α =0.90; α =0.51) Ability to care (α =0.88; α =0.58) Personal growth (α =0.84; α =0.59) Caring support (α =0.85; α =0.76) Financial matters (α =0.84, α =0.82) |
| Mckenna et al. (2020) ¹⁴⁹ United Kingdom | ADRD | Alzheimer's Patient Partners Life Impact Questionnaire (APPLIQUE) (Questionnaire specific to AD spousal carers) | Needs-based quality-of-life One factor: Quality-of-life | 25 items, 3-point scale (1=Lower, 2=Medium, 3=Higher) | <u>Content validity</u> was established through cognitive debriefing interviews with 76 CGs, across the five countries included in the study, to assess and comment on the applicability, relevance and comprehensiveness of the questionnaire, instructions, and omitted aspects of their experiences. <u>Structural validity</u> was demonstrated by a Rasch analysis producing a unidimensional scale supporting internal construct validity. <u>Concurrent validity</u> was assessed by correlating scores on the APPLIQUE with other scores that tap into related constructs: the Nottingham Health Profile (NHP) and the General Well-Being Index (GWBI). Spearman's rank correlations between NHP subscales and APPLIQUE were "moderate" ranging from 0.27 to 0.74. Spearman's rank correlations between GWBI and APPLIQUE was also moderate (ρ =0.67). All correlations were significant ($p < 0.05$). | <u>Internal consistency reliability</u> was assessed by the polychoric-based ordinal version of coefficient α (α =0.93) <u>Test-retest reliability</u> (two-week interval) was assessed with Spearman's correlation with a sample of 95 respondents (r =0.88). <u>PSI</u> produced by the Rasch analysis =0.85. |
| Perry-Duxbury et al. (2020) ¹⁵⁰ Germany; Ireland; Italy; The Netherlands; Norway; Portugal; Sweden; United Kingdom | ADRD | Investigating Choice Experiments for the Preferences of Older People Capability-based measure of general quality of life: the ICEPOP Capability (ICECAP-O) instrument. | General capability wellbeing Five domains: (1) Attachment (Love & friendship) (2) Security (Thinking about the future) (3) Role (Doing things that makes you feel valued) (4) Enjoyment (Enjoyment and pleasure) (5) Control (Independence) | 5 items (only one item per domain), 4-point Likert scale (1=No capability, 2=A little capability, 3=A lot of capability, and 4=Full capability) | <u>Content validity</u> of ICECAP has been ascertained in earlier work (e.g., Grewal et al., 2006) through in-depth interviews with selected informants aged 65 and over to explore their views about what is important to them in terms of quality of life. <u>Concurrent validity</u> . There was a moderate positive Spearman's correlations between the ICECAP-O scores and the EQ-5D-5L utility tariff (ρ =0.46, $p < 0.01$) and EQ-VAS scores (ρ =0.45, $p < 0.01$), a moderate negative correlation with the EQ-5D-5L health problems index (ρ =-0.45, $p < 0.01$), and a strong positive correlation with the CarerQol tariff (ρ =0.53, $p < 0.01$) and CarerQol-VAS scores (ρ =0.54, $p < 0.01$). <u>Group discriminant validity</u> . Student's t tests or ANOVA were performed to identify significant differences in ICECAP-O scores by subgroups. ICECAP-O scores significantly discriminated between informal carers who were (a) old or young, (b) employed or unemployed, (c) with low or high "positive affect index" (PAI) scores, (d) in danger or not in danger of social isolation scores (LSNS), and (e) who felt they could or could not continue caregiving for 2 years or more "perseverance time" (PT) scores. | This study did not assess reliability in the international population of informal carers of people with dementia. <u>Note</u> : Two prior studies, however, reported "good" test-retest reliabilities of the scale but in older 70 year-olds (non-patients) (Horder et al., 2016) ¹⁵¹ and frail older adults (Van Leeuwen et al., 2015). ¹⁵² |
| Voormolen et al. (2021) ¹⁵⁵ The Netherlands; Germany; Ireland; United Kingdom; | ADRD | The Care-Related Quality of Life (CarerQol) questionnaire | CG burden and wellbeing (happiness) Seven dimensions: (1) Fulfillment; (2) Relationship problems; (3) Mental health problems; (4) Daily activity problems; (5) Financial problems; (6) Social support with care; (7) | CarerQol-7D: 7 items, 3-point Likert scale (1=No, 2=Some, 3=A lot) CarerQol-VAS: 1 item, Visual analog scale (ranging from 0=Completely unhappy to | <u>Content validity</u> . A previously published study on the initial phase of the scale development by Brouwer et al. (2006), ¹⁵⁶ reported reviewing the literature and existing burden measures to create a comprehensive set of dimensions of family CG burden that were likely to be most important describing their experience. The authors also conducted a small pilot to gather preliminary information of dimensions of CG burden that might have been ignored in the instrument. The pilot also showed that the instrument was clear and understandable for CGs and easy to use. The previous study tested the tool in a heterogeneous (non-disease specific) sample of informal CGs (N=175). The current study tested the tool in a sample of family CGs of individuals with dementia (N=433). <u>Concurrent validity</u> was established by a significant positive Spearman's rank correlation coefficient | No reliability of the scale in the population of dementia CGs is reported. |

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| Sweden; Norway; Italy; Portugal | | | Physical health problems | 10=Completely happy). | (rho=0.530, p<0.001) between total scores on the 7-item CarerQoI and the "ICEpop Capability measure for Older people" (a broad measure of wellbeing) as well as a significant negative correlation (rho= -0.44, p<0.001) with the "EuroQoI-5D-L" (a measure of health-related quality-of-life). | |
| Clemmensen et al. (2021) ¹⁵⁸ Denmark | ADRD | Dementia Carer Assessment of Support Needs Tool (DeCANT) | Support needs Four factors: (1) Environmental factors (2) Activity and participation components (3) Personal factors (4) Body structure/function components (wellbeing) | 25-item, 4-point Likert scale (0=No; 1=Yes, A little more; 2=Yes, quite a bit more; 3= Yes, very much more) | Face and content validity were established iteratively. Face validity was conducted through cognitive interviews with carers. Content validity was conducted by a panel of experts representing dementia carers, in general, or professionals in the area of dementia from different professions and care settings. The expert panel independently evaluated the representativeness, relevance, and clarity of the items using a rating scale. The <u>structural validity</u> of the scale was established through CFA and the evaluation of competing models. The final 4-factor structure produced acceptable goodness of fit indices (e.g., RMSEA=0.073; CFI=0.946, and TLI=0.938). | Cronbach's α by subscales: Environmental factors (α =0.84) Activity and participation components (α =0.80) Personal factors (α =0.73) Body structure/function components (α =0.84) |
| Durepos et al. (2021) ¹⁵⁹ Canada | ADRD | Caring Ahead: Preparing for End-of-Life with Dementia Questionnaire | Preparedness for end-of-life Four factors: (1) Actions; (2) Dementia Knowledge; (3) Communication; (4) Emotions and Support Needs | 20 items, 7-point Likert scale (ranging from 1=Strongly disagree to 7=Strongly agree) | <u>Content validity</u> was established by first conducting semi-structured interviews with a sample of bereaved CGs of persons with dementia to identify preparedness core concepts and generate measurable indicators (items). Indicators of preparedness were defined as questionnaire items and further reduced and refined through a Delphi survey with CGs and professional experts. The <u>structural validity</u> of the scale was determined by PCA as the factor/component extraction method and Promax rotation producing a 4-factor model that explained 61.7% of the cumulative variance in the scale items. <u>Concurrent validity</u> was demonstrated by Pearson's correlations between a single-global "preparedness question" and the scores on the four subscales. Correlations ranged from (0.43-0.55, $p < 0.001$). | Cronbach's α by subscales: Actions (α =0.85) Dementia Knowledge (α =0.86) Communication (α =0.78) Emotions and Support Needs (α =0.80) <u>Test-retest reliability</u> was calculated with the ICC and an N=32 (average of 28.9 days interval). Estimates by subscales: Actions (ICC=0.89); Dementia Knowledge (ICC=0.95); Communication (ICC=0.87); Emotions and Support Needs (ICC=0.91) |
| Wuttke-Linnemann et al. (2021) ¹⁶⁰ Germany | Mixed | Resilience and Strain Questionnaire (ResQ-Care) | Resilience (inner attitude towards caregiving and energy sources) Strain (caregiving difficulties and burden) Four factors: (1) Inner attitude (IA); (2) Sources of energy (SE); (3) Difficulties dealing with the person in need of care (DIFF); (4) General burdens of my living situation (GB) | 20 items, 4-point Likert scale (0=No, 1=Rather no, 2=Rather yes, 3=Yes) | <u>Content validity</u> . Authors developed a 20-item pool based on a literature review on CG burden constructs underlying published scales. The <u>structural validity</u> of ResQ-Care was established through an EFA with ML likelihood factor extraction method and Oblimin rotation to interpret the factor structure. The EFA revealed a 4-factor structure explaining 43.3% of variance in scale items. (Authors acknowledge that sample size was not adequate for a cross-validation study.) <u>Concurrent validity</u> was examined by calculating Pearson's correlations between the ResQ-Care subscales and the Brief Resilience Scale (BRS), the Perceived Stress Scale (PSS-4), and the Geriatric Depression Scale (GDS-15). The results confirmed the convergent validity for the subscales. For example, correlations between the two strain subscales (DIFF and GB) and the resilience BRS scores were negative (-0.27 and -0.37, respectively). As expected, however, correlations between the resilience subscales (IA and SE) and resilience BRS scores were positive and low to moderate in magnitude (0.52 and 0.37, respectively). | Cronbach's α and McDonald's ω estimates by subscales: Inner attitude (α =0.67; ω =0.68) My sources of energy (α =0.71; ω =0.72) Difficulty dealing with the person in need of care (α =0.81; ω =0.81) General burdens of living situation (α =0.82; ω =0.83). |
| Gallego-Alberto et al. (2021) ¹⁶¹ Spain | ADRD | The Interpersonal Triggers of Guilt in Dementia Caregiving Questionnaire (ITGDCQ)--Scale I: Care Receiver (ITGDCQ-CR) | Guilt : guilt-triggering behavior employed <u>by the care recipient</u> Two factors: (1) Care recipient's criticism of the CG's role; (2) Personal disparagement | 10 items, Each item is scored on two scales: frequency and magnitude of guilt. Frequency: 5-point Likert scale (ranging from 0=Never to 4=Always Magnitude: 5-point Likert scale (ranging from 0=Not at all to 4=Extremely) | Although the authors do not address the <u>content validity</u> of the scale, a literature review is conducted establishing the rationale for the development of the ITGDCQ subscales to address the lack of measures capturing the occurrence and frequency of behaviors performed by the care recipient and other relatives that may act as guilt triggers. The <u>structural validity</u> of the scale was established by EFA followed by a Horn's parallel test to determine the scale dimensionality, and a CFA. The analyses supported a 2-factor structure. Goodness-of-fit indices for the CFA model were acceptable (e.g., RMSEA=0.04; CFI=0.97; and TLI=0.94). <u>Concurrent validity</u> was established by calculating Pearson's correlations between the Caregiver Guilt Questionnaire (CGQ) developed by Losada et al. (2010) ⁷⁴ and the two subscales: (1) Care recipient's criticism of the CG's role ($r=0.33$, $p<.01$) and (2) Personal disparagement-CG guilt ($r=0.44$, $p<.01$) | The Cronbach's α , full scale = 0.81. Cronbach's α by subscales: Care recipient's criticism of the CG's role (α =0.73) Personal disparagement (α = 0.80) |
| | | Scale II. Other Relatives (ITGDCQ-OR) | Guilt: guilt-triggering behavior employed <u>by other relatives</u> (e.g., siblings, husband) Two factors: (1) Accusations of harming the patient; (2) Shifting responsibility onto the CG | 8 items, As above, each item is scored on two scales: frequency and magnitude of guilt. | The <u>structural validity</u> was established by EFA followed by a Horn's parallel test to determine the scale dimensionality, and a CFA. The analyses supported a two-factor structure. Goodness-of-fit indices for the CFA model were acceptable (e.g., RMSEA=0.01; CFI=0.99; and TLI=0.99). <u>Concurrent validity</u> was established by Pearson correlations between the Caregiver Guilt Questionnaire (CGQ) developed by Losada et al. (2010) ⁷⁴ and the two subscales. Only the "shifting responsibility onto the CG guilt" subscale was associated with CGQ ($r = 0.25$, $p < 0.01$). | The Cronbach's α , full scale =0.78. Cronbach's α by subscales: Accusations of harming the care recipient. (α =0.81) Shifting responsibility onto the CG (α =0.80) |

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| Horton et al. (2021) ¹⁶² | ADRD | Impact of DEmentia on CARers (SIDE CAR) Battery: | Carers needs and quality-of-life (QoL) One factor: <u>Direct</u> Impact on Carers | (The Impact of DEmentia on CARers (SIDE CAR) battery has a total of 39 items. The following are the items per scale) 18 items, binary response options: Agree/ Disagree | Content validity was established through interviews with 42 carers of a relative with dementia living in the community and generating an initial bank of items based on the interviews. Items were further subject to checks regarding ambiguity, content, and face validity. Twenty-two cognitive interviews with carers were conducted to pretest and assess response formats. The <u>structural validity</u> for the original 70-item bank was established by EFA followed by Geomin (Oblique) rotations to increase factor structure interpretability. EFA revealed a 4-factor solution. Within each identified factor, a Rasch analysis for scale refinement was conducted iteratively producing three final separate scales: SIDE CAR-D, SIDE CAR-I, and SIDE CAR-S. The <u>concurrent validity</u> of the SIDE CAR scales was assessed with Spearman's rank correlations (all <i>p-values</i> < 0.001) between total scores in each of the scales and (a) a measure of wellbeing (the Short Warwick-Edinburgh Mental Well-being Scale, SWEMWBS) and (b) a measure of health valuation (the EuroQoL Group Visual Analogue Scale, EQ-5D VAS). (Hypothesized to be negatively correlated with SIDE CAR scales scores.) Spearman's rank correlation (SWEMWBS, SIDE CAR-D) <i>r</i> = -0.57; Spearman's rank correlation (EQ-5D VAS, SIDE CAR-D) <i>rho</i> = -0.35 <u>Responsiveness</u> : SIDE CAR-D demonstrated a "moderate" responsiveness, ES=0.43. | The Cronbach's α , full scale =0.83. <u>Test-retest reliability</u> (within 6 weeks with N=100 carers) was estimated with the ICC=0.86. PSI obtained from a Rasch analysis of the scale=0.81. |
| | | SIDE CAR-I: Indirect Impact on Carers | Carers needs and QoL: One factor: <u>Indirect</u> Impact on Carers | 10 items, binary response options: "agree"/"disagree" | <u>Concurrent validity</u> Spearman's rank correlation (SWEMWBS, SIDE CAR-I) <i>rho</i> = -0.40 Spearman's rank correlation (EQ-5D VAS, SIDE CAR-I) <i>rho</i> = -0.21 <u>Responsiveness</u> : SIDE CAR-I demonstrated a "small" responsiveness effect size, ES=0.29 | The Cronbach's α , full scale =0.70. PSI obtained from a Rasch analysis of the scale=0.58. <u>Test-Retest reliability</u> (within 6 weeks) estimated with ICC= 0.86. |
| | | SIDE CAR-S: Support and Information | Carers needs and QoL: One factor: <u>Support and information</u> | 11 items, binary response options: Agree/ Disagree | <u>Concurrent validity</u> Spearman's rank correlation (SWEMWBS, SIDE CAR-S) <i>rho</i> = -0.36 Spearman's rank correlation (EQ-5D VAS, SIDE CAR-S) <i>rho</i> = -0.24 <u>Responsiveness</u> : SIDE CAR-S demonstrated a "small" responsiveness effect size, ES=0.11 | The Cronbach's α , full scale =0.81. PSI obtained from a Rasch analysis of the scale=0.69. <u>Test-retest reliability</u> (within 6 weeks) estimated with ICC=0.85. |
| Schlomann et al. (2021) ¹⁶³ | ADRD | Berlin Inventory of Caregiver Stress-Dementia (BICS-D) <u>Note</u> : A test battery with 6 dimensions) | CG <u>Stress</u> : Subjective & objective <u>burden</u> Six dimensions: (1) Objective practical caregiving tasks (5 subscales-25 items) (2) Subjective burden from behavior change (6 subscales-26 items) (3) Conflicts in perceived needs and positive aspects of care (6 subscales-28 items) (4) Role conflict (2 subscales-9 items) (5) Aggression toward the patient (one scale-6 items) (6) Coping (5 subscales-27 items) | 121 items, (across 25 subscales) Mixed response options per domain: (1) 5-point Likert scale (from Hardly to Not at all) (2) 5-point Likert scales (varied per subscale) (3) & (4) & (5) 5-point Likert scale (from Never to Always) | <u>Content validity</u> . The development of the inventory is based on stress-theory models that conceptualize burden as a situation-specific, multidimensional construct. An initial literature review and extensive qualitative data on stress from a pilot testing of N=80 caregiving relatives served as the basis from the generation of the initial pool of items. The pilot testing resulted in the refinement of the item pool and item reduction. Face to face interviews with CGs were applied to discuss the item selection. <u>Structural validity</u> . A total of <u>six</u> separate PCAs with Varimax rotation and inter-item correlations were applied to examine the factorability of <u>each domain</u> . The proportion of variance explained per domain varied from 56.6% to 64.5%. <u>Concurrent validity</u> . The 25 subscales were significantly (<i>p-values</i> < 0.05) correlated with the following criterion measures: wellbeing (assessed with CES-D, Self-esteem, Quality of life management and positive relationships to others) <u>and</u> a measure assessing "the sum of physical illnesses. Most of the subscales measuring "Objective practical caregiving" had low, but statistically significant correlations with the wellbeing criterion scales. Most of the subscales included in the "Coping" domain had relatively low correlations with both the wellbeing and the "Sum of physical illness" criterion measures. The <u>responsiveness</u> (sensitivity to change) of some of the BICS-D subscales was demonstrated by significant burden-reducing effects over a period of 3 months on a) practical caregiving tasks, b) subjective burden, and c) subjectively perceived need conflicts. (These results were obtained by comparing responses from 36 CGs using day-care and a matched sample of 30 non-day care users.) | The Cronbach's α estimates across the 25 subscales ranged between 0.72 to 0.95. <u>Guttman's split-half reliability</u> estimate per subscale varied from 0.21 to 0.90. |
| Cheon et al. (2022) ¹⁶⁴ | ADRD | The Competence Scale in Managing Behavioral and Psychological Symptoms of Dementia (CS-MBPSD) | Competence in managing behavioral and psychological symptoms of dementia. Six factors: (1) Person-centered attitude, (2) Introspection for improvement, (3) Symptom occurrence analysis, (4) Application of various strategies, (5) Awareness of symptoms, | 28 items, 5-point Likert scale (ranging from 1=Strongly disagree to 5=Strongly agree. <u>Note</u> : The last item is a single general question for the self-evaluation of overall competence in managing behavioral and psychological symptoms of dementia. | Face validity was assessed by asking five family CGs to identify inappropriate questions checking the ease of understanding, item length, and readability. <u>Content validity</u> assessments were conducted by eight experts with the initial pool of items. Items were deleted or revised according to the experts' opinions. After the content validation, 39 of the initial 48 items remained. The <u>structural validity</u> of the CS-MBPSD was established through EFA and CFAs. EFA used principal components to extract and identify the factors/components followed by Varimax rotations. After further revisions, the analysis with 28 items revealed six factors/components with loadings per factor ranging from 0.493 to 0.789. Next, CFA models using the six-factor structure underlying the 28 items were estimated with a cross-validation sample (N=230). Goodness-of-fit indices, however, were found to be below recommended thresholds (RMSEA = 0.08, CFI = 0.81, and TLI = 0.79) indicating poor model-data fit. Standardized regression weights, (SRW), CR and AVE were used to assess the <u>reliability and convergent validity</u> of the factors extracted through the CFA model. The resulting SRWs ranged from 0.529 to 0.769; | The Cronbach's α , full scale =0.922. <u>Each sub-factor estimate ranged from</u> 0.610 to 0.846. <u>Test-retest reliability</u> (two-week interval) was calculated with the ICC with <u>nine participants</u> . The ICC for the total score was 0.781 (<i>p</i> =0.004) The ICC of Factors 1 to 6 ranged from 0.151 to 0.701 (very poor to moderate). |

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| | | | (6) Caring for one's own mind and body. | | CR values ranged from 0.726 to 0.889; and the AVE values from 0.385 to 0.538. (Note: recommended thresholds are SRW>0.50, CR>0.70, and AVE>0.50.) <u>Concurrent validity</u> was established estimating Pearson's correlation between the CS-MBPSD total scores against, respectively, the Behavior Management Skill-BMS, the Visual Analogue Scale-VAS, and one general question (the last item) of the CS-MBPSD. (CS-MBPSD total scores were moderately correlated with a general question (CS-MBPSD item 29) (r=0.534, p < .01), the BMS (r=0.396, p < .01), and the VAS (r=0.339, p < .01). | |
| Wawrziczny et al. (2022) ¹⁶⁵ France | ADRD | Control and Stimulation in Dementia Caregiving (CSDC-13) Scale | CG management behaviors and approaches. Two factors/components: (1) Negative control behaviors, (2) Positive stimulation behaviors. | 13 items, 5-point Likert scale (ranging from 1=Strongly disagree to 5=Strongly agree) | <u>Content validity</u> was established by five expert reviewers and 10 CGs who assessed items in terms of expression of a single, unambiguous idea; ease of understanding; and relevance and usefulness in clinical practice. <u>Structural validity</u> was established through PCA and CFA. The PCA used a Varimax rotation to explore item loadings and scree plots to define a final 2-component solution of the 13-item scale explaining 46.20% of the cumulative variance. CFA analyses for the 13-item scale exhibited a satisfactory goodness of fit indexes (e.g., RMSEA=0.08, CFI=0.91; TLI=0.90). <u>Concurrent and discriminant validity</u> were established through Pearson's correlations between factors (subscales) and criterion measures. For example, "Negative control" scores were significantly (p-values < 0.001) correlated with anxiety (0.25), burden (0.25) and impact on finances (0.22). "Positive stimulation" scores were significantly correlated with self-esteem (r = 0.44). As expected, "Positive stimulation" scores were not associated with anxiety (r= -0.06) or depression (r= -0.10). | <u>Cronbach's α estimates by subscales:</u> Negative control (α =0.82) Positive stimulation (α =0.70) <u>Test-retest reliability</u> (15-day interval, N=63) was 0.62 for the "Negative control" factor and 0.71 (p < 0.001) for the "Positive stimulation" |
| Gallego-Alberto et al. (2022) ¹⁶⁶ Spain | ADRD | Caregiving Compassion Scale (CCS) | Compassion and distress Two factors: (1) Distress from witnessing the care recipient suffering for helping or alleviating distress of their relative with dementia | 10 items, 5-point Likert scale (ranging from 1=strongly agree to 5=strongly disagree) | Support for the <u>content validity</u> of the CSS is provided by its original developer (Schulz et al., 2017). ¹⁶⁷ The present study analyzes its psychometric properties in a sample of dementia CGs. The <u>structural validity</u> was established through EFA using a ML likelihood estimator and Geomin rotation followed by a Horn parallel analysis to determine the optimal number of factors to retain. The solution supported a two-factor structure. <u>Concurrent validity</u> . Scores of the total compassion scale (CCS) showed significant and positive Pearson correlations with guilt levels (r=0.23, p < -0.01), overall frequency of behavioral and psychological symptoms of dementia (BPSD) (r=0.20, p < 0.01), and frequency (r=0.31, p < 0.01) and reactions (r=0.26, p < 0.01) of the RMBPC depressive behaviors subscale. | <u>The Cronbach's α, full scale</u> = 0.81. <u>McDonald's ω, full scale</u> =0.83 <u>Cronbach's α and McDonald's ω by subscales:</u> Distress from witnessing the care-recipient suffering (α =0.79; ω =0.79) Motivation/disposition for helping (α =0.72; ω =0.79) |
| Bernaards et al. (2022) ¹⁷⁰ United States United Kingdom Australia Canada Czechia France Germany Italy Korea Poland Spain Sweden | ADRD | 27-item Zarit Caregiver Interview for Alzheimer's Disease (ZCI-AD-27) | Burden impact of caregiving Twelve factors/domains: (1) Physical (2) Emotional (3) Social (4) Daily life (5) Exhaustion (6) Dependence (7) Worry (8) Role perception (9) Financial impact (10) Difficulty with medication, (11) Overall difficulty of caregiving, (12) Sadness | 27 items, 11-point numerical rating scale with items ranging from (0=None to 10=All of the time) or (0=Not at all to 10=Extremely) | The <u>structural validity</u> of the scale was evaluated through iterative CFAs. A final CFA model with a <u>second order factor</u> (comprised of Physical, Emotional, Social, and Daily life) named "Humanistic Impact", provided a satisfactory fit to the data. Loadings for the multi-item factors Exhaustion, Dependence, Worry, and Role perception, and the single-item "factors" Overall Difficulty of caregiving, Difficulty with medication, Financial impact, and Sadness <u>did not meet the stringent fit criteria</u> . Authors, however, considered the full 12-factor model "acceptable" based on less stringent criteria. Goodness-of-fit indexes were below usual thresholds (e.g., RMSEA=0.07; CFI=0.91; and GFI=0.87). <u>Convergent validity</u> . Correlations between the items <i>with their own dimension</i> were satisfactory (≥ 0.40) for the following 8 domains: Physical, Emotional, Social, Daily life, Exhaustion, Dependence, Worry, and Role perception. Discriminant validity was met by all items in the <i>Dependence</i> and <i>Worry</i> scores and by all the <i>Humanistic impact domains</i> and <i>Role perception</i> . No items from the <i>Exhaustion</i> score met the discriminant validity criterion. <u>Concurrent validity</u> . Stronger Spearman's correlations were observed between the ZCI-AD-27 domains and scales with related concepts (e.g., the Alzheimer's Disease Cooperative Study-Basic ADLs and the Humanistic Impact-Total domain; rho= -0.30, p < 0.001). Also the correlation between ADL Total score and the Dependence scores was rho=0.35, p < 0.001. <u>Responsiveness</u> . A subset of 312 caregivers was used to assess responsiveness of ZCI-AD-27 to "detect change" at Week 52. Effect sizes showed a small increase in ZCI-AD-27 scores for those reporting an "improved experience" on the <i>Caregiver Global Impression of Change-Alzheimer's Disease</i> . | <u>The Cronbach's α estimates for the subscales</u> ranged from 0.66 for the Exhaustion score to 0.93 for the Humanistic Impact-Total score. <u>Test-retest reliability</u> was assessed with a subset of 219 care partners at Week 24 calculating the ICC. The ICC for the 12 domains ranged from 0.71 to 0.53 (Emotional Impact to Difficulty with medication respectively). |
| Bhatt et al. (2022) ¹⁷¹ United Kingdom | ADRD | Family Stigma Instrument (FAMSI) | Contribution of stigma to burden among carers of people with dementia. Three domains: (1) Stigma by Association; (2) Positive Aspects of Caring; (3) Affiliate Stigma (with 3 subdomains: affective, behavioral and | 26-items, 5-point Likert scale (1=Strongly disagree, 2=Somewhat disagree, 3=Neither disagree/agree, 4=Somewhat agree, 5=Strongly Agree) | The theoretical basis for the development of FAMSI is presented in Mitter et al., 2018. ¹⁷² The current study validates the instrument in a sample of dementia CGs. Only the <u>concurrent validity</u> was examined. The Rosenberg Self-Esteem Scale (RSES) was used to measure self-esteem of CGs. Authors hypothesized that stigma by association and affiliate stigma would be negatively correlated with RSES, whereas Positive aspects of caring subscale would be positively correlated with RSES. However, <u>no significant correlations between the FAMSI scales and RSES were observed</u> . Correlations ranged from r= 0.04 (p=0.74) to r=0.12 (p=0.32). <u>Note</u> : Authors define "stigma" directed at family carers of a stigmatized individual as 'stigma by association' or 'courtesy stigma'. When stigma by association becomes internalized, termed 'affiliate | <u>Cronbach's α by subscales:</u> Stigma by association (α =0.917) Positive aspects of caregiving (α =0.72) Affiliate stigma (total) (α = 0.858) Subdomains of Affiliate Stigma: Affective (α =0.857); Perceived (α =0.875); Behavioral (α =0.759) <u>Test-retest reliability</u> estimates (2-week interval, N=70) obtained with |

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| | | | 'perceived') | | stigma', it can have negative affective, behavioral and cognitive consequences, such as unhappiness, withdrawal and sense of inferiority. | ICC's ranged, from 0.73 (Affiliate stigma total) to 0.82 (Stigma by association). |
| Cartwright et al. (2022) ¹⁷³ United Kingdom | ADRD | Multidimensional scale of perceived social support (MSPSS) | Perceived adequacy of social support Three Factors: (Factors are the sources of social support) (1) Family (2) Friends (3) Significant | 12-Items, 7-point Likert type scale (ranging from 1=Very strongly disagree to 7=Very strongly agree) | The content validity of MSPSS was established by its original developer (Zimet et al., 1988). ¹⁷⁴ The current study evaluates the measure's full psychometric properties in a sample of dementia CGs. The <u>structural validity</u> of the MSPSS scale was established through CFA yielding a 3-factor solution: All 12 items significantly loaded onto their hypothesized factor. Standardized factor loadings ranged from 0.79 to 0.93. The CFA analysis replicated the 5-factor structure and indicated a good model fit (e.g., GFI =0.967, CFI=0.959, and RMSEA=0.048). <u>Concurrent validity</u> . HADS scores were significantly and negatively correlated with the total MSPSS scores ($r = 0.48$, $p < 0.001$), as well as 'significant other' ($r = 0.34$, $p < 0.001$), 'family' ($r = 0.33$, $p < 0.001$) and 'friends' ($r = 0.45$, $p < 0.001$). The total MSPSS score was significantly positively correlated with the SF-12 physical component score (PCS) ($r = 0.17$, $p = 0.003$) and mental component score (MCS) ($r = 0.32$, $p < 0.0001$) | Cronbach's α by subscales: Significant other ($\alpha = 0.93$); Family ($\alpha = 0.94$); Friends ($\alpha = 0.92$) <u>Test-retest reliability</u> (28 to 42.5 days interval) of the full MSPSS scale was estimated in a subsample of 58 participants with the ICC=0.90. <u>Test-retest reliability per subscales</u> : Significant other (ICC=0.89); Family (ICC=0.86); Friends (ICC =0.84) |
| Kim et al. (2022) ¹⁷⁵ Australia | Mixed | Dementia Public Stigma Scale (DePSS) | Stigma Five factors: (1) Fear and discomfort (2) Incapability and loss (3) Acknowledgement of personhood (4) Burden (5) Exclusion | 16 items, (items were statements about dementia and people living with dementia) 7-point Likert-type scale (ranging from 1=Strongly disagree to 7=Strongly agree) | Content <u>validity</u> was established by an expert panel who reviewed items for relevance and clarity of expression. The <u>structural validity</u> of DePSS was evaluated through EFA and CFA. EFA used ML likelihood as factor extraction method and Oblique rotation to increase factor interpretability producing a 5-factor structure. The CFA analysis replicated the 5-Factor structure and indicated a good model fit (e.g., GFI=0.967, CFI=0.959, and RMSEA=0.048). Tests of <u>measurement invariance</u> were conducted to examine the generalizability of the DePSS between gender and exposure groups (knowing or not knowing someone with dementia). The fit of the model was consistent with that of the configural model for both gender and exposure groups. That is, the findings indicated that all items designed to measure the public stigma of dementia are operating equivalently across gender and exposure groups. | Cronbach's α , full scale =0.818. <u>Cronbach's α by subscales</u> showed moderate to high reliability. Cronbach's α ranged from 0.738 to 0.805. |
| Hosseini et al. (2022) ¹⁷⁶ Iran | ADRD | Family Caregivers' Hardiness Scale (FCHS) | Hardiness Five factors: (1) Religious Coping; (2) Self-Management; (3) Empathic Communication; (4) Family Affective Commitment; (5) Purposeful Interaction | 21 items, 5-point Likert scale (1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always) | Face validity was attained by asking 11 family caregivers to examine items in terms of the level of difficulty, relevancy, or ambiguity. <u>Content validity</u> . Twelve experts in nursing, psychology, and instrument development were asked to evaluate the items in terms of grammar, wording, item allocation, and scaling. The <u>structural validity</u> of the FCHS scale was examined using EFA and CFA on a split sample of participants (N=435 was split into two subsamples: EFA sample with N=210 and a cross-validation sample for the CFA analysis with N=225. EFA used ML for factor extraction and Promax rotation. Horn's parallel analysis and Exploratory Graph Analysis revealed a two-factor structure. A CFA supported the 2-factor structure determined by EFA. The results showed all of the model fit indices were in the acceptable range (e.g., CFI=0.93, TLI=0.92, and RMSEA=0.065). Four out of the five factors (religious coping, self-management, empathic communication, and family affective commitment) showed <u>convergent validity</u> (AVE ranged from 0.50 to 0.62 and CR range from 0.75 to 0.89). The full factor structure also showed <u>discriminant validity</u> . <u>Note</u> : AVE > 0.50 and CR > 0.70 (or CR > AVE) are considered minimum requirements of convergent validity. Discriminant validity is achieved if the heterotrait-monotrait ratio (HTMT) of the correlations matrix values are all < 0.85. ¹⁷⁷ | With the exception of the factor "purposeful interaction", the internal consistency reliability estimates (<u>Cronbach's α and McDonald's ω for the subscales</u>) were > 0.70. Religious coping ($\alpha = 0.889$, $\omega = 0.900$) Self- management ($\alpha = 0.880$, $\omega = 0.882$) Empathic communication ($\alpha = 0.764$, $\omega = 0.766$) Family affective commitment ($\alpha = 0.749$, $\omega = 0.773$) Purposeful interaction ($\alpha = 0.691$, $\omega = 0.692$) The stability of the CCS was also assessed by the ICC with the <u>test-retest reliability method</u> (two-week interval) with N=15 cases. (ICC=0.903). |
| Sharif-Nia et al. (2022) ¹⁷⁸ Iran | ADRD | The Care Challenge Scale (CCS) | Caregiving challenges Two factors: (1) Effective role-play challenges reflecting physical, emotional, and psychological aspects of CGs' health. (2) Lack of social-financial support reflecting effects of caregiving on social life. | 10-items, 5-point Likert scale (1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always) | Face validity was performed by asking 10 family CGs to examine items in terms of the level of difficulty, relevancy, or ambiguity in answering. <u>Content validity</u> . Twelve experts in nursing, psychology, and instrument development were asked to evaluate the items in terms of grammar, wording, item allocation, and scaling. The <u>structural validity</u> of the scale was examined using EFA and CFA on a split sample of participants. That is, N=435 was split into two subsamples: EFA sample with N=210 and a cross-validation sample for the CFA analysis with N=225. Horn's parallel analysis and Exploratory Graph Analysis revealed a two-factor structure. CFA confirmed the factor structure determined by EFA. Commonly used goodness of fit indexes indicated a satisfactory solution (e.g., CFI=0.929, TLI=0.903, and RMSEA=0.042). Only the first factor (Effective Role Play Challenges) showed <u>discriminant validity</u> (heterotrait-monotrait ratio of correlations matrix (HTMT=0.765) and <u>convergent validity</u> (AVE=0.537 and CR=0.848). | <u>Cronbach's α and McDonald's ω by subscales</u> : Effective role play challenge ($\alpha = 0.838$; $\omega = 0.837$) Lack of social - financial support ($\alpha = 0.765$; $\omega = 0.773$) The stability of the CCS was assessed by evaluating the ICC with the <u>test-retest reliability method</u> (two-week interval) in 30 family CGs. The scale stability was acceptable (ICC = 0.902). |
| Sharif-Nia et al. (2023) ¹⁷⁹ Iran | ADRD | Care Stress Management Scale (CSMS) | Stress management Two factors: (1) Emotional-focused coping; (2) Problem-focused | 8 items, 5-point Likert scale (1=Never, 2=Rarely, 3=Sometimes, 4=Often, | <u>Face and content validity</u> were established as in the previous study by Sharif-Nia et al. (2022) ¹⁷⁸ The <u>structural validity</u> of the scale was examined using EFA and CFA on a split sample of participants: EFA sample (N=210) and a cross-validation sample for the CFA (N=225). EFA yielded a 2-factor solution explaining 51% of the total variance. Horn's parallel analysis and Exploratory Graph Analysis also | <u>Cronbach's α and McDonald's ω by subscales</u> : Emotional-focused coping ($\alpha = 0.774$; $\omega = 0.778$); Problem-focused coping |

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| | | | coping | 5=Always) | revealed a 2-factor solution. CFA confirmed the factor structure determined by EFA. Goodness of fit indexes indicated a satisfactory solution (e.g., CFI=0.980, TLI=0.971, and RMSEA=0.052). Only the first factor (Emotional-focused coping) showed <u>discriminant validity</u> (heterotrait-monotrait ratio of correlations matrix, HTMT=0.76) and <u>convergent validity</u> (AVE=0.537 and CR=0.848). | (α =0.791; ω =0.802) The stability of the CSMS was assessed by evaluating the ICC with the <u>test-retest method</u> (two-week interval) in 25 family CGs. (ICC=0.844). |
| Olthof-Nefkens et al. (2023) ¹⁸³ The Netherlands | ADRD | Experienced Communication in Dementia Questionnaire-Caregiver (ECD-C) | Self-perceived communication (Three domains/themes: (1) Experience communication from the perspective of the CG; (2) Judgment/assessment of the conversation quality; (3) Experienced emotions with communication problems | 29 items, 4-point Likert scale for agreement (0=Fully disagree to 3=Fully agree) or frequency (0=Never to 3=Every conversation) | Content validity was demonstrated in a previous study in collaboration with experts in the field of dementia and through interviews with dyads (people with dementia and their CG). Reflexive thematic analysis of the interviews was used to generate items. Further pilot testing with a small sample of dyads and discussions with dementia experts contributed to the final version of the questionnaire. Concurrent validity was assessed with Pearson correlation coefficients. All parts of ECD-C correlated substantially with both the Dementia Quality of life Instrument by the Caregiver (DQI-C) and the ZBI short form (ZBI-12). Correlations were significant ($p < 0.05$) and in the predicted direction ranging from 0.36 to 0.47. Discriminant validity coefficients were, as expected, not significant and less than 0.20 when comparing ECD-C to the MMSE, the ADLs, and the IADLs. | Cronbach's α estimates by subscales: Experience communication (α =0.78) Judgment/assessment of the conversation quality (α =0.82) Experienced emotions (α =0.75) <u>Test-retest reliability</u> (2-week interval, N=49) was measured by intra-class ICC's: Experience communication (ICC=0.76); Judgment/assessment of the conversation quality (ICC=0.75); Experienced emotions (ICC=0.78) |
| Potter et al. (2023) ¹⁸⁴ United Kingdom | ADRD | The Long-Term Conditions Questionnaire for Carers (LTCQ-Carer) | Effectiveness of carer support (a quality-of-life measure for carers) One factor: Effectiveness of caregiving support | 21 items, 5-point Likert scale (0=Never, 1=Rarely, 2=Sometimes, 3=Often, 4=Always) | <u>Content validity</u> was established through cognitive interviewing with carers of people living with MCI on the comprehensibility, clarity, appropriateness and content of a draft questionnaire. <u>Structural validity</u> . An EFA using PAF as the factor extraction method followed by a Horn's parallel analysis provided support for a one-factor solution. To evaluate <u>concurrent validity</u> , gold standard measures for health-related quality of life were correlated with LTCQ-Carer scores: 1) the EuroQoL five-dimensional descriptive system with visual analogue scale: EQ-5D-5L with EQ VAS; and 2) a measure for social-care-related quality of life (ASCOT-Carer). Associations with EQ-5D and ASCOT-Carer supported construct validity. Concurrent validity was supported by Pearson's correlation estimates between the LTCQ-Carer scores and the following criterion measures: a) EQ-5D-5L index value ($r=0.52$, $p < 0.001$), b) EQ VAS ($r = 0.61$, $p < 0.001$), and c) the ASCOT-Carer ($r = 0.85$, $p < 0.001$). | Cronbach's α , full scale =0.95. |
| Risch et al. (2023) ¹⁸⁵ Germany | ADRD | The Caregiver Thoughts Scale (CTS) | Dysfunctional thoughts Four "domains:" (1) Dysfunctional caregiving standards; (2) Self-care; (3) Dysfunctional assumptions about dementia; (4) Acceptance | 28 items, 5-point Likert scale (ranging from 0=Never to 4=Very often) | <u>Content validity</u> . Six experts (five German, one Australian) with experience in cognitive behavior therapy for dementia CGs rated each potential question for content representativeness with possible classifications of 1 (should be excluded), 2 (would need to be revised) or 3 (should be included). This process resulted in a 28-item scale. The authors conceptualized CGs' thoughts as being <i>formative constructs</i> and allocated the 28 items into four domains (subscales) based on theoretical considerations. Therefore, construct validity was evaluated through the relationship of these four subscales with theoretically meaningful correlates. <u>Concurrent and discriminant (divergent) validity</u> were assessed through significant ($p < 0.05$) correlations between the CTS subscales and several scales: a) depression (General Depression Scale) ($r=0.36$), b) anxiety (HADS) ($r=0.36$), c) grief (Caregiver Grief Scale) (0.39), d) quality of life (WHO Quality of Life) (psychological, $r=-0.31$; physical, $r=-0.27$), e) dysfunctional thoughts (Dysfunctional Thoughts about Caregiving Questionnaire-DTQC) ($r=0.29$). As expected, no significant associations were obtained between the CTS subscales and the number of care recipients' behavior problems (divergent measure) (pairwise correlations ranged from 0.02 to 0.18). | Authors provide estimates of <u>interrater agreement</u> (for the six expert raters) using the ICC for the complete initial item pool. The obtained ICC=0.77) was considered a "good" measure of the scale reliability. <u>Note</u> : CTS is a formative scale. <i>Formative constructs</i> don't need to be internally consistent. ¹⁸⁶ |
| Pendergrass et al. (2023) ¹⁸⁷ Germany | Mixed | Benefits of Being a Caregiver Scale (BBCS) | Benefits (or positive aspects of caregiving) One factor: Benefits conferred by caregiving and benefits leading to personal enrichment) | 14 items, 5-point Likert scale (4=Strongly agree, 3=Agree, 2=Neutral, 1=Disagree, 0=Strongly disagree) | <u>Content validity</u> was established in a "participatory" manner by including assessment of items by experts from different disciplines and also by family CGs. <u>Structural validity</u> . An EFA yielded one-factor solution explaining 49.8% of the total variance of the 14-item scale. A scree plot supported the solution. <u>Concurrent validity</u> . The Pearson's correlation coefficient between BBCS and the Positive Aspects of Caregiving Scale (PACS) was significant ($r=0.75$, $p < 0.001$). Expected associations were found between BBCS scores and better a) emotion-focused coping ($r=0.18$, $p < 0.001$) and b) problem-focused coping ($r=0.23$, $p < 0.001$). <u>Discriminant validity</u> . BBCS scores were not associated with a) subjective burden ($r = -0.05$, $p=0.240$) and b) dysfunctional coping ($r = -0.07$, $p=0.142$). | Cronbach's α , full scale =0.922 |
| Pione et al. (2023) ¹⁸⁸ United Kingdom | ADRD | Positive Psychology Outcome Measure-Carer Version (PPOM-C) | Hope and Resilience in family carers of persons with dementia Two factors: (1) Hope; (2) Resilience | 14 items, 5-point Likert scale (0=Not true at all to 4=True nearly all of the time) <u>Note</u> : The reference to | The <u>content validity</u> of PPOM was previously reported by Stoner et al., 2018. ¹⁸⁹ The current study validates the scale in a sample of dementia CGs. <u>Structural validity</u> . A CFA supported the hypothesized two-factor structure (hope and resilience). Commonly used goodness of fit indices showed an acceptable model fit (CFI=0.904; RMSEA=0.114; SRMR=0.057. The two-factor structure showed convergent validity, AVE=0.61. <u>Concurrent validity</u> . HADS-D scores were significantly (p -values < 0.001) and negatively correlated with | Cronbach's α , full scale =0.948. Cronbach's α by subscales: Hope (α =0.912) and Resilience (α =0.918) <u>Test-retest reliability</u> (4-week interval, N=48) was estimated using the ICC. |

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| | | | | answer each item is the last month. | PPOM-C total scores ($r=-0.66$) and the hope and resilience subscales ($r= -0.67$; $r= -0.58$, respectively). The hope and resilience subscales were positively correlated with the SF-12 mental component score ($r=0.62$, $r=0.57$, respectively.) in addition to the PPOM-C ($r=0.63$). The PPOM-C, and its hope and resilience subscales were significantly correlated with the SF-12 physical component score ($r=0.19$, $r=0.17$, $r=0.19$, respectively). Lastly, total MSPSS scores were significantly correlated with the PPOM-C ($r= 0.39$), the hope ($r=0.45$) and resilience ($r=0.29$) subscales. | Full PPOM-C scale (ICC=0.908) <u>Test-retest reliability by subscales:</u> Hope (ICC=0.891) and Resilience (ICC=0.874) |
| Suganuma et al. (2024) ¹⁹⁰ Japan | ADRD | Caregiving Competence Scale for Dementia (CCSD) | Caregiving competence Five factors: (1) Positive Emotions; (2) Presence of Consultation Partners/Family Support; (3) Caregiving Burden/Coping Skills; (4) Dementia Literacy; (5) Involvement & Emotion Control | 27 items, 5-point Likert scale (ranging from 5=Strongly agree (always or frequently) to 1=Strongly disagree (never)). | <u>Face validity</u> was assessed by asking 15 family CGs of persons with dementia to review a preliminary pool of 45 items compiled by authors from previous studies. <u>Content validity</u> assessments were conducted by five experts (faculty and medical professionals specializing in dementia care) with the 45-item pool. The <u>structural validity</u> of the scale was established through iterative EFAs and CFAs. The EFA analyses used ML and Promax rotation to extract the underlying factors and a scree plot to determine the optimal number of factors to retain. The repeated EFA models resulted in a final 27-item scale with 5 factors. CFA analyses for the 27-item scale exhibited satisfactory commonly used goodness of fit indexes (e.g., RMSEA=0.07, CFI = 0.905). | <u>Cronbach's α</u> , full scale =0.892 <u>Cronbach's α by subscales:</u> Positive Emotions ($\alpha=0.903$); Presence of Consultation Partners/family support ($\alpha=0.802$); Caregiving Burden/Coping Skills ($\alpha=0.743$); Dementia Literacy ($\alpha=0.782$); Involvement & Emotion Control ($\alpha=0.783$) |

Note: AD = Alzheimer's disease; ADRD = Alzheimer’s disease and related dementias; ADL = Activities of Daily Living; AGFI = adjusted goodness-of-fit index; AVE = average variance extracted. A recommended threshold for convergent validity is an AVE > 0.50; CG = Caregiver; CATPCA = categorical principal component analysis; CES-D = Center for Epidemiological Studies Depression Scale; CFA = confirmatory factor analysis; CFI = comparative fit index; CR = composite reliability. A recommended threshold for convergent validity is a CR > 0.70; CVI = content validity index;¹⁹¹ EFA = exploratory factor analysis; GFI = goodness of fit index; Hamilton Depression Rating Scale = HAM-D; Hospital and Anxiety Depression Scale = HADS; IADL = instrumental activities of daily living; ICC = Intra-class correlation coefficient; IFI = incremental fit index; IRT = item response theory; LSNS= Lubben Social Network Scale; ML = maximum likelihood; MLE = maximum likelihood estimation; MMSE = Mini-Mental State Examination; NPI = Neuropsychiatric Inventory; NFI = Normed Fit Index; NNFI = non-normed fit index; PAF = principal axis factoring; PCA = principal components analysis; POMS= Profile of Mood States; RMPBC = Revised Memory and Behavior Problems Checklist; RMSEA = root mean square error of approximation; SF-36 = Short form 36 Health Survey; SRMR = standardized root-mean-square residual; TLI = Tucker-Lewis Index; ZBI = Zarit Burden Interview; PSI = person separation index.¹⁹² PSI values above 0.70 indicate good to excellent reliability in differentiating persons along the measured trait. Proposed rule of thumb thresholds for ICCs are: between 0.50 and 0.75 (moderate); ≥ 0.75 (good), and ≥ 0.90 (excellent).¹⁹³ Generally accepted threshold for “good” Cronbach’s α test of reliability is considered to be ≥ 0.70 . Responsiveness (longitudinal validity) refers to the ability of an instrument to detect clinically important changes over time.¹⁹⁴ Measures such as minimal important change (MIC), smallest detectable change (SDC), effect size (ES), and area under the receiver operating curve (ROC) can be used to describe responsiveness.