Reference	Name of the Scale(s)	Characteristics of the Caregiver Sample Used in Tool Validation Process							
		Age of carer (range and mean)	Race/Ethnic distribution	Sample size and % Female	Relationship of carer to person receiving care	Sample selection description	Diagnosis of person receiving care	Years/Months/ Hours per week providing care	Caregiver Education
Kinney & Stephens (1989)[2]	**Caregiver Hassles Scale (CHS)**	Range: 24–81 Mean: 57.4 (SD=13.3)	Not reported	N=60 Female=81.7%	Spouses=46.7% Daughters (natural and in-law)=41.7% Other=11.6%	Participants were recruited from local Alzheimer's Disease and Related Disorders Association Chapter.	AD=93.3% Other=6.7%	Range: 0.08-11.0 years Mean: 4.1 years (SD=2.9)	Not reported
Lawton *et al.* (1989)[3]	**Caregiver Appraisal Scale (CAS)**	Mean: 59.9 (SD=13.40)	Non-White=25.5% White=74.5%	N=632 Female=78.3%	Spouse=45.1% Adult child=38.6% Child-in-Law=4.4% Sibling=4.3% Friend=1.9% Other relative=5.7%	Recruited from caregiver support groups at the Philadelphia Geriatric Center and the Alzheimer's Disease and Related Disorders Association.	AD	Hours per day of care=8.5	Mean=12.1 years of schooling (SD=3.16)
Ellis *et al.* (1989)[5]	**Scale1:** **Caregiver Reactions Scale (CRS)** **Scale 2:** **Social Resources Scale (SRS)**	Not reported	Not reported	N=120 Female=Not reported	Relationship of the family CG to care recipient is not reported.	Family caregivers were recruited through community agencies and local chapters of the Alzheimer's Disease and Related Disorders Association. Data from individuals meeting eligibility criteria were collected with telephone interviews conducted by trained interviewers.	Diagnosis of AD or related disorders	Not reported	Not reported
Kosberg *et al.*(1990)[6]	**The Cost of Care Index (CCI)**	Mean: 66	Not reported	N=127 Female=64%	Spouses=68% Other relatives=32%	Participants were recruited through the cooperation of local AD supports groups in the area. Caregivers were interviewed in their homes by trained personnel.	AD	Not reported	Not reported
Goodman (1991)[7]	**Scale 1:** **Perceived Social Support for Caregiving (PSSC)** **Scale 2:** **Social Conflict (SC)**	Mean: 62	Not reported	N=206 Female=69.2%	Spouse=72.1% Adult child=25.2% Other relative=2.7%	Convenience sample recruited from members of support groups and applicants to a telephone network program (that is, a telephone-based support group).	AD	Not reported	Not reported
Theut *et al.* (1991)[8]	**Anticipatory Grief Scale (AGS)**	Range: 59-76 Mean: 68.1	Not reported	N=27 Female=100%	Spouse=100%	Recruited from the Geropsychiatry Outpatient Clinic at the Veterans Administration Medical Center	Diagnosed with ADRD using DSM-III-R criteria; all had progressive deterioration	Not reported	Range=1-6 years beyond high school Mean=2.48 years beyond high school
Vitaliano *et al.* (1991)[9]	**The Screen for Caregiver Burden (SCB)**	Mean: 67.4 (SD=7.4)	Not reported	N=79 Female=68.4%	Spouse=100%	Spouse caregivers and care recipients were recruited in western Washington State. No further details are provided.	Diagnosis of possible/probable Primary Degenerative Dementia	Not reported	Mean: 13.4 years (SD=2.8)
Given *et al.* (1992)[10]	**Caregiver Reaction Assessment (CRA)**	Mean: 61.1 (SD=12.0)	Not reported	N=377 Female=81.4%	Spouse=55.4% Other family=44.6%	Participants were recruited from community health agencies (physically impaired, N=267) and eight chapters of the Alzheimer's Association (N=110)	ADRD=29.2% Physically impaired=70.8%	Mean=5.0 years of caring (SD=5.7)	At least some college=59.2%
Semple (1992)[11]	**Family Conflicts Scales (FCS)**	Mean: 62.2	Unknown=64% White=30% Black=4% Asian=1% Hispanic=1%	N=555 Female=26%	Spouse=58.7% Adult child=39.8% Child-in-Law=%1.4	Recruited from local Alzheimer's Association contact records of self-described primary caregivers of a noninstitutionalized spouse or parent (including parent-in-law) with AD or similar dementia.	AD or similar dementia from caregiver reports	Unknown=64% 0-1 year=9% 1-2 years=13% 3-5 years=11% 6+ years= 3%	Unknown=64% <High school=4% High school=10% Some college=10% College graduate=6% >College=6%
Teri *et al.* (1992)[12]	**The Revised Memory and Behavior Problem Checklist (RMPBC)**	Mean: 54 (SD=13.4)	Not reported	N=201 Female=61%	Spouse=46% Adult child=41% Other relative=10% Friend=3%	The sample recruitment pool consisted of all new patients participating in a comprehensive assessment for cognitive impairment at a geriatric clinic. Most patients were referred by family member or primary care physician because of concern about cognitive changes or mood disturbances.	Dementia=85% Depression=10% Other=5% Note: Because the sample represented a consecutive series of patients in a hospital clinic, the study included carers of patients with and without dementia.	Not reported	< Grade school=1% Grade school=3% High School=47% College=27% Graduate Degree=15% Unknown=7%

Macera *et al.* (1993)[13]	**Caregiver Burden Scale (CBS)**	Mean: 61	Black=24% Non-Black=76%	N=82 Female=84%	Spouse=54% Other relative=46%	Potential participants were contacted through support groups and the Statewide AD Registry.	Moderate to severe AD	Mean: 63 months of caregiving	Not reported
Hinrichsen & Niederehe (1994)[16]	**The Dementia Management Strategies Scale (DMSS)**	Range: 25-93 Mean: 59.6 (SD=14)	Not reported	N=152 Female=70.4%	Spouse=36.1% Adult child=58.6% Other=5.3%	Participants were recruited from medical, psychiatric, neurologic, and specialized dementia evaluation clinics, and a social service program.	Dementia Note: The MMSE mean for the patient sample was 9.2 (SD=7.5), indicating significant cognitive impairment.	Not reported	Not reported
Carruth (1996)[18]	**Caregiver Reciprocity Scale (CRS)**	Range: 51-60	Black=7.6% Hispanic=1.0% White=91.1%	N=303 Female=83.8%	Adult child=100%	A convenience sample was recruited through letters sent to retired teachers, employees of a state university, and employees of a regional hospital. Caregivers also asked others to participate.	Dementia=36.3% Arthritis=58.7% Hypertension=46.2% Heart Disease=42.9%	Not reported	Not reported
Davis *et al.* (1997)[22])	**Caregiver Activity Survey (CAS)**	Range: 34-83 Mean: 66.5 (SD=13.1),	Not reported	N=42 Female=67%	Spouse=71% Other relative=17% Friend/Neighbor=5% Paid caregiver=7%	Recruited from the patients (and their caregivers) at two Alzheimer's Disease Research Centers: the University of Washington and the Mount Sinai School of Medicine in New York	MMSE scores from 0 to 29 and met the "National Institute of Neurological and Communicative Disorders and Stroke" criteria for probable AD.	Not reported	Not reported
Picot *et al.* (1997)[23]	**Picot Caregiver Rewards Scale (Picot-CRS)**	Range: 28-82 Mean: 58.9 (SD=12.1)	Black=100%	N=83 Female=100%	Adult child=60.2% Child-in-Law=3.6% Spouse=13.3% Sibling=6.0% Other=16.9%	Recruited from a variety of community agencies that served an aging population and from written media.	Medical diagnosis of ADRD or identified by agency as probably demented or a history of confusion in the past 6 months.	Not reported	Some High school=35% High school graduate=49% College graduate=16%
Kaufer *et al.* (1998)[25]	**The Neuropsychiatric Inventory Caregiver Distress (NPI-D) Scale**	Range: 40-89 Mean: 64.2 (SD=13.0)	Not reported	N=85 Female=71.8%	Spouse=63.5% Adult child=32.9% Child-in-Law=3.5%	Recruitment targeted caregivers of patients enrolled in the memory disorder clinics at the University of California at Los Angeles and the University of Pittsburgh	Possible AD=30.6% Probable AD=69.4% Note: Measured by National Institute of Neurological and Communicative Disorders and Stroke -Alzheimer's Disease and Related Disorders Association Work Group criteria.	Not reported	Not reported
Zeiss *et al.* (1999)[26]	**Scale 1:** **Caregiver Self-Care Self-Efficacy** **Scale 2:** **Problem-Solving Self-Efficacy**	Range: 30-85 Mean: 59.5 (SD= 11.3)	Not reported	N=217 Female=83%	Spouse=53% Adult child=45% Other=2%	Participants were caregivers who completed a research program to judge the effectiveness of two psycho-educational classes designed to reduce the emotional distress of caregivers of frail older adults at the Palo Alto Veterans Administration Medical Center.	Cognitive deficits, in particular, AD=53% No cognitive impairment=47%	Not reported	Not reported
Farran *et al.* (1999)[27]	**Finding Meaning Through Caregiving Scale (FMTCS)**	Mean: 71.67 (SD=8.54)	Black=35.8% White=64.2%	N=215 Female=63.7%	Spouse=100%	Respondents were recruited by referrals from Alzheimer's clinics, Veterans Administration hospital programs, community home-care programs, and adult day care centers in a large metropolitan area which provided services to persons with presumed medical diagnoses of possible dementia. Five participants were recruited from African American churches who were caring for a spouse who had trouble remembering the time, things that were told them, and recognizing people they knew, or were confused about everyday life.	Dementia	Not reported	Mean=13.1 years of education

Gitlin *et al.* (2002)[32])	**Task Management Strategy Index (TMSI)**	Sample 1 Mean: 60.79 (SD=13.87) Sample 2: Mean: 61.01 (SD=14.30)	Sample 1: White=74.3% Black=24.3% Other=1.5% (Sample 2: White=48.2% Black=47.8% Other=3.9%)	Sample 1: N=202 Female=71.8% (Sample 2: N=255 Female=74.5%)	Sample 1: Spouse=24.1% Non-spouse= 75.9% (Sample 2: Spouse=38.8% Non-Spouse=61.2%)	Sample 1: (N=202) Participants were drawn from a dementia-management intervention study recruited from local social service and medical centers as well as media announcements. Sample 2: (N=255) Participants were drawn from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study. They were recruited primarily from the Philadelphia Corporation for Aging (PCA), the area agency on aging for Philadelphia County, and from media announcements.	Sample 1: ADRD. (Sample 2: Documented diagnosis of dementia or a MMSE < 24.)	Sample 1: Mean=3.67 years of caregiving (SD=2.82) (Sample 2: Mean=4.24 years of caregiving (SD=3.77))	Sample 1: Mean=13.86 years of formal education (SD=3.05) (Sample 2: Mean=12.23 years of formal education (SD=2.62))
Fortinsky *et al.* (2002)[33]	**Family caregiver self-efficacy for managing dementia**	Range: 29–81 Mean: 56 (SD=14)	Black=19% Non-Black=81%	N=197 Female=82%	Spouse=28% Adult child (natural and in-law)=62% Other=10%	Participants were recruited from family caregivers who called the Help Line of the Cleveland Area Alzheimer's Association.	AD or another irreversible dementia	Not reported	Not reported
Marwit *et al.* (2002)[34]	**Marwit–Meuser Caregiver Grief Inventory (MM-CGI)**	Mean: 61.64 (SD=13.002)	White=92.8% Other=7.2%	N=166 Female=81.3%	Spouse=50% Adult child=50%	Participants were recruited through the Memory and Aging Project (the clinical research arm of the Alzheimer's Disease Research Center at Washington University School of Medicine), the St. Louis Chapter of the Alzheimer's Association, and the Alzheimer List (an e-mail–based support group.	AD=82.5% Other dementias=17.5%	Mean % Monthly Care=67.54% (SD=31.251)	Range: 3-24 years of education Mean: 14.63 years of education (SD=2.71)
Steffen *et al.* (2002)[35]	**Revised Scale for Caregiving Self-Efficacy (R-SCSE)**	Sample 1: Mean: 63.8 (SD=8.3) (Sample 2: Mean: 60.2 (SD=13.3))	Sample 1: White=89.4% Hispanic=6.4% Black=2.1% Asian/Pacific=2.2% (Sample 2: White=84% Black=16%)	Sample 1: N=169 Female=100% (Sample 2: N=145 Female=80%)	Sample 1: Spouse=56.8% Adult child=39.1% Other=4.1% (Sample 2: Spouse=46.2% Adult child=46.2% Other=7.6%)	Sample 1: Recruited as part of an ongoing randomized trial of psycho-educational classes to reduce caregiver distress. Means of recruitment included media announcements, targeting mailings, churches, senior centers, medical clinics, and senior service professionals. (Sample 2: Recruited for a measurement development study. Similar means of recruitment except for a higher reliance on the local Alzheimer's Association.)	AD	Sample 1: Mean=45.9 months of care (SD=45.3) (Sample 2: Mean=35.6 months of care (SD=27.8))	Sample 1: Mean=14.5 years of education (SD=2.0) Median (Sample 2: Mean=13.6 years education (SD=2.4) Median
Mahoney *et al.* (2003)[37]	**Caregiver Vigilance Scale (CVS)**	Range: 22-95 20-44=11% 45-54=19% 55-64=22% 65-75=25% 76-84=20% 85+=2%	White=56% Black=24% Hispanic=19% Other=1%	N=1,229 Female=81%	Spouse=47.9% Adult child=44.2% Other=7.9%	Caregivers recruited for this study were enrolled in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project. REACH participants were enrolled from memory-disorder clinics, primary care clinics, social service agencies, and physicians' offices with special attention to enrolling diverse participants.	Medical diagnosis of probable AD or a MMSE < 24.	At least 6 months	< High school=19% High school=24% > High school=56%
Stevens *et al.* (2004)[40]	**The Leisure Time Satisfaction (LTS)**	Range: 22-95 Mean: 62.3 (SD=13.6)	White=56.3% Black=24.0% Hispanic=18.9% Other=0.8%	N=1,225 Female=81.4%	Spouse=48.0% Adult child=44.3% Sibling=2.3% Other=5.5%	Caregivers recruited for this study were enrolled in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project to carry out social and behavioral research on interventions designed to enhance family caregiving for persons with ADRD. REACH participants were enrolled from memory-disorder clinics, primary care clinics, social service agencies, and physicians' offices with special attention to enrolling diverse participants.	Medical diagnosis of probable AD or a MMSE < 24.	At least 6 months	< High school=19.2% High school diploma=24.4% > high school=56.4%
Gaugler *et al.* (2004)[42]	**Percieved Unmet Need (PUN)**	Mean: 61.17 (SD=13.24)	White=98.4% Other=1.6%	N=694 Female=70.9%	Spouse=37.3% Non-Spouse=62.7%	Listed contacts of patients who visited the University of Kentucky Alzheimer's Disease Research Center (UK-ADRC) since 1989 were considered for inclusion in the study. The sample included three groups of caregivers based on the "stage" of the care recipient: still living in the community (N=344, 49.6%), institutionalized (N=134, 19.3%), or deceased (N=216, 31.1%).	ADRD	Not reported	Mean=5.39 (SD=2.09) (1=No junior high diploma, 2=No high school diploma, 3=High school diploma, 4=Some college, 5=Associate degree, 6=College

									degree, 7=Some graduate, 8=Graduate degree)
Tarlow *et al.* (2004)[43]	**The Positive Aspects of Caregiving (PAC)**	Range: 22-95 Mean: 62.2	White=57% Black=22.3% Hispanic=19.8% Other=1%	N=1,229 Female=81.4%	Husband=12.4% Wife=36.4% Adult child=46.2% Other=5.0%	Caregivers recruited for this study were enrolled in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project to carry out social and behavioral research on interventions designed to enhance family caregiving for persons with ADRD. REACH participants were enrolled from memory-disorder clinics, primary care clinics, social service agencies, and physicians' offices with special attention to enrolling diverse participants.	Medical diagnosis of probable AD or a MMSE < 24.	≥ 6 months of caregiving for a minimum of 4 hours per day	High School graduate=80.8%
Mitrani *et al.* (2005)[44]	**Structural Family Systems Ratings-Dementia Caregiver (SFSR-DC)**	Mean: 69.2 (SD=11.3)	Hispanic=53% White=47%	N=177 Female=71.8%	Spouse=68.4% Adult child=23.2% Other relative=8.5%	Family caregivers recruited for this study were enrolled in the <u>Miami</u> site of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project. REACH participants were enrolled via medical providers, social service agencies, and mass media announcements.	Medical diagnosis of probable AD or a MMSE < 24.	Mean: 3.7 years of caregiving (SD=3.1)	< High school=17.5% High school education=19.8% > high school=62.7%
Gitlin *et al.* (2005)[45]	**Caregiver Assessment of Function and Upset (CAFU)**	Mean: 61.9 (SD=13.5)	Black=43% White=53% Mixed=4%	N=640 Female=77%	Adult child=41.9% Spouse=45% Other=13.1%	Family caregivers recruited for this study were enrolled in the <u>Birmingham,</u> <u>Memphis,</u> and <u>Philadelphia</u> sites of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project. REACH participants were enrolled via community sites, health and social agencies, primary care clinics, and physician offices. (Caregivers were eligible if older than 21 years of age and lived with and provided an average of 4 hours of supervision or direct care each day for a relative with ADRD for at least the past 6 months.)	Medical diagnosis of probable AD or a MMSE < 24. <u>Note</u>: Care recipients should also had at least one limitation in basic activities of daily living (ADLs) or two dependencies IADLs to ensure that caregiving involved potentially burdensome daily tasks.	≥ 6 months of caregiving for a minimum of 4 hours per day	>=High school=80%
Kuhn *et al.* (2005)[50]	**Knowledge about Memory Loss and Care test (KAML-C)**	Overall: Mean: 44.4 (SD=15.44) (*Caregivers*: Range: 25-83 Mean: 54.3 (SD=15.3))	Overall: Not reported (Caregivers: White=95.5% Non-White=4.5%)	N=121 Female=66.4% (Caregivers: N=45 Female=73.3%) <u>Note</u>: Discrimination and difficulty indexes for the KAML-C test were calculated with the sample of caregivers <u>and</u> experts (N=82).	Overall: Not reported (Caregivers: Adult child=57.8% Spouse=28.9% Other=13.3%)	<u>Caregivers</u> (N=45) were recruited for a five-week educational program from memory disorder clinics, a continuing care retirement community, a senior center, and the local chapter of the Alzheimer's Association. <u>Experts</u> (N=37) were recruited from medicine, nursing, social work, health services research, psychology, gerontology, and employment in Alzheimer's disease Research. <u>Medical students</u> (N=39) were a fourth-year class from the Oregon Health & Science University.	(For caregiver respondents: care receivers were early-stage AD)	Not reported	*(Caregivers:* High school graduate=13.3% Some college =35.6% College graduate=28.9% Advanced degree=22.2%) *(Experts:* Mean: 18.7 (SD=2.1)) (Students: Mean: 19.9 (SD=0.6))
Gitlin *et al.* (2006)[51]	**Perceived Change Index (PCI)**	Mean: 61.06 (SD=14.31)	Black=47.8% White=48.2% Other=4.0%	N=255 Female=74.5%	Non-Spouse=61.2% Spouse=38.8%	Family caregivers recruited for this study were enrolled in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project. REACH participants were enrolled via community sites, health and social service agencies, primary care clinics, and physicians' offices.	Medical diagnosis of probable AD or a MMSE < 24.	Mean=4.25 years of caring (SD=3.77)	Mean=12.23 years of education (SD=2.62)
Reilly *et al.* (2006)[52]	**Partner-Patient Questionnaire for Shared Activities (PPQSA)**	Mean: 66.4	Not reported	N=100 Female=64%	Spouse=71% Non-spouse=29%	Participants were a convenient sample of caregivers accompanying patients at five medical treatment centers.	Diagnosed with AD at a medical treatment center and scored between 16 and 27 on the MMSE.	Not reported	Some college=64.7%
Menne *et al.* (2008)[58]	**Decision-Making Involvement Scale (DMIS)**	Mean: 61 (SD= 13.87)	White=63% Black=37%	N=217 Female=79%	Spouses=57% Adult child (natural or in-law)=31%	Participants were recruited from client lists of the Family Caregiver Alliance in San Francisco, the Eldercare Services Institute in Cleveland, and the	Diagnosis of a dementing condition or a MMSE score between 13 and 26.	Not reported	Not reported

					Other=12%	University Memory and Aging Center in Cleveland.			
Wilks (2008)[60]	**Shortened Resilience Scale (RS-15)**	Mean: 45	White=72.9% Black=24.5% Asian=2.6%	N=229 Female=90%	Adult child=49.3% Spouse=29.3% Friend=7.9% Grandchild=5.2% In-law=3.9% Other=3.9%	Questionnaires were administered to attendees at two large conferences for Alzheimer's caregivers in the eastern USA.	ADRD	Not reported	Not reported
Wilks (2009)[62]	**Shortened Perceived Social Support Scale (S-PSSS):** **Scale 1:** ***S-PSSS Family (SSfa)*** (Family support among AD CGs) **Scale 2:** ***S-PSSS Friends (SSfr)*** (Friends support among AD CGs)	Range: 18-72 Mean: 44.8 (SD=13.12) (Demographically, the two subsamples: N=115 (Scale 1) and N=114 (Scale 2) were reasonably homogenous.	White=72.8% Black=24.6% Asian=2.6% (Demographically, the two subsamples were reasonably homogenous.)	N=115 Female=89.9%	Adult child=48.6% Spouse=29.7% Friend=8.1% Grandchild=5.4% In-law=4.1% Other=4.1% (Relationship distributions for the two subsamples were relatively similar.)	Questionnaires were administered to attendees at two large conferences for Alzheimer's caregivers in the eastern USA.	ADRD	Not reported	Not reported
Carpenter *et al.* (2009)[65]	**The Alzheimer's Disease Knowledge Scale (ADKS)**	**Overall** Mean: 35.11 (SD=21.90) **Dementia Caregivers** Mean: 62.48 (SD=12.33)	**Overall** American Indian/Alaskan=1.2% Asian/Pacific Is=13.7% Black/African American=6.1% White=59.0% Multiracial=9.2% Hispanic=10.8% **Dementia Caregivers** American Indian/Alaskan=3.4% Asian/Pacific Is=12.1% Black/African American=20.7% White=46.6% Multiracial=5.2% Hispanic=12.1%	Overall: N=763 Female=70.2% (Caregivers: N=54 Female=81.5%)	Relationship of the family CG to care recipient is not reported.	The study used convenience samples (e.g., asking for volunteers at an agency, soliciting undergraduates in a subject pool, etc.) Some questionnaires were distributed by hand and others were mailed. The study uses a mixed sample composed of the following five groups: Students (N=484); General public-Older adults (N=89); Senior center staff (N=61); Dementia Caregivers (N=54); and Dementia professionals (N=75)	Dementia	Not reported	Not reported
Czaja *et al.* (2009)[67]	**REACH Risk Appraisal Measure (RAM)**	Range: 22 to 89 Mean: 60.57 (SD=13.32)	Hispanic=33.0% Black=32.9% White=34.1%	N=642 Female=82.9%	Spouse=42.4% Adult child=47.8% Sibling=2.8% Other=7.0%	Study participants were recruited through media, university medical clinics, community agencies, etc. Eligibility requirements included age 21 and older, lived with or shared cooking facilities with the patient, had provided care for a minimum of 4 hours per day for at least the past 6 months, and reported distress associated with caregiving.	Physician-diagnosed ADRD or a MMSE < 24 and have a limitation in at least one activity of daily living or two instrumental activities of daily living.	≥ 4 hours/day for ≥ 6 months	< High school=11.8% High school=22.6% > High school=57.8% Missing=7.8%
Vickrey *et al.* (2009)[70]	**Caregiver-targeted quality-of-life (CGQOL)**	Mean: 61.5 (SD=13.5)	White=66% Black=9% Asian=7% Hispanic=18% Other=1%	N=200 Female=79%	Spouse=45.5% Adult child/Child-in-Law=42.5% Sibling/Sibling-in-Law=3.5% Niece/Nephew=1% Grandchild=1.5% Friend=4% Other=3%	The initial group of participants (N=51) were recruited from UCLA Alzheimer's Disease Center longitudinal registry study. Another group (N=149) of participants were recruited from flyers, announcements in newsletters, and websites.	Dementia Dementia Severity: Mild=17% Intermediate=60% Advanced=23%	<1 year of care=11% 1-2 years of care=14% 2-3 years of care=14% 3-5 years of care=21% >5 years of care=42%	≤ 8 years=3% Some high school=3% High school graduate=8% Some college=33% College graduate=29% > College=24%
Epstein-Lubow *et al.* (2010)[71]	**Caregiver Self-Assessment**	Not reported	White=97.2% Other=2.8%	N=106 Female=66%	Spouse=39.0% Adult child=50.5%	Family caregivers were recruited from an inpatient geriatric psychiatry unit, an outpatient	Dementia or MCI=91.5% Other (other chronic	Not reported	Not reported

	Questionnaire (CSAQ)				Other=10.5%	memory disorders program, and community outpatient programs related to caregiving and mental health.	illnesses: mental or Parkinson disease)=8.5%		
Gough *et al.* (2010)[72]	**Intrinsic Spirituality Scale (ISS)**	Mean: 62.7 (SD=13.53)	Black=13.2% White=85.9% Hispanic=0.7% Multiethnic=0.3%	N=304 Female=76%	Spouse=43.1% Adult child=38.8% Friend=4.3% Other=13.8%	Recruited from a sampling frame of attendees of Alzheimer's caregiver support groups. Group facilitators distributed surveys among group members and then submitted completed surveys to the researcher.	AD	Not reported	Not reported
Savundranayagam *et al.* (2011)[78]	**Montgomery Borgatta Caregiver Burden Scale (MB-CBS)**	Spouses*:* Range: 24-91 Mean: 63 Adult Child*:* Range: 23-71 Mean: 52	Spouses*:* White: 91.0% Black: 4.0% Hispanic: 3.0% Other 3.0% Adult child*:* White: 77.0% Black: 8.0% Hispanic: 5.0% Other: 9.0%	Spouses: N=280 Female=76.4% Adult child: N=243 Female=87.9%	Spouse=53% Adult child=47%	All participants were part of the League of Experienced Family Caregivers, a registry of family caregivers who volunteer to help others with caregiving, housed at the University of Wisconsin-Milwaukee. The study used two recruitment methods: 1) staff from 100 provider organizations like home health agencies and Alzheimer's Association chapters in six states shared details of the study with caregivers and 2) study information was also distributed at caregiver conferences and support groups.	Cognitive or memory problems or a diagnosis of probable AD or dementia. (Proportions not reported.)	Spouses: <6 months of caregiving=1.1% 6-12 months=6.5% 13-24 months=9.0% 25 months to 5 years=30.7% >=5 years=52.7% Adult child: <6 months of caregiving=5.4% 6-12 months=11.3% 13-24 months=14.6% 25 months to 5 years=32.6% >=5 years=36.0%	Spouses*:* < High school (HS)=0.4% Some HS=3.9% HS graduate=13.6% Some college=33.9% College graduate=27.1% Graduate degree=21.1% Adult child*:* < HS=0.0% Some HS=0.8% HS graduate=11.6% Some college=31.0% College graduate=33.5% Graduate degree=23.1%
Erder *et al.* (2012)[81]	**Caregiver-Perceived Burden Questionnaire (CPBQ):** **Scale 1: Caregivers' Assessment of the Patient (CAP)** **Scale 2: Caregivers' Assessment of Themselves (CAT)**	Range: 18 to 93 Mean=58.2 (SD=15.6)	Not reported	N=676 Female=71%	Adult child=39% Spouse=37% Other=24%	Participants were recruited as part a multinational, randomized, double-blind, placebo controlled trial designed to investigate the safety and efficacy of ER memantine.	Moderate to severe AD (i.e., MMSE between 3 and 14)	Not reported	Not reported
Lopez & Guarino (2013)[84]	**Surrogate Decision Making Self-Efficacy Scale (SDM-SES)**	Mean: 63.77 (SD=11.76)	White=95.5% Other=4.5%	N=155 Female=59.5%	Spouse, Sibling, or Adult child=83.9% Other=16.1%	Family caregivers surrogate decision makers (SDMs) were drawn from 8 for-profit nursing homes in New England. A member of the nursing home staff abstracted SDMs' names and addresses from the records of nursing home residents with impaired decision making.	Nursing home residents with impaired decision making capabilities.	Not reported	Not reported
Bekhet & Zauszniewski (2013)[86]	**Depressive Cognition Scale (DPS)**	Range: 22-87 Mean: 57.5 (SD=15.6)	White=56.3% Black=35% Hispanic, Asian, or other=8%	N=80 Female=90%	Parent=15% Adult child=26.3% Spouse=20% Sibling=3.8% Other relative=35%	Participants were recruited from Alzheimer's Association early stage programs.	Dementia	Not reported	High school=25% Associate or some college=30% College degree=20% Graduate/Professional=25%
Wilks *et al.*(2013)[89]	**Spiritual Support Scale (SSS)**	Mean: 61	White=62% Black=36% Other=1.3% Hispanic=0.9%	N=691 Female=79.8%	Adult child=51.5% Other=16.9% Spouse/partner=16.8% Grandchild=6.6% Sibling=4.4% Friend=3.8%	Recruited through 1) mailing lists of Alzheimer's service organizations and 2) quota sampling within homes and areas of assembly within the African American community (adult day care centers, churches, and community centers).	AD: Early stage=22.3% Middle stage=36.1% Late stage=41.5%	Not reported	Not reported

Cole *et al.* (2014)[92]	**Impact of Alzheimer's Disease on Caregiver Questionnaire (IADCQ)**	18-29 years=11%, 30-49 years=39.5%, 50-69 years=47%, 70+ years=2.5%	White=84.5% Black=7% Asian=4.5% Native American=1% Other=3%	N=200 Female=60%	Relationship of the family CG to care recipient is not reported.	AD caregivers, who previously indicated their willingness to be contacted for research purposes, were recruited via e-mail from a panel of caregivers in the US managed by a research-panel vendor. Interested and eligible participants provided informed consent electronically before completing the demographic questions and the study instrument.	AD	<6 months= 10% 6-12 months= 22.5% 13-24 months= 25.5% >2 years= 42%	Not reported
Solberg *et al.* (2014)[96]	**Caregiver Stress Impact Scale (CGQ-13)**	Mean: 54.69 (SD=9.60)	Not reported	N=45 Female=80%	Adult child/Child-in-law=100%	Adult (over 18 years old) children/children-in-law who self-identified as primary caregiver (no dimensions of this) of parents with dementia, recruited from private outpatient geriatric clinic.	Dementia	Not reported	Not reported
Sadak et al. (2015)[100]	**Partnering for Better Health-Living with Chronic Illness: Dementia (PBH-LCI:D)**	Mean: 65.9 (SD=11.1)	White=91% Asian=4% Black=4% Native American=1%	N=130 Female=80%	Spouse or partner=63% Adult child=25% Relative or Friend=12%	A convenience sample was recruited from community sources including: a) support groups led by the Alzheimer's Association, local Senior Services, assisted living facilities, and memory clinics and b) dementia workshops, conferences, and dementia advocacy events. A packet containing the PBH-LCI:D questionnaire and other measures was mailed to participants.	Dementia	Not reported	High school graduate=23% College graduate=77%
Powers & Whitlach (2016)[103]	**Cultural Justifications for Caregiving Scale (CJCS)**	Mean: 64.74 (SD=12.56)	African American=35% White=65%	N=202 Female=79%	Spouse=56.4% Adult child=35.6% Other=7.9%	Participants were recruited from Family Caregiver Alliance's client lists in the San Francisco Bay Area and community outreach. Prospective participants were sent a letter describing the study and asking for their participation. Screening to determine preliminary eligibility was conducted by phone.	Confirmed diagnosis of a dementing condition or a MMSE score between 13 and 26.	Mean: 38.0 months (SD=39.75) (Mean: 3.17 years)	No high school=0.5% Some high school=6.8% High school graduate=19.9% Some college=36.6% College graduate=16.2% Post graduate degree=19.9%
Piersol *et al.* (2016)[106]	**Functional Capacity Card Sort (FCCS)**	Mean: 65.8 (SD=12.2)	Non-White=22.7% White=77.3%	N=88 Female=88.6%	Spouse=55.7% Non-spouse=44.3%	Convenience sample recruited from mailings, physician offices, and media advertisements.	Dementia	Range: 0.5 to 22 years Mean: 5.1 years (SD=3.5)	High school=2.3% More than High School=97.7%
Sadak et al. (2017)[110]	**Kingston Caregiver Stress Scale (KCSS)**	Mean: 67.1 (SD=12.3)	White=98% Non-White=2%	N=205 Female=75%	Spouse=62% Other=38%	Recruited from memory clinics and support organizations (e.g., senior centers, Alzheimer's Association)	ADRD=87%	Not reported	12 years or more=97% Other=3%
Piggott *et al.* (2017)[112]	**Caregiver Confidence in Sign/Symptom Management (CCSM) Scale**	Range: 23-90 Mean: 62	White=79% Black/African American=18% Asian=3%	N=194 Female=83%	Spouse=41% Daughter=43% Daughter-in-law=6% Other relative=10%	Potential participants were identified though flyers, websites, and outreach by various organizations (e.g., the Alzheimer's Association), and an effort was made to solicit white/nonwhite, college/non-college–educated, and spouse/non-spouse caregivers.	ADRD	Not reported	College or graduate degree=53%
Weisman de Mamani *et al.* (2018)[121]	**Stigma Impact Scale (SIS)**	Range: 25–83 Mean: 50.73 (SD = 12.73)	White=53.8% Black=28.3% Hispanic=6.6% Asian-American=1.9% Other=9.4%	N=106 Female=81.1%	Adult child=51.9% Spouses=14.2% Grandchildren=17.9% Nieces/nephews=8.5% Children in-law=5.7% Siblings=1.9%	Caregivers were recruited throughout the United States through Craigslist and Google advertisements posted nationally. Also calls were placed to various agencies throughout the country that service elderly populations to let them know about the study and to provide contact information.	Diagnosis of dementia or age-related memory impairment (confirmed through the CDR Scale)	Not reported	Advanced degree=19.8% College degree=38.7% Some college=37.7% High school=2.8% Some H.S.=0.9%
Peipert *et al.* (2018)[126]	**Dementia Burden Scale – Caregiver (DBS-CG)**	Range: 22-99 Mean: 63 (SD=14)	Race: White=44% Black=6% Asian=5% Other=5%	N=1,091 Female=67%	Adult child= 49% Spouse/partner= 35% Friend= 2% **Paid or hired**	Caregivers were recruited from UCLA Alzheimer's disease Center programs.	Dementia type not specified=43% AD=38% Mixed dementia=8% Vascular dementia=4%	Not reported	High school graduate=9% Some college=16% College

			Missing=39% Ethnicity: Hispanic=10% Not Hispanic=50% Missing=40%		**caregiver= 3%** Other= 10%		Other dementia=6%		graduate=40%
Davis *et al.* (2019)[129]	**Guilt After Placement Questionnaire (GAP-Q)**	Mean: 56.79 (SD=13.19)	Caucasian=71.8% African American=21.2% Hispanic=2.4% Other=4.6%	N=170 Female=69.4%	Spouse=12.4% Adult child=54.7% Other family member=32.9%	Participants were recruited through nursing home coordinators. The remainder of the study group was recruited at a long term care nursing facility while visiting the family member.	Dementia	Not reported	Not reported
Wynn & Carpenter (2020)[137]	**The Frontotemporal Dementia Knowledge Scale (FTDKS)**	Mean: 51.5 (SD=15.7)	White=90.2%	N=174 Female=76.4%	**Caregivers of people with FTD**=58.6% (*Spouses, Adult children, Relatives, and Friends)* **Professional caregivers of people with FTD**=41.4%	The study included a mixed sample consisting of family/friend caregivers (58.6%) and professional carers (41.4%). Participants were recruited primarily via online and support networks/groups associated with the Association for Frontotemporal Degeneration.	FTD	Level of care provided: Never been involved=9.8% Helped arrange=2.0% Assisted in caregiving=15.7% Primary caregiver=72.5%	High school=4.9% Some college=16.7% Associate's degree=3.9% Bachelor's degree=40.2% Master's degree=25.5% Doctoral degree8.8%
Van Houtven *et al.* (2020)[138]	**Caregiver Perceptions About Communication with Clinical Team Members (CAPACITY) Instrument**	Mean: 70.3 (SD=9.6)	White=95.8%	N=1,746 Female=67.7%	Spouse/Significant Other=89.1% Other=10.9%	Participants were recruited from the CAREIDEAS study, a supplemental survey study to the Imaging Dementia—Evidence for Amyloid Scanning or **IDEAS study**. The IDEAS Study recruited Medicare beneficiaries aged 65 years and older with progressive MCI and/or dementia of uncertain cause from 592 dementia practices. The IDEAS Study transferred contact information of patients who agreed to be contacted for the CAREIDEAS supplemental study. Dyads (patients and their care partners) were recruited.	MCI=72.4% Dementia=27.6%	Time providing care for the patient (hours) 5 hours or fewer a week (wk) =29.8% 6–19 hours a wk=13.8% 20–39 hours a wk=5.6% 40 or more hours a wk=4.7% Not providing care or don't know =46.0%	High school graduate or less=14.1% Some college=28.8% Bachelor's degree=27.4% Graduate degree=29.8%
Galvin *et al.* (2020)[142]	**The Positive and Negative Appraisals of Caregiving (PANAC) Scale**	Mean: 55.5 (SD=15.1)	White=92.9% Hispanic=8%	N=253 Female=62.7%	Spouses= 68.6% Adult child= 18.8% Other= 12.6%	The sample was recruited through the Comprehensive Center for Brain Health, University of Miami, Miller School of Medicine: patient-caregiver dyads attending the center for clinical care or participated in cognitive aging research who completed all questions in the PANAC.	Cognitively normal= 14.6% MCI=31.2% AD=15.0% Lewy bodies= 32.0% Vascular dementia= 4.7% FTD=2.4%	Not reported	Mean=16 years (SD=2.6)
Teresi *et al.* (2020)[153]	**Perceived Stress Scale (PSS)**	Range: 19-92 Mean: 58.4 (SD = 11.2)	Hispanic=100% (Dominican, Puerto Rican, and Mexican)	N=453 Female=84%	Majority female (84%) and most were spouses or daughters.	Caregivers were recruited through the Alzheimer's Association, an outpatient geriatric clinic, an academic center memory clinic, and through community outreach and caregiver programs.	ADRD	Not reported	Mean: 12.6 years of education (SD=3.8) High school graduate=55% ≥High School=45%
Thompson *et al.* (2020)[154]	**Fear of Incompetence—Dementia Scale (FOI-D)**	Range: 18–80 Mean: 36.44 (SD=11.29)	Caucasian=79%	N=636 Female=65.2%	Grandchildren= 54% Adult child= 21% Niece/nephew= 15% Great-grandchild= 2% Other= 8%	Caregivers were recruited via an advertisement placed on Mechanical Turk (MTurk). (MTurk is a widely used online marketplace through which participants can complete a variety of tasks in exchange for a nominal fee.)	Dementia (diagnosed with dementia an average of 3.94 years ago)	Range: 2 months–30 years Mean: 3.94 years	Not reported
Rose *et al.* (2021)[157]	**Family Quality of Life in Dementia (FQOL-D) scale.**	Mean: 52 (SD=2.0)	White=74.2% African American=21.3% Native American/Asian/Pacific Islander/Other=4.5%	N=244 Female=56.6%	Spouse/partner=45.5% Daughter=27% Son=4.5% Other	Participants were identified through the support of a memory and aging neurology practice site, as well as several aging centers and agencies. Once individuals were identified, surveys were distributed to participants using multiple	ADRD	At least 8 hours per week of care to an older adult.	7–11 years=2.0% High school graduate=28.3% 13–15 years=25.0%

					relative=13.1% Friend/neighbor=5.3% Other=4.5%	methods (e.g., hand delivered at meetings/workshops, flyers with contact information for participants to be mailed a survey).			College graduate=29.1% 17–18 years=7.0% >18 years=8.6%
Park *et al.* (2022)[168]	Pre-Loss Grief-10-Dementia (PG-10-D)	Range: 23-89 Mean: 60.20 (SD=10.75)	Non-Hispanic White=95.3% African American=1.4% Asian=0.6% Native American=0.4% Pacific Islander=0.3%	N=699 Female=88.7%	Spouse=56.8% Adult child=37% Other family=2.9% Non-family=3.3%	Caregiver of a patient with dementia, including AD, dementia with Lewy bodies, Parkinson disease dementia, or other dementias were eligible to participate. Caregivers were recruited using email lists from selected organizations such as the Lewy Body Dementia Association, the Alzheimer's Foundation of America, the National Family Caregiver Alliance, and other relevant organizations. The study information was also listed on social media and selected webpages.	**Diagnosis:** Lewy bodies= 65.8% AD= 11.4% Parkinson's disease dementia= 10.9% Other dementias= 8.9% **Disease stage:** Mild= 6.7% Moderate= 55.4% Severe= 34.6%	Not reported	Post-college=34.9% Less than 7 years=0.3% Partial high school=0.7% High school=9.0% Partial college=22.7% College=31.9%
Kuzmik *et al.* (2023)[180]	**Modified Caregiver Strain Index (MCSI)**	Mean: 61.9 (SD=14.0)	Non-Hispanic White=66% (n=279) Non-Hispanic Black=34% (n=144)	N=423 Female=72.3%	Adult child=52% Spouse=29% Nephew/niece=4% Sibling=4% Granddaughter/son=3% Goddaughter=1% Friend=2% Daughter-in-law=2% Partner=1% Other-e.g., sister in law, cousin=3%	Family caregivers were recruited from a cluster randomized clinical control trial of family-centered function-focused care. Caregivers were 18 years or older and family members. (Hospitalized patients were 65 years or older and not admitted from a nursing home or enrolled in hospice.)	Diagnosed with very mild to moderate dementia: {Montreal Cognitive Assessment (≤25), AD8 Dementia Screening Interview (≥2), Clinical Dementia Rating Scale (Range: 0.5-2.0), Functional Activities Questionnaire (≥9).}	Not reported	Less than high school=8% High school graduate=25% Some college or technical school=30% College graduate=21% Graduate or professional school=14%

AD = Alzheimer's disease; ADRD = Alzheimer's disease and related disorders; CDR = Clinical Dementia Rating; FTD=frontotemporal dementia; GCSE = General Certificate of Secondary Education (high school grading system in some European countries); MCI = mild cognitive impairment; MMSE = Mini-Mental State Examination.