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**
Hebert *et al.* (2000)[30]	**Zarit Burden Interview (ZBI)**	Mean: 61.7 (SD=13.4)	Not reported	N=312 Female=79.2%	Spouse=32.1% Adult child=48.6% Sibling (natural or in law)=4.0% Other family=6.4% Friend=8.9%	Participants were recruited as part of the Canadian Study of Health and Aging (CSHA). The CSHA sampled 9,008 community dwelling elderly people across Canada. Researchers screened this sample and identified individuals with mild, moderate or severe dementia using DSM-III criteria and a modified MMSE score < 78. Informal caregivers of these individuals were invited to participate in the validation study.	Dementia Note: Dementia was diagnosed and classified as mild, moderate or severe according to the DSM-III R.	Not reported	Not reported
Guberman *et al.* (2001)[31]	**The Caregiver Risk Screen (CRS)**	Range: 24-89 Mean: 60	Not Reported	N=76 Female=82%	Spouse=27.6% Mother=36.8% Other (fathers, mothers/fathers in law, sisters in law, friend or neighbors)=35.6%	Researchers chose a purposive sample from seven home care agency sites in Quebec (N=4) and Nova Scotia (N=3). Assessors within each research site selected known family caregivers and invited them to participate in the study. Over half of the respondents were giving care to cognitively-impaired family members (57%) and the rest were not (43%).	Cognitive impairment=57% Other health conditions=43%	Range: 2 months to 32 years	Not reported
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
Suwa (2003)[36]	**Assessment Scale for Caregiver's Experience with Dementia (ASCED)**	Mean: 51.4 (SD=11.3)	Japanese=100%	N=90 Female=72.2%	Spouse=23.3% Adult child=38.9% Child-in-Law=36.7% Other=1.1%	The study recruited a convenience sample of caregivers to outpatients of a Senile Dementia Center in Japan.	AD=71.1% Vascular dementia=18.9% Mixed type of dementia=8.9% Other dementia=1.1%	Not reported	Mean: 11.6 years of education (SD=2.8)

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%
Goolieb & Rooney (2003)[38]	**RIS Eldercare Self-efficacy Scale**	Range: 31-88 Mean: 61 (SD=13.4)	Not reported	N=146 Female=73%	Spouse=37% Adult child=60.3% Other=2.7%	Caregivers were recruited into the study with the help of two urban geriatric agencies that provided community services to the caregivers or registered the patient for possible future placement in long-term care.	AD or another dementia disorder	Mean: 5.4 years of care (SD= 16.1)	< High school=18.6% High school=32.4% College=26.9% > College=22.1%
Gräßel *et al.* (2003)[39]	**Burden Scale for Family Caregivers (BSFC)**	Mean: 58 (SD=11.9)	Not reported	N=1,143 (Dementia sample) Female=84.5% (N=548-Independent/cross-validation "non-dementia" sample)	Spouse=44% Adult child=38% Child-in-Law=10% Others=8%	BSFC questionnaires were distributed by the staff of three cooperating support services from the city of Erlangen, Germany or via the regional branch of the Society for Alzheimer's sufferers and their caregivers.	Dementia=100% (Dementia caregivers sample) Note: 45% of the "*non-dementia caregivers sample*" were caring for elderly people with relatively unimpaired cognitive performance and the remaining 55% were carers of individuals with neurological disorders.	Mean: 3.2 years of caregiving (SD=1.4)	Not reported
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-**	Mean: 69.2 (SD=11.3)	Hispanic=53% White=47%	N=177 Female=71.8%	Spouse=68.4% Adult child=23.2%	Family caregivers recruited for this study were enrolled in the Miami site of the Resources for	Medical diagnosis of probable AD or a MMSE <	Mean: 3.7 years of caregiving	< High school=17.5%

	Dementia Caregiver (SFSR-DC)				Other relative=8.5%	Enhancing Alzheimer's Caregiver Health (REACH) project. REACH participants were enrolled via medical providers, social service agencies, and mass media announcements.	24.	(SD=3.1)	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 Birmingham, Memphis, and Philadelphia 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. Note: 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%
Andrén & Elmståhl (2005)[48]	**Carers' Assessment of Satisfactions Index (CASI)**	Range: 27–90 Mean: 62	Not reported	N=153 Female=61%	Spouse=24% Adult child=60% Others=16%	Subjects 70 or older and receiving any form of social services according to the Social Act, were invited to participate by letter (N=1694). Those replying to the letter were telephoned, screened for cognitive decline, and diagnosed for dementia by a physician. The person with dementia was asked to nominate the relative who had the main responsibility for their care (i.e., the relative who looked after the person the most).	Dementia per DSM-IV diagnostic criteria and MMSE < 24.	Not reported	Not reported
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%) Note: Discrimination and difficulty indexes for the KAML-C test were calculated with the sample of caregivers and experts (N=82).	Overall: Not reported (Caregivers: Adult child=57.8% Spouse=28.9% Other=13.3%)	Caregivers (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. Experts (N=37) were recruited from medicine, nursing, social work, health services research, psychology, gerontology, and employment in Alzheimer's disease Research. Medical students (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%
Charlesworth *et al.* (2007)[53]	**Carers Assessment of Difficulties Index (CADI)**	Range: 36 to 91 Mean: 68 (SD=11.5)	Not reported	N=232 Female=65.1%	Spouse=65.9% Adult child=24.6% Other=9.5%	Participants were recruited into the Befriending and Costs of Caring (BECCA) trial. Recruitment took place through primary, secondary, and voluntary sector care with some self-referrals following media publicity and word of mouth. Inclusion criteria for the trial limited participation to those carers providing 20 or more hours of assistance per week to a community-dwelling relative with primary progressive dementia.	Primary progressive dementia	Not reported	Not reported

Losada *et al.* (2008)[54]	**Revised Familism Scale (R-FS)**	Mean: 59.97 (SD=13.25)	Basque, Spanish	N=135 Female=77%	Spouse=44.4% Adult child=46.7% Other relative=8.9%	Caregivers recruited through health and social services centers.	Dementia	Mean: > 3 hours per week of caregiving	Mean=10.1 (SD=4.49) years of formal education
Cooper *et al.* (2008)[55]	**The Brief-Coping Orientation to Problems Experienced (Brief-COPE)**	Range: 30-90 Mean: 63.8 (SD=13.3)	Not reported	N=125 Female=64.8%	Spouse=41.6% Adult child=44.8% Other relative=9.6% Friend=4.0%	Caregivers were recruited through psychiatric services, the voluntary sector, and care homes. Purposefully chosen to be representative in terms of dementia severity as part of the London and South-East Region Alzheimer's Disease (LASER-AD) Study.	DSM-IV diagnoses of dementia and standardized diagnoses of AD	caregiving for >= 4 hours a week	Not reported
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% Other=12%	Participants were recruited from client lists of the Family Caregiver Alliance in San Francisco, the Eldercare Services Institute in Cleveland, and the University Memory and Aging Center in Cleveland.	Diagnosis of a dementing condition or a MMSE score between 13 and 26.	Not reported	Not reported
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 <u>attendees</u> at <u>two</u> 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):** **<u>Scale 1:</u>** ***S-PSSS Family (SSfa)*** (Family support among AD CGs) **<u>Scale 2:</u>** ***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 <u>attendees</u> at <u>two</u> 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 <u>five</u> 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%

Montorio *et al.* (2009)[68]	**Dysfunctional Thoughts about Caregiving Questionnaire (DTCQ)**	Mean: 58 years (SD=14.1)	Not reported	N=227 Female=75.3%	Spouse=44.1% Adult child=45.8% Child-in-Law=4.8% Other relative=5.3%	Community health and social services centers were contacted by the researchers to obtain their support and to ask caregivers to participate in the study.	Dementia	<1 year=28.4% 1-4 years=39.6% >4 years=32%	Mean: 8.7 years (SD=5.1)
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 Questionnaire (CSAQ)**	Not reported	White=97.2% Other=2.8%	N=106 Female=66%	Spouse=39.0% Adult child=50.5% Other=10.5%	Family caregivers were recruited from an inpatient geriatric psychiatry unit, an outpatient memory disorders program, and community outpatient programs related to caregiving and mental health.	Dementia or MCI=91.5% Other (other chronic illnesses: mental or Parkinson disease)=8.5%	Not reported	Not reported
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
Losada *et al.* (2010)[74]	**Caregiver Guilt Questionnaire (CGQ)**	Range: 29-87 Mean: 59.63 (SD=12.60)	Spaniards=100%	N=288 Female=79.2%	Spouse=37.2% Parent=57.6% Other relative=5.2%	Participants were recruited from social and health care centers in Madrid, Spain.	AD=58.4% Other dementias=41.6%	Range: 3-312 months Mean: 53.15 months (SD=46.10)	Not reported
Wimo *et al.* (2010)[75]	**Resource Utilization in Dementia (RUD)**	Not reported	Not reported	N=14 Female=85.7%	Spouse=100%	Participants were recruited from a health center. Eligibility for recruitment required the caregiver to live with and spend a minimum of 2 hours per day with the dementia patient.	AD=35.7% Vascular dementia=35.7% Mixed dementia=7.1% Other cognitive problems=21.4%	Not reported	Not reported
Yap *et al.* (2010)[77]	**Gain in Alzheimer Care INstrument (GAIN)**	Mean: 50.1 (SD=10.1)	Chinese=95.4% Indian=2.9% Eurasian=1.3% Other=0.4%	N=238 Female=68.1%	Spouse=7.6% Adult child=81.5% Child-in-Law=5.9% Other=5.0%	Participants were recruited from two sources: family carers visiting an ambulatory dementia clinic of a tertiary hospital and clients' registry of local Alzheimer's association.	Early-Stage Dementia=24.4% Moderate Stage=47.9% Severe Stage=27.7%	<1 year of caregiving=12.6% 1-3 years of caregiving=33.8% >3 years of caregiving=53.6%	Primary=1.7% High school=39.5% Tertiary=58.8%
Savundranayagam *et al.* (2011)[78]	**Montgomery Borgatta Caregiver Burden Scale (MB-CBS)**	<u>Spouses</u>*:* Range: 24-91 Mean: 63 <u>Adult Child</u>*:* Range: 23-71 Mean: 52	<u>Spouses</u>*:* White: 91.0% Black: 4.0% Hispanic: 3.0% Other 3.0% <u>Adult child</u>*:* White: 77.0% Black: 8.0% Hispanic: 5.0% Other: 9.0%	<u>Spouses</u>: N=280 Female=76.4% <u>Adult child</u>: 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.)	<u>Spouses</u>: <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% <u>Adult child</u>: <6 months of caregiving=5.4%	<u>Spouses</u>*:* < 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% <u>Adult child</u>*:* < HS=0.0%

								6-12 months=11.3% 13-24 months=14.6% 25 months to 5 years=32.6% >=5 years=36.0%	Some HS=0.8% HS graduate=11.6% Some college=31.0% College graduate=33.5% Graduate degree=23.1%
Werner *et al.* (2011)[80]	**Family Stigma in Alzheimer's Disease Scale (FS-ADS):** **Scale 1: Family Stigma** **Scale 2: Lay persons' stigma** **Scale 3: Structural stigma**	Mean: 52.7 (SD=8.8)	Place of Birth: Israel=75.7% Europe/America=17.3% Asia/Africa=5.9% Other=1.1%	N=185 Female=74.6%	Adult child=100%	Participants were a convenience sample of 185 children of persons with AD recruited from support groups organized by the Israeli Alzheimer's Association (N=41), from psychogeriatric clinics (central and northern parts of Israel, N=91), and by snowball sampling (N=53). Interviews with participants were conducted face to face.	AD	Mean: 5.4 years (SD=4.1)	Mean years of education: 15 years (SD=2.6)
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
Quirk *et al.* (2012)[82]	**The Carer Well-being and Support (CWS) questionnaire**	Range: 26-102 Mean: 65.5 (SD=13.1)	White=92.8% Black=2% Asian=1.7% Mixed=0.9%	N=361 Female=65.3%	Adult child=30.1% Spouse/Partner=4% Sibling=1.6% Parent=14.3% Friends=1.6% Other=2.1%	Recruited from local health services organizations, mental health and Alzheimer's associations, and training courses run by these associations.	Care receivers were diagnosed with dementia or a mental health problem.	Not reported	Not reported
Riley *et al.* (2013)[83]	**Birmingham Relationship Continuity Measure (BRCM)**	Range: 56-88 Mean: 71.6 (SD=7.8)	White=92% Other=8%	N=84 Female=69%	Spouse=100%	Recruited through various agencies providing support for people with dementia and their families in urban areas of the UK. Participants were identified by staff at the agency, or they made themselves known to a researcher following an oral presentation about the research.	Dementia, AD, and Vascular Dementia.	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
Tebb et al (2013)[85]	**The Caregiver Well-Being Scale: Short Form Rapid Assessment:** **Scale 1: Basic Needs Scale** **Scale 2: Activities of Daily Living Scale**	Range: 29-82 Mean: 53.50 (SD=7.90)	White=87% Black=11% Hispanic=1% Asian=1%	N=486 Female=96.1%	Spouse=13.6% Adult child=69.2% Child-in-Law=8.3% Other relative=2.0% Other=7.0%	The sample comprised a combination of three previously-conducted studies with caregivers. Participants in the original studies were recruited in different ways. For example, one study recruited participants through church newsletters, local newspapers, service agencies, and referrals. Another study recruited family members of dementia patients in long-term care homes. A third group of participants were randomly selected from the registry of College of Nurses of Ontario, Canada.	AD, dementia, or cognitive impairment=24% Other diseases or conditions=76%	Range: 4 months-30 years Mean: 5 years of caregiving	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%
Orgeta *et al.* (2013)[88]	**Warwick–Edinburgh Mental Well-Being Scale (WEMWBS)**	Range: 24-88 Mean: 62.42 (SD=11.22)	White=92.5% Other=7.5%	N=170 Female=81.2%	Spouse=52.6% Adult child=29.3% Other=18.1%	Convenience sample - participants were contacted by voluntary sector organizations offering support services to carers of people with dementia.	Dementia	1–2 years of caregiving=15.8% 2-4 years of caregiving=22.6% 4-6 years of caregiving=23.3% >=6 years of caregiving=38.3%	Left school before 14 years old=2.45% Left school at 14 years old=48.4% Left school at 18 years old=49.2%
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
Crellin *et al.* (2014)[90]	**Caregiver Efficacy Scale (CES)**	Mean: 66.39 (SD=13.06)	White (British/Irish/other)=92.6% Black (African/Caribbean/other)=2.9 Asian/Indian/other=4.5% Other=0.8%	N=245 Female=70.6%	Spouse/partner=62.1% Adult child=28.6% Family= 6.9% Other=2.4%	Recruited through primary and secondary healthcare, health professionals, voluntary organizations, and social services.	Dementia severity: Mild=62.6% Moderate=27.5% Severe=9.9%	Not reported	School leaver (14–18 yrs.)=72.2% Higher education=27.8%
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
Gillanders *et al.* (2014)[93]	**Cognitive Fusion Questionnaire (CFQ)**	Range: 31 to 95 Mean: 68.6 (SD=11.5)	Not reported	N=219 Female=66%	Spouse=87% Adult child=13%	The Caregiver sample was recruited as part of a larger study on caregiver distress. Recruitment occurred through a postal survey sent to caregivers enrolled on the Scottish Dementia Clinical Research Network research register, advertisements placed in a local Carers' Centre newsletter and presentations given at local Alzheimer Scotland caregiver meetings.	ADRD	Not reported	Not reported
Liu *et al.* (2014)[94]	**Finding a Balance Scale (FBS)**	Range: 28–85 Mean: 52 (SD = 10.29)	Not reported	N=183 Female=57.4%	Spouse=13.1% Son/daughter=65% Daughter-in-law=21.9%	Convenience sample recruited from the neurological clinics of a 3,700-bed medical center as well as the neurological ward and day care center affiliated with a regional hospital in northern Taiwan.	Dementia	Mean: 5.83 years providing care (SD=5.81)	≤ Primary school=10.9% Junior high school=14.8% High school=30.6% ≥ College=43.7%
Losada *et al.* (2014)[95]	**Experiential Avoidance in Caregiving Questionnaire (EACQ)**	Mean: 61.37 (SD=14.84)	Not reported	N=263 Female=78.3%	Sons/daughters=49.5% Spouses=41.8% Other=8.7%	All recruited through social and healthcare centers in Madrid and advertisements in the media.	AD=60.2% Other dementias=39.8%	Mean: 3.8 years (SD=3.05) Mean: 14.04 hours per day spent on caregiving duties	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
Toye *et al.*	**Dementia**	Family	Not reported	Family Caregivers:	Family Caregivers:	Sample was recruited from four residential aged	Dementia and	At least 3 months	Not reported

(2014)[97]	**Knowledge Assessment Tool (DKAT2)**	Caregivers: Mean: 55 Care workers: Mean: 45		N=34 Female=Not reported Care workers: N=70 Female=Not reported	Adult child= 59% Other family=41%	care settings. The sample included family members involved in the care or support of residents with dementia for at least three months. (The study also recruited all available workers providing care for residents with dementia.)	Meeting criteria for moderate to very severe cognitive decline		
Kraijo *et al.* (2014)[98]	**The Perseverance Time (Pt)**	Range: 29-93 Mean: 66.4 (SD = 13.4)	Not reported	N=223 Female=65.5%	Partner=54.3% Parent (in-law)=38.6% Other (family) relationship=7.2%	Informal carers participating in this study were recruited in cooperation with regional assessment agencies. These have a registry of diagnosed dementia patients living at home who receive formal help. The assessment agency sent a letter to the home address of all the patients in their registry diagnosed with dementia.	Dementia	Range: 0.5–16 years Mean: 3.1 years (SD=2.1)	Low=12.6% Middle=58.7% High =28.7%
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%
Chang *et al.* (2016)[101]	**Affiliate Stigma Scale**	Mean: 52.8 (SD=12.18)	Chinese=100%	N=271 Female=53.1%	Adult child= 61.6% Other=38.4%	Caregivers of outpatients at a local general hospital volunteered to take part in the study. Each participant had at least one family member diagnosed with dementia.	Dementia (including AD and vascular dementia) based on diagnostic criteria from the Diagnostic and Statistical Manual of Mental Disorders, 4th Ed.	Mean: 2.45 years (SD=2.43)	Junior high school or less=33.9% High school=31.7% Some college=34.3%
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%
Kiriake & Moriyama (2016)[107]	**The Partnership Scale (PS)**	Mean: 60.398 (SD=11.35)	Japanese=100%	N=261 Female=76.5%	Spouse=23.4% Adult child=46.7% Daughter/Son-in-law=25.3% Sibling=1.1% Other=3.4%	Caregivers were recruited from five different facilities in a particular prefecture in Japan	Suspected dementia=2.3% Light dementia=6.1% Moderate dementia=30.3% Severe dementia=61.3%	Less than 6 months=6.2% 6 months-1 year=8.2% 1-3 years=28.8% 3-5 years=23.0% 5-9 years=21.0% 9-12 years=7.0% 12 years or more=5.8%	Not reported
Maneewat *et al.* (2016)[108]	**Caregiver resilience scale (CRS)**	Range: 20 to 60	Thai=100%	N=150 Female=Not reported	Relationship of the family CG to care recipient is not reported.	Caregivers of patients with appointments at the Memory Clinic, Neurological Clinic, or Geriatric Clinic in the Out Patient Department at a regional hospital in upper southern Thailand were recruited through purposive sampling according to the following inclusion criteria: (1) primary	Mild to moderate dementia or any subtypes of dementia	Not reported	Not reported

						caregivers who provided care for older persons with dementia, (2) aged 20 to 60 years, (3) able to speak and understand the Thai language.			
Sullivan *et al.* (2016)[109]	**The Thoughts Questionnaire (TQ)**	Range: 36–85 Mean: 64.30 (SD = 10.65)	Caucasian =94.3% non-Caucasian=5.7%	N=35 Female=86%	Spouses=68.6% Non-spousal family=31.4%	Participants recruited by snowball sampling beginning with flyers distributed to community-support agencies.	AD=34.3% Mixed type =5.7% FTD=5.7% Early onset AD=31.4% Vascular dementia=5.7% Lewy bodies=5.7% Unknown=11.4%	Mean: 4.45 years (SD = 4.12)	Not reported
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%
Romero-Moreno *et al.* (2017)[113]	**Valued Living Questionnaire Adapted to Caregiving (VLQAC)**	Range: 21–89 Mean: 60.97 (SD=14.34)	Not reported	N=253 Female=76.7%	Spouse=41.4% Son/daughter=50.2% Other (e.g., mother-in-law)=8.4%	Recruited from social and health care centers in Madrid, Spain	AD=70.4% Other dementia=29.6%	Range: 0.5–20 years Mean: 3.76 years (SD = 3.08)	Not reported
Stott *et al.* (2017)[115]	**Hospital Anxiety and Depression Scale (HADS)**	Mean: 68 (SD=19)	White=93% Black and minority ethnicity=7%	N=284 Female=68%	Spouse, sibling (same generation)=63.4% Adult child, niece, nephew (generation below)=35.6%	Participants were drawn from previous randomized trials of people with dementia and their CGs.	AD=46.1% Vascular dementia=17.3% Other dementia=36.6%	Mean: 31.46 months (SD=7.37)	School dropout=69.7% Higher/further education=30.3%
Losada *et al.* (2017)[117]	**The Caregiving Ambivalence Scale (CAS)**	Mean: 60.9 (SD=13.77)	Spanish	N=401 Female=77.1%	Adult child=51.4% Spouses=41.1% Other=7.5%	Recruited from social and health care centers in Madrid, Spain	AD=67.5% Other dementias=32.5%	Caregivers provided at least 1 hour of care daily, and at least 3 consecutive months of care.	Not reported
Abdollahpour *et al.* (2017)[119]	**Positive Aspects of Caregiving Questionnaire (PACQ)**	Range: 19-81 Mean: 51.5 (SD=12.4)	Not reported	N=132 Female=84.7%	Relationship of the family CG to care recipient is not reported.	The study used the Iran Alzheimer Association and Roozbeh Memory Clinic of Tehran University of Medical Sciences as the sampling frame.	Dementia	(Caregivers spent at least 6 hours per day for patient's care.) Total years providing care was not reported.	Illiterate or primary school (age 7-11 years)= 16.67% Guidance school (age 12-14 years)= 11.36% High school (age 15-18 years)= 36.36% Associate or bachelor's degree= 31.82% Master's degree and higher= 0.79%
Fabà & Villar (2017)[120]	**Gains Associated with Caregiving (GAC) scale**	Mean: 63.0 (SD=12.30)	Not reported	N=260 Female=66.5% (final field study) (An initial EFA study was conducted in an independent sample of N=152 participants)	Partner=48.8% Adult child=47.4% Other=3.8%	Participants were recruited from a list of caregivers provided by health professionals and over 20 organizations advocating for dementia patients and caregivers (e.g., Alzheimer's associations, adult day care centers).	Dementia	Caregiver for at least 6 months.	No formal schooling=7.7% Primary education=37.3% Secondary education=38.1% Higher education=16.9%

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%
Moholt *et al.* (2018)[123]	**Carers of Older People in Europe (COPE) Index** (Scale validation with family carers of people with dementia-Norway)	Range: 29–95 Mean: 61.8 (SD = 11.7)	Sami=7% Other=93%	N=430 Female=68.9%	Spouses=28.8% Adult child=60.7% Other=10.5%	Dementia caregivers in 32 community care agencies in Northern Norway were invited to participate in the study.	Dementia	Not reported	Not reported
Oliveira & Aubeeluck (2018)[125]	**Dementia Quality of Life Scale for Older Family Carers (DQoL-OC)**	Mean: 72.15 (SD = 8.31)	White=96.1% Afro-Caribbean=1.1 % Asian=1.1% Other ethnic group=0.6%	N=182 Female=64.6%	Spouses=80.1% Son/daughter=16% Other=0.6% Missing=3.3%	Participants were recruited from voluntary organizations (Alzheimer's Society, Carers Trust, Carers Federation) and community-based carers' groups. Information about the study was also publicized in public areas and online advertisements were placed on social media (e.g. Facebook, Twitter, and blogs from Alzheimer's Society).	Dementia	Less than 1 year=2.2% 1 to 3 years=44.2% 4 to 6 years=34.3% 7 to 10 years=9.9% 10+ years=9.4%	Not reported
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% Missing=39% Ethnicity: Hispanic=10% Not Hispanic=50% Missing=40%	N=1,091 Female=67%	Adult child= 49% Spouse/partner= 35% Friend= 2% **Paid or hired caregiver= 3%** Other= 10%	Caregivers were recruited from UCLA Alzheimer's disease Center programs.	Dementia type not specified=43% AD=38% Mixed dementia=8% Vascular dementia=4% Other dementia=6%	Not reported	High school graduate=9% Some college=16% College graduate=40%
Stansfeld *et al.* (2019)[127]	**Sense of Coherence Scale-13 (SOC-13)**	Range: 18–89 Mean: 59.5 (SD=12.3)	White British or Irish=94.2% Mixed British=0.7% Indian/British Indian=0.7% Black Caribbean/African=0.7% Other=3.7%	N=583 Female=80.3%	Spouse/partner= 30.1% Son/daughter= 58.9% Other= 11%	Recruitment into the study occurred through a) an online database of people with dementia and their family caregivers who have registered their interest in taking part in research, b) from relevant charitable organizations for older people, c) people with dementia and their family caregivers. Caregivers who expressed an interest in the study were emailed or contacted by phone with a link to the online version of the survey and offered a paper copy with a freepost envelope to return the completed survey as an option.	AD=50.5% Vascular dementia=18.9% Lewy Bodies=7.2% FTD=23.3%	Not reported	Primary education or less=0.5% Secondary education=23.7% Further education=71.3% Other general education=3.5%
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
Ying *et al.* (2019)[130]	**Center for Epidemiological Studies Depression Scale (CES-D)**	Mean: 53.0 (SD: 10.7)	Chinese=86.6% Malay=6.3% Indian=4.6% Other=2.5%	N=394 Female=59.9%	Spouses= 13.7% Adult child=86.3%	Caregivers caring for community-dwelling people with dementia were recruited from the two dementia clinics serving North-East Singapore and also from the inpatient wards of the geriatric psychiatry unit at the Institute of Mental Health. A consecutive sampling method was used to achieve a desirable response rate.	Dementia: Mild=15.7% Moderate=41.4% Severe=42.9%	Mean= 6.8 years (SD=6.7)	Primary or no formal=10.4% Secondary=57.9% Tertiary =31.7
Barello *et al.* (2019)[131]	**Caregiving Health Engagement Scale (CHE-s)**	Mean: 53.3 (SD=12.5)	Italian=100%	N=198 Female=76.5%	Parent=56.1% Adult child=13.6% Spouse/Partner=24.7 %	Convenience sample of family caregivers of patients with complex health care needs. Participants were recruited from a list of names who met selection criteria provided to the	Pulmonary disease=8.4% **ADRD=12.6%** Diabetes=7.1% Cystic fibrosis=7.1%	At least six months	Not reported

					Other=5.6%	researchers by general practitioners. Potential participants included caregivers with diverse demographic backgrounds and with different experience of caregiving across different disease conditions including Alzheimer's disease and dementia.	Other (various)=34.8%		
Brown *et al.* (2019)[132]	**Carer Dementia Quality of Life (C-DEMQOL)**	Range: 21-90 Median: 62	White British=84.9% White Other=8.7% Black/African/ Caribbean=3% Mixed Ethnic Background=1.7% Indian/Bangladeshi=0.7% Arab=0.3% Other=0.7%	N=300 Female=72.9%	Adult child=49.5% Spouse/long-term partner=42.8% Family friend=1.3% Sibling=1.0% Other family member=0.7% Other=4.7%	Family carers of people with a clinical diagnosis of dementia were recruited from Sussex and North London. Carers were visited in their own homes, where researcher-administered interviews took place.	AD=58% Mixed=19% Vascular dementia=13.1% FTD=3.6% Lewy bodies=2.2% Other dementia=4.0%	Not reported	Not reported
Cheng *et al.* (2019)[133]	**Caregiver Grief Questionnaire (CGQ)**	Range: 36-84 Mean: 58.27 (SD=10.42)	Chinese=100%	N=173 Female=84%	Spouse= 32% Sibling= 1% Adult child= 59% Child-in-law= 7% Grandchild= 1%	Recruited from psychogeriatric clinics in China and a list of those agreeing to be contacted for research participation.	Formal physician diagnosis of AD or meeting the NINCDS-ADRDA criteria for possible AD.	At least 14 hours of care per week.	Primary= 18% Secondary= 51% Tertiary= 25% None= 6%
McCaffrey *et al.* (2020)[135]	**Carer Experience Scale (CES)**	Mean: 52 (SD=14)	Not reported	N=500 Female=79.1%	Adult child=32% Partner=25% Parent=31% Other (friend, family, or neighbor)=12%	The study recruited a mixed sample of informal/family caregivers of persons with different disease conditions including carers of dementia, aging-related or neurological problems. The participants were recruited through a statewide non-profit organization representing and providing support to carers to improve their health and wellbeing. Persons age 18 and over who self-identified as primary, informal carer were invited to participate in an online survey.	Dementia, memory, aging, or neurological problems=43% Mental health problems=34% Other=23%	≤ 24 months=26% > 24 months=74%	≤ 11 years=17% 12 years=9% Diploma=27% Undergraduate=26% Postgraduate=18% Other=1%
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%
Doherty *et al.* (2020)[139]	**Consumer Access, Appraisal and**	Mean: 46.1 (SD=14.2)	Not reported	N=3,146 Female=86.1%	Relationship of the family CG to care	Participants were volunteers who had enrolled the Understanding Dementia Massive Open	Dementia	Not reported	Primary school=0.2%

	Application of Services and Information for Dementia (CAAASI-Dem)				recipient is not reported. Authors described the sample as comprised carers with a family member with dementia (52.4%) or other close associate with dementia (47.4%)	Online Course (UDMOOC) and who consented to participate in the CAAASI-Dem study.			Secondary school (years 11–12)=7.9% Secondary school (years 7–10)=4.7% Certificate or apprenticeship=18.6% Associate degree=20.6% Bachelor's=26.9% Higher University degree(Grad, Masters, PhD)=17% Not indicated=4.0%
Furukawa & Greiner (2020)[140]	**Social Capital Scale for Caregivers of People with Dementia**	Mean: 63.7 (SD=12.1)	Japanese	N=178 Female=75.8%	Spouse= 29.8% Sibling= 1.7% Adult child/child-in-law= 60.1% Grandchild= 2.8% Other= 5.6%	Randomly selected 1,373 facilities (community general support centers, daycare centers, Alzheimer's cafes, home-visit nursing stations, and federations for families with dementia) to distribute questionnaires to 2,825 primary caregivers.	Dementia	Mean=5.5 years (SD=4.2)	Junior high school=8.4% High school=39.9% Junior college/technical school=28.7% College=21.9% Graduate school=1.1%
Sakanashi & Fujita (2020)[141]	**The Empowerment Scale for Family Caregivers of Community-dwelling People with Dementia (EFCD)**	Mean: 65.27 (SD=12.06)	Japanese	N=304 Female=68.4%	Spouse=45.1% Daughter-/son-in-law=48.7% Other=4.3% Missing=2%	A convenience sample was recruited from users of the outpatient unit of a university hospital, five homecare support clinics, and 13 homecare facilities in 17 prefectures in Japan. Participants from 22 self-help groups in 17 prefectures were also approached for recruitment. Questionnaires were mailed to participants.	AD=59.5% Lewy bodies=11.8% Vascular dementia=4.6% FTD=3.6% Unknown=15.1% Missing=5.3%	≤ 1 year=15.1% > 1–5 years=44.0% > 5–10 years=27.0% > 10 years=8.9% Missing=4.9%	Not reported
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)
Losada *et al.* (2020)[143]	**Revised Familism Scale (RFS)**	Range: 29-87 Mean: 59.6 (SD=13.10)	Not reported	N=119 Female=77.9%	Relationship of the family CG to care recipient is not reported. Authors state that all CGs were caring for a relative with AD (57.1%) or other cognitive disorder (42.9%).	Family caregivers recruited through health and social care centers in Madrid.	AD=57.1% Other dementia=42.9%	Range: 3-312 months Mean: 54.44 months (SD=46.50)	Not reported
Maltby *et al.* (2020)[146]	**Adult Carers for Older Adults Quality of Life Questionnaire**	**United States**: Mean: 37.77 (SD=12.00) **China**: Mean: 32.71 (SD=7.57)	**United States**: White=75.6% Black=10.4% Asian=6.7% Hispanic=6.1%	**United States:** N=164 Female=58.5% **China:** N=131 Female=54.9%	Relationship of the family CG to care recipient is not reported.	The samples were recruited via online survey data recruitment platforms including Mturk (USA) and Wenjuanxing (China).	**United States:** **Dementia (including AD)=30.5%** Diabetes=23.2% Heart disease=21.3% Stroke=5.5% **China:** **Dementia (including AD)=14.5%** Diabetes=40.5% Heart disease=45.8% Stroke=6.9%	United States: 0 to 40 hours per week= 82.3% China: 0 to 40 hours per week= 95.6%%	Not reported

Mckenna *et al.* (2020)[149]	**Alzheimer's Patient Partners Life Impact Questionnaire (APPLIQue)** (Questionnaire specific to spousal caregivers of people with AD)	Mean: 70.3 (SD=9.6)	Not reported	N=116 Female=75.9%	Spouse=100%	Informal caregivers providing ≥75% of the care activities for, and living in the same household as, a person with AD were invited to take part. A broad range of participants representing different caregiver-patient relationships, living situations and disease severity of the people with AD were recruited.	AD	Mean: 6.6 years (SD=9)	Not reported
Perry-Duxbury *et al.* (2020)[150]	**Investigating Choice Experiments for the Preferences of Older People Capability-based measure of general quality of life: the ICEPOP Capability (ICECAP-O) instrument.**	Range: 25-92 Mean: 66.42 (SD=13.23)	Not reported	N=451 Female=66.4%	Spouse/partner=63.9 % Son/daughter-in-law=31.9% Other=4.2%	Data were collected in eight European countries in the context of the Actifcare project: Germany, Ireland, Italy, the Netherlands, Norway, Portugal, Sweden and the UK. Care receivers meeting eligibility criteria and their informal carers were invited to complete the questionnaires, available in seven different languages.	Mild or moderate degree of dementia (i.e., CDR scores 1 or 2) or scores on the MMSE ≤ 24.	**Care hours per day**: Less than 4 hours=48.5% 4 hours or more=51.5%	Education Range: 0-24 years Mean: 11.91 years (SD: 4.42)
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
Voormolen *et al.* (2021)[155]	**The Care-Related Quality of Life (CarerQol) questionnaire**	Mean: 66.2 (SD=13.4)	Not reported	N=433 Female=66.0%	Spouse or partner=63% Other=37%	Caregivers of individuals with dementia were recruited from the Access to Timely Formal Care (Actifcare) project.	Dementia	Not reported	<13 years=56.3% 13 years=43.7%
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 relative=13.1% Friend/neighbor=5.3 % Other=4.5%	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 methods (e.g., hand delivered at meetings/workshops, flyers with contact information for participants to be mailed a survey).	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% College graduate=29.1% 17–18 years=7.0% >18 years=8.6%
Clemmensen *et al.* (2021)[158]	**Dementia Carer Assessment of Support Needs Tool (DeCANT)**	Mean: 61.7 (SD=13.68)	Not reported	N=301 Female=78.4%	Spouse/partner=53.7 % Adult child=41% Sibling=0.7% Other=4.7%	A heterogeneous sample of carers were recruited by purposive sampling to achieve a study population representative of carers in different care settings and levels of progression of dementia in the person cared for. Participants were recruited from (1) nine municipalities in Denmark, (2) one dementia clinic in a hospital, and (3) social media.	AD=67.35% FTD=5.78% Lewy bodies=4.76% Vascular dementia=4.42% Mixed dementia diagnosis=4.76% Other=7.82% Do not know=5.10%	Not reported	Elementary education=7.22% Secondary education=38.49% Higher education=47.77% Other=6.53%
Durepos *et al.* (2021)[159]	**Caring Ahead: Preparing for End-of-Life with Dementia Questionnaire**	Mean: 61.7 (SD=11.43)	White=93.2% Black=0.8% Southeast Asian=1.5% East Asian=1.5% Latin American=0.8% Indigenous=2.3%	N=134 Female=78.2%	Spouse=23.9% Adult child or child-in-law=69.4% Other=6.7%	A nonprobability sample recruited by advertising, telephone calls, and email messages from staff and family councils in long-term care homes and associations for caregivers.	AD=40.6% Vascular dementia=13.5% Mixed =9.8% Lewy bodies =6.8% FTD=3.0v Korsakoff's =1.5v Unknown =19.5%	Not reported	Less than high school=2.3% High school=13.5% College or university=64.7% Graduate school=19.5%

							Other =5.3%		
Wuttke-Linnemann *et al.* (2021)[160]	**Resilience and Strain Questionnaire (ResQ-Care)**	Mean: 56.60 (SD=10.63)	Not reported	N=291 Female=84.5%	Adult child=51.4% Spouse=33.8% Parents taking care of child=9.7% Other=5.1%	Recruitment for the online survey was performed by distributing the link on various websites. The printed version of the survey, along with the prepaid envelopes, was sent to registered physicians, outpatient clinics, care support offices, and welfare organizations, among others.	Physical impairment=88.3% **Dementia diagnosis=47.6%** <u>Note</u>**:** Mixed sample of carers; patients had AD or other physical disabilities.	Hours (h) spent caregiving: <20 h/week=33.0% 20–40 h/week=33.0% >40 h/week=34.0%	Medium-track secondary school diploma or lower (46.4%)
Gallego-Alberto *et al.* (2021)[161]	**The Interpersonal Triggers of Guilt in Dementia Caregiving Questionnaire (ITGDCQ)** **<u>Scale 1:</u>** <u>Care Receiver</u> (ITGDCQ-CR) **<u>Scale 2:</u>** Other Relatives (ITGDCQ-OR)	Mean: 62.7 (SD=12.9)	Not reported	N=201 Female=66.2%	Spouse=46.3% Adult child=50.1% Other=3.6%	Recruited through health and adult day care centers in Madrid.	AD=61.2% Mild cognitively impaired=26.4% Other dementia=1.5%	Mean=49.7 months (SD=45.2) (Daily hours of care, Mean=14.5 hours (SD=8.9)	Low= 15.4% Medium= 58.2% High=26.4%
Horton *et al.* (2021)[162]	**Impact of DEmentia on CARers (SIDECAR) Battery:** **<u>SIDECAR-D</u>:** *Direct Impact on Carers* **<u>SIDECAR-I</u>:** *Indirect Impact on Carers* **<u>SIDECAR-S</u>:** *Support and Information*	Range: 34-92 Median age: 70	White=97% Other=3%	N=570 Female=72.3%	Spouse or partner=74.4% Son or daughter=18.9% Son-in-law or daughter-in-law=1.9% Other (relative/ friend)=3.4% Missing=1.4%	Participants were supporting a partner or family member in the community; 22 clinical network teams in England and Wales recruited carers via health and social care services.	Dementia severity: Mild=36.7% Moderate=47.5% Severe=13.0% Missing=2.8%	Not reported	Not reported
Schlomann et al (2021)[163]	**Berlin Inventory of Caregiver Stress-Dementia (BICS-D)** (Inventory comprising 25 subscales)	Mean=60 SD=11.4	Not reported	N=594 Female=79%	Daughter/son=42% Daughter-in-law=9% Female partner=28% Male partner=16%	Caregiving relatives from across Germany were recruited through newspaper announcements and articles in pharmacy magazines. Following a telephone screening interview, respondents were sent a refined version of the inventory and other outcome measures by postal mail including a return envelope with paid postal fees.	Dementia severity: Mild=4% Moderate=42% Severe=54%	Mean=41.1 months (SD=32.4)	Not reported
Cheon *et al.* (2022)[164]	**The Competence Scale in Managing Behavioral and Psychological Symptoms of Dementia (CS-MBPSD)**	Mean: 69.82 (SD=11.08)	Not reported	N=460 Female=78.7%	Spouse=65.7% Son=6.1% Daughter=19.8% Daughter-in-law=5.2% Sibling=1.7 Other=1.5	Participants were recruited from local dementia centers in 21 out of the 25 districts in the city of Seoul after gaining permission to collect data from the heads of the centers. Participants were recruited through posted announcements or notification about the study from center staff. Researchers went to the local dementia centers and directly explained to the recruited participants the purpose and contents of the study, how to participate in the study, and how to withdraw consent from the study.	Dementia	Mean=4.55 years (SD=3.36) (average care time per day was 11.30 hours (SD=5.47)	Less than elementary=2.0% Elementary=19.6% Junior high=17.6% Senior High=37.6% College and above=23.3%
Wawrziczny *et al.* (2022)[165]	**Control and Stimulation in Dementia Caregiving (CSDC-13) Scale**	Mean: 59.43 (SD=12.54)	Not reported	N=282 Female=69.5%	Relationship of the family CG to care recipient is not reported.	Caregivers were recruited online. Eligibility criteria: caring for a community-dwelling person with ADRD.	Cognitive impairment or dementia. Persons with cognitive impairment had been diagnosed for an average of 6.75 years (SD=5.41) and persons with dementia had been diagnosed for an average of 4.54 years (SD=4.28).	Not reported	Not reported

Gallego-Alberto *et al.* (2022)[166]	**Caregiving Compassion Scale (CCS)**	Mean: 62.29 (SD=12.7)	Not reported	N=236 Female=68.6%	Adult child=54.3% Spouse=41.9% Other relatives=3.8%	Recruitment was conducted through different health and adult day care centers in Madrid, Spain. Nursing homes were excluded. Study inclusion criteria included: older than 18 years old; primary caregiver of the relative with dementia; performing caregiving tasks at least one hour per day during the last three months, and not being under psychiatric and/or psychological treatment.	Dementia	A criterion for participation was performing caregiving tasks during at least one hour per day during the last three months.	Not reported
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%
Bernaards *et al.* (2022)[170]	**27-item Zarit Caregiver Interview for Alzheimer's Disease (ZCI-AD-27)**	Not reported.	Not reported.	N=519 Female=43.9%	Spouse/partner=62.8% Son/daughter=30.6% Other family member=5.2% Other=1.3%	The data used to validate the ZCI-AD-27 were gathered as part of a 12-month, randomized, multicenter, and placebo controlled study in participants with moderate AD. All participants had an informal (unpaid) care partner.	Moderate AD (MMSE scores between 13 and 20)	Minimum of 10 hours per week.	Not reported
Bhatt *et al.* (2022)[171]	**Family Stigma Instrument (FAMSI)**	Range: 27–87 Mean: 60 (SD=13.19)	White=93% (n=65) Black/African/Caribbean=1% (n=1) Mixed multiple=1% (n=1) Other ethnic group=3% (n=2) Not disclosed=1% (n=1)	N=70 Female=76%	Spouse/partner=34% Adult child/child-in-law=54% Other=10% Not disclosed=1%	Participants were a convenience sample in South-East England, UK. They were recruited via the Join Dementia Research database and through social media, community advertising or researcher outreach activities where the study was presented to carers' groups (e.g. Alzheimer's Society groups).	AD=37.1% Vascular dementia= 18.6% FTD= 11.4% Lewy bodies= 2.9% Mixed= 24.3% Not disclosed/unknown= 5.7%	Not reported	Not reported
Cartwright *et al.* (2022)[173]	**Multidimensional scale of perceived social support (MSPSS)**	Range: 20-92 Mean: 60.5 (SD=14.40)	White (British)=92.2% (n=249) White (other)=4.8% (n=13) Black=0.7% (n=2) Asian= 0.7% (n=2) Mixed=1.1% (n=3) Other=0.4% (n=1)	N=270 Female=65.6%	Husband=21.9% Wife=15.9% Son=9.6% Daughter=40.7% Son-in-law=1.9% Daughter-in-law=1.9% Granddaughter=3.7% Grandson=0.4% Other=4.1%	Researchers emailed invitations for the study to individuals who had identified themselves as a caregiver of someone with dementia on Join Dementia Research Network. Electronic adverts were emailed to UK charities and organizations including Age UK and Alzheimer's Society, who recruited participants through their internal adverts. The study was also advertised via social media.	AD=48.1% Vascular dementia=12.2% Dementia with Lewy bodies=2.2% Parkinson's dementia=1.9% FTD=4.8% Mixed dementia=22.6% Dementia (subtype unknown)=4.8% Other=3.3%	0–1 year=5.9% 1–2 years=14.8% 3–4 years=31.9% 5–8 years=28.1% 9 years or more=9.3%	Postgraduate degree =27.0% University degree (or equivalent)=30.4% Higher education (or equivalent)=16.3% A level (or equivalent)=10%) GCSE grades A*-C (or equivalent=8.9% Other or no qualifications=7.4%
Kim *et al.* (2022)[175]	**Dementia Public Stigma Scale (DePSS)**	Mean: 46.2 (SD=15.4)	Not reported	N=3,250 Female=87.5%	Relationship of the family CG to care recipient is not reported.	Total sample (including the 49% dementia caregivers) were voluntary enrollees in the Understanding Dementia Massive Open Online Course (UDMOOC), a free online course accessible to anyone with an Internet connection, widely advertised through news media, social media, email, flyers and word of mouth. Course typically attracts participants of broad demographic characteristics, education, and experience of dementia.	Dementia (73.4% of the sample reported knowing someone living with dementia and almost half (49%) indicated they provided care for a person living with dementia.)	Not reported	Primary school=0.2% Secondary school=5.5% Certificate/apprenticeship=17.8% Associate degree=16.5% Bachelor's=28.6% Higher university degree=20.4%
Hosseini *et al.*	**Family Caregivers'**	Mean: 50.26	Not reported	N=435	Daughter=52.9%	Convenience sample of family/informal	AD	Care hours per	Illiterate=2.5%

(2022)[176] (The following studies used the same validation sample.) Sharif-Nia *et al.* (2022)[178] Sharif-Nia *et al.* (2023)[179]	**Hardiness Scale (FCHS)** **The Care Challenge Scale (CCS)** **Care Stress Management Scale (CSMS)**	(SD=13.24)		Female=50.6%	Son=13.1% Wife=8.5% Husband=4.6% Friend=7.8% Relative=13.1%	caregivers willing to participate in the study and who were able to use social networks such as Telegram and WhatsApp.		day: Mean=7.51 hours (SD=5.51)	Less than diploma=6.9% Diploma=46% Academic=44.6%
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%
Olthof-Nefkens *et al.* (2023)[183]	**Experienced Communication in Dementia Questionnaire-Caregiver (ECD-C)**	Range: 41-86 Mean=65 (SD=11.4)	Not reported	N=57 Female=68% (N=57 dyads consisting of a community dwelling person with dementia and primary caregiver)	All CGs were either partners, relatives, or close friends (no percentages are reported).	Participants were recruited from the Geriatrics Department of the Radboud University in The Netherlands, visiting between September 2015 and January 2016.	Diagnosed by a geriatrician as having mild to moderate dementia (Clinical Dementia Rating score between 0.5 and 2). AD=87.7% FTD=1.8% Lewy bodies=1.8% Progressive aphasia=1.8% Mixed=7%	Not reported	Not reported
Potter *et al.* (2023)[184]	**The Long-Term Conditions Questionnaire for Carers (LTCQ-Carer)**	Range: 41-90 Mean:67	Quantitative (Phase 2): White British (94%) Non-white (3%)	Quantitative: N=107 Female=63% (plus 10 cognitive "think aloud" interviews with carers -completed in Phase 1 qualitative study)	Qualitative Phase 1: (think aloud): Spouse (70%) Adult child (30%) Quantitative (Phase 2): Family member=94% Other=6%	Family caregivers were recruited through one of 14 memory clinics based within two National Health Service (NHS) Trusts in South East England.	Recently diagnosed with MCI or dementia. Diagnosis of the patient and regular support from an informal carer were confirmed by clinical staff during assessment at one of 14 memory clinics in south-east England.	Not reported	Not reported
Risch *et al.* (2023)[185]	**The Caregiver Thoughts Scale (CTS)**	Mean: 63 (SD=11.1)	Not reported	N=322 Female=80%	Spouse=59% Adult child=39.8% Other=1.2%	Caregivers were recruited by numerous public relation methods (regional and national newspapers, television and radio interviews, project homepage) and cooperation partners (clinics, practices, home support services).	Care recipients were diagnosed as having dementia, or at least fit criteria for MCI. AD=44.1% Vascular dementia=10.2% FTD=5.3% Other/unknown=40.3%	Mean: 4.9 years (SD= 3.7)	Primary or other =3.1% Secondary: Level 2 =50.9% Secondary: Levels 3 & 4 =12.4% Tertiary: Levels 5 & 6 =33.2%
Pendergrass *et al.* (2023)[187]	**Benefits of Being a Caregiver Scale (BBCS)**	Mean: 62.1 (SD=12.6)	Not reported	N=961 Female=75.7%	Spouses=30.5% Adult child/in-law=59.5% Other carers (e.g., aunts, uncles, nieces, nephews)=10%	Care assessors from the Medical Service of the Bavarian Health Insurance distributed self-report questionnaires to statutorily insured informal caregivers.	Dementia=**37.9%** Other conditions related to ADL and IADL needs requiring family caregiving=**62.1%**	Mean: 48.45 months (SD=78.72)	Not reported
Pione *et al.* (2023)[188]	**Positive Psychology**	Range: 20-92 Mean: 60.51	White British (96.6%)	N=267 Female=65.2%	Daughter=40.4% Husband=21.7%	Unpaid family carer for a person living with dementia. They must have been over 18 years	AD=47.6% Dementia of mixed	0–12 months=5.6%	Undergraduate=31.1%

	Outcome Measure-Carer Version (PPOM-C)	(SD=14.37)			Wife=16.1% Son=9.7% Granddaughter=3.7% Other=4.1% Daughter-in-law=1.9% Son-in-law=1.9% Grandson=0.4%	old, able to communicate in English. Volunteers were contacted via email inviting them to participate. An advertisement was also circulated to other organizations including Age UK and the Alzheimer's Society.	etiology=22.5% Vascular dementia=11.6% FTD=5.6% Other=7.1% Lewy bodies=2.2% Posterior cortical atrophy=1.9% Parkinson's Dementia=0.5%	1–2 years=15% 3–4 years=31.5% 5–6 years=19.9% 7–8 years=8.6% 9–10 years=7.1% 10 years+ =12.4%	Postgraduate=26.6 % Higher education=15.7% a-level=10.5% GCSE's=8.6% Other=3.4%
Suganuma *et al.* (2024)[190]	**Caregiving Competence Scale for Dementia (CCSD)**	Mean: 68.4 (SD=9.5)	Japanese	N=150 Female=63.3%	Spouse=61.3% Son or daughter =28.7% Son or daughter in-law=6.0% Sibling=2.7% Others=1.3%	Participants were recruited in collaboration with a random sample of 23 "Alzheimer's Association Japan" branches. Scale questionnaires were distributed to each branch along with selection criteria. Branch executives distributed them to the eligible participants. A return envelope was also included and collection was performed via postal mail.	AD=48.7% Vascular dementia=6.0% Lewy bodies=6.0% FTD=2.7% Young onset AD=12.7% Mixed-type dementia=6.7% MCI=7.3% Unknown=10.0%	Mean: 60 months (SD=51.3)	≤ Ninth grade=4% 10–12=36% ≥13 years of schooling=60%

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.