| Reference | Name of the Scale(s) | Characteristics of the Caregiver Sample Used in Tool Validation Process | | | | | | | |
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| | | 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 |
| Greene *et al.* (1982)[1] | **Scale 1:**<br>**Behavioral and Mood Disturbance Scale (BMDS)**<br>**Scale 2:**<br>**Relatives' Stress Scale (RSS)** | Not reported | Not reported | N=38<br>Female=Not reported | Daughters=42.1%<br>Spouses=39.5%<br>Other relatives=18.4% | Primary family caregivers of a relative diagnosed with dementia, who was attending a "day hospital," were approached by researchers to participate in the study.<br>The major criterion for selection was that each care recipient should have a relative capable of providing a reliable assessment of the person's behavior. | Senile Dementia | Not reported | Not reported |
| Kinney & Stephens (1989)[2] | **Caregiver Hassles Scale (CHS)** | Range: 24–81<br>Mean: 57.4 (SD=13.3) | Not reported | N=60<br>Female=81.7% | Spouses=46.7%<br>Daughters (natural and in-law)=41.7%<br>Other=11.6% | Participants were recruited from local Alzheimer's Disease and Related Disorders Association Chapter. | AD=93.3%<br>Other=6.7% | Range: 0.08-11.0 years<br>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%<br>White=74.5% | N=632<br>Female=78.3% | Spouse=45.1%<br>Adult child=38.6%<br>Child-in-Law=4.4%<br>Sibling=4.3%<br>Friend=1.9%<br>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) |
| Novak & Guest (1989)[4] | **Caregiver Burden Inventory (CBI)** | Range: 25-87<br>Mean: 60.13 (SD=13.06) | Not reported | N=171<br>Female=73.8% | Spouse=44.9%<br>Adult child (natural and in-law)=48.8%<br>Other relative=6.3% | Study participants were recruited from community care professionals including care coordinators, physicians, and directors of care facilities within the Manitoba Community Services and Home Care Division. | AD, senile dementia, or "organic brain syndrome" (neurocognitive disease). (Diagnosis was made by health care professionals trained to recognize the symptoms of these disorders. No proportions per group were provided.) | Mean=63.09 months | Not reported |
| Ellis *et al.* (1989)[5] | **Scale1:**<br>**Caregiver Reactions Scale (CRS)**<br>**Scale 2:**<br>**Social Resources Scale (SRS)** | Not reported | Not reported | N=120<br>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<br>Female=64% | Spouses=68%<br>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:**<br>**Perceived Social Support for Caregiving (PSSC)**<br>**Scale 2:**<br>**Social Conflict (SC)** | Mean: 62 | Not reported | N=206<br>Female=69.2% | Spouse=72.1%<br>Adult child=25.2%<br>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<br>Mean: 68.1 | Not reported | N=27<br>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<br>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<br>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<br>Female=81.4% | Spouse=55.4%<br>Other family=44.6% | Participants were recruited from community health agencies (physically impaired, N=267) and eight chapters of the Alzheimer's Association | ADRD=29.2%<br>Physically impaired=70.8% | Mean=5.0 years of caring (SD=5.7) | At least some college=59.2% |

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| | | | | | | (N=110) | | | |
| Semple (1992)[11] | **Family Conflicts Scales (FCS)** | Mean: 62.2 | Unknown=64%<br>White=30%<br>Black=4%<br>Asian=1%<br>Hispanic=1% | N=555<br>Female=26% | Spouse=58.7%<br>Adult child=39.8%<br>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%<br>0-1 year=9%<br>1-2 years=13%<br>3-5 years=11%<br>6+ years= 3% | Unknown=64%<br><High school=4%<br>High school=10%<br>Some college=10%<br>College graduate=6%<br>>College=6% |
| Teri *et al.* (1992)[12] | **The Revised Memory and Behavior Problem Checklist (RMPBC)** | Mean: 54<br>(SD=13.4) | Not reported | N=201<br>Female=61% | Spouse=46%<br>Adult child=41%<br>Other relative=10%<br>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%<br>Depression=10%<br>Other=5%<br><u>Note</u>**:** 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%<br>Grade school=3%<br>High School=47%<br>College=27%<br>Graduate Degree=15%<br>Unknown=7% |
| Macera *et al.* (1993)[13] | **Caregiver Burden Scale (CBS)** | Mean: 61 | Black=24%<br>Non-Black=76% | N=82<br>Female=84% | Spouse=54%<br>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 |
| Gerritsen *et al.* (1994)[14] | **Care-Giving Burden Scale (C-GBS)** | Mean: 60.1 | Not reported | N=89<br>Female=75% | Spouse=49%<br>Adult child=27%<br>Other=24% | Eligible caregivers were referred by general practitioners to geriatric outpatient clinic of a psycho-geriatric nursing home. | AD=37%<br>Amnestic disorder=15%<br>Organic psycho-syndrome=20%<br>Multi-infarct dementia=7%<br>Unknown=21% | Not reported | Not reported |
| Gilleard *et al.* (1994)[15] | **Dementia Quiz (DQ)** | Mean=61.7<br>(SD=14.19) | Not reported | N=298<br>Female=Not reported | Relationship of the family CG to care recipient is not reported. | Recruited through advertisements in the Alzheimer's Disease Society Newsletter asking for volunteers to complete the quizzes. Quizzes were also given to relatives of dementia patients participating in research (family caregivers = 87.6%). Nursing home staff (7.0%) and nursing and social work professionals (5.4%) who were participating at workshops or seminars on dementia were also given the quiz. | Dementia=87.6%<br>Non-dementia=12.4% | Not reported | Not reported |
| Hinrichsen & Niederehe (1994)[16] | **The Dementia Management Strategies Scale (DMSS)** | Range: 25-93<br>Mean: 59.6<br>(SD=14) | Not reported | N=152<br>Female=70.4% | Spouse=36.1%<br>Adult child=58.6%<br>Other=5.3% | Participants were recruited from medical, psychiatric, neurologic, and specialized dementia evaluation clinics, and a social service program. | Dementia<br><u>Note:</u> 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%<br>Hispanic=1.0%<br>White=91.1% | N=303<br>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%<br>Arthritis=58.7%<br>Hypertension=46.2%<br>Heart Disease=42.9% | Not reported | Not reported |
| Keady & Nolan (1996)[19] | **Behavioral and instrumental stressors in Dementia (BISID)** | Not reported | Not reported | <u>Sample 1:</u><br>N=205<br>Female=Not reported<br><u>Sample 2</u>:<br>N=264<br>Female=Not reported | Not reported | Samples were drawn from three populations: The Wales Alzheimer's Disease Society, Alzheimer's Scotland, and the Crossroads Care Network in Wales. Surveys were administered to two independent samples. The BISID measure was included as part of both surveys. | AD | Not reported | Not reported |

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| Vernooij-Dassen *et al.* (1996)[20] | **Sense of Competence Questionnaire (SCQ)** | Mean: 63 | Not reported | N=141<br>Female=67% | Wife=26%<br>Husbands=24%<br>Daughters (natural or in-law)=28%<br>Sons (natural or in-law)=8%<br>Friend/Neighbor=14% | Participants were recruited from community general practitioners (GPs). GPs were approached by the researchers and were asked to collaborate in finding potential eligible patients who had been diagnosed with AD or multi-infarct dementia, who lived in the community, and who had a family caregiver. | Mild Dementia=13%<br>Moderate Dementia=58%<br>Severe Dementia=29% | Not reported | Not reported |
| Davis *et al.* (1997)[22]) | **Caregiver Activity Survey (CAS)** | Range: 34-83<br>Mean: 66.5 (SD=13.1), | Not reported | N=42<br>Female=67% | Spouse=71%<br>Other relative=17%<br>Friend/Neighbor=5%<br>Paid caregiver=7% | Recruited from the patients (and their caregivers) at two Alzheimer's Disease Research Centers: the University of Washington<br>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<br>Mean: 58.9 (SD=12.1) | Black=100% | N=83<br>Female=100% | Adult child=60.2%<br>Child-in-Law=3.6%<br>Spouse=13.3%<br>Sibling=6.0%<br>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%<br>High school graduate=49%<br>College graduate=16% |
| Schoefield *et al.* (1997)[24] | **Comprehensive instrument to assess the experience of caregiving: A battery of scales**<br>**<u>Scale 1:</u>**<br>**Social Support**<br>**<u>Scale 2:</u>**<br>**Family environment**<br>**<u>Scale 3:</u>**<br>**Caring role**<br>**<u>Scale 4:</u>**<br>**Help Needed by Recipient**<br>**<u>Scale 5:</u>**<br>**Behavior Problem** | Range: 15-80<br><35 =12%<br>35-49 =39%<br>50-64 =31%<br>>64 =18% | Not reported | N=976<br>Female=78% | Parent=20.4%<br>Adult child=39.3%<br>Spouse=23.0%<br>Other=17.3% | Participants were selected through a statewide random survey of households using computer-assisted telephone technology with a team of 25 trained interviewers and four supervisors. Respondents who self-identified as caring for someone who was aged or had a long-term illness, disability or other problem were asked to participate. | Dementia or cognitive impairments=20%<br>Other long-term illnesses and disabilities=80%<br>(Other long-term illnesses and disabilities included: physical impairments, cancer, stroke, diabetes, cardiovascular disease, cerebral palsy, Down syndrome, etc.) | <=1 year of care=16%<br>1-2 years of care=15%<br>3-5 years of care=27%<br>6-9 years of care=16%<br>>=10 years of care=26% | <10 years=32%<br>10-11 years=35%<br>>11 years=33% |
| Kaufer *et al.* (1998)[25] | **The Neuropsychiatric Inventory Caregiver Distress (NPI-D) Scale** | Range: 40-89<br>Mean: 64.2 (SD=13.0) | Not reported | N=85<br>Female=71.8% | Spouse=63.5%<br>Adult child=32.9%<br>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%<br>Probable AD=69.4%<br><u>Note</u>: 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] | **<u>Scale 1:</u>**<br>**Caregiver Self-Care Self-Efficacy**<br>**<u>Scale 2:</u>**<br>**Problem-Solving Self-Efficacy** | Range: 30-85 ,<br>Mean: 59.5 (SD= 11.3) | Not reported | N=217<br>Female=83% | Spouse=53%<br>Adult child=45%<br>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%<br>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%<br>White=64.2% | N=215<br>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 | Dementia | Not reported | Mean=13.1 years of education |

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| | | | | | | 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. | | | |
| Matsuda (1999)[28] | **Subjective Burden Scale (SBS)** | Mean: 55.0<br>(SD=9.9) | Japanese | N=255<br>Female=Not reported | Spouse=12.2%<br>Adult child=58.4%<br>Child-in-Law=26.3%<br>Other=3.1% | Participants (N=213) were recruited from a patient registry at a private geriatric hospital. The remaining 42 participants were recruited from psychiatric outpatient clinics. | Dementia | Not reported | Not reported |
| Hebert *et al.* (2000)[30] | **Zarit Burden Interview (ZBI)** | Mean: 61.7<br>(SD=13.4) | Not reported | N=312<br>Female=79.2% | Spouse=32.1%<br>Adult child=48.6%<br>Sibling (natural or in law)=4.0%<br>Other family=6.4%<br>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<br>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<br>Mean: 60 | Not Reported | N=76<br>Female=82% | Spouse=27.6%<br>Mother=36.8%<br>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%<br>Other health conditions=43% | Range: 2 months to 32 years | Not reported |
| Gitlin *et al.* (2002)[32]) | **Task Management Strategy Index (TMSI)** | Sample 1<br>Mean: 60.79<br>(SD=13.87)<br>Sample 2:<br>Mean: 61.01<br>(SD=14.30) | Sample 1:<br>White=74.3%<br>Black=24.3%<br>Other=1.5%<br>(Sample 2:<br>White=48.2%<br>Black=47.8%<br>Other=3.9%) | Sample 1:<br>N=202<br>Female=71.8%<br>(Sample 2:<br>N=255<br>Female=74.5%) | Sample 1:<br>Spouse=24.1%<br>Non-spouse= 75.9%<br>(Sample 2:<br>Spouse=38.8%<br>Non-Spouse=61.2%) | Sample 1: (N=202)<br>Participants were drawn from a dementia-management intervention study recruited from local social service and medical centers as well as media announcements.<br>Sample 2: (N=255)<br>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:<br>ADRD.<br>(Sample 2:<br>Documented diagnosis of dementia or a MMSE < 24.) | Sample 1:<br>Mean=3.67 years of caregiving<br>(SD=2.82)<br>(Sample 2:<br>Mean=4.24 years of caregiving<br>(SD=3.77)) | Sample 1:<br>Mean=13.86 years of formal education<br>(SD=3.05)<br>(Sample 2:<br>Mean=12.23 years of formal education<br>(SD=2.62)) |
| Fortinsky *et al.* (2002)[33] | **Family caregiver self-efficacy for managing dementia** | Range: 29–81<br>Mean: 56<br>(SD=14) | Black=19%<br>Non-Black=81% | N=197<br>Female=82% | Spouse=28%<br>Adult child (natural and in-law)=62%<br>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<br>(SD=13.002) | White=92.8%<br>Other=7.2% | N=166<br>Female=81.3% | Spouse=50%<br>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%<br>Other dementias=17.5% | Mean % Monthly Care=67.54%<br>(SD=31.251) | Range: 3-24 years of education<br>Mean: 14.63 years of education<br>(SD=2.71) |

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| Steffen *et al.* (2002)[35] | **Revised Scale for Caregiving Self-Efficacy (R-SCSE)** | Sample 1:<br>Mean: 63.8 (SD=8.3)<br>(Sample 2:<br>Mean: 60.2 (SD=13.3)) | Sample 1:<br>White=89.4%<br>Hispanic=6.4%<br>Black=2.1%<br>Asian/Pacific=2.2%<br>(Sample 2:<br>White=84%<br>Black=16%) | Sample 1:<br>N=169<br>Female=100%<br>(Sample 2:<br>N=145<br>Female=80%) | Sample 1:<br>Spouse=56.8%<br>Adult child=39.1%<br>Other=4.1%<br>(Sample 2:<br>Spouse=46.2%<br>Adult child=46.2%<br>Other=7.6%) | Sample 1:<br>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.<br>(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:<br>Mean=45.9 months of care (SD=45.3)<br>(Sample 2:<br>Mean=35.6 months of care (SD=27.8)) | Sample 1:<br>Mean=14.5 years of education (SD=2.0) Median<br>(Sample 2:<br>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<br>Female=72.2% | Spouse=23.3%<br>Adult child=38.9%<br>Child-in-Law=36.7%<br>Other=1.1% | The study recruited a convenience sample of caregivers to outpatients of a Senile Dementia Center in Japan. | AD=71.1%<br>Vascular dementia=18.9%<br>Mixed type of dementia=8.9%<br>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<br>20-44=11%<br>45-54=19%<br>55-64=22%<br>65-75=25%<br>76-84=20%<br>85+=2% | White=56%<br>Black=24%<br>Hispanic=19%<br>Other=1% | N=1,229<br>Female=81% | Spouse=47.9%<br>Adult child=44.2%<br>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%<br>High school=24%<br>> High school=56% |
| Goolieb & Rooney (2003)[38] | **RIS Eldercare Self-efficacy Scale** | Range: 31-88<br>Mean: 61 (SD=13.4) | Not reported | N=146<br>Female=73% | Spouse=37%<br>Adult child=60.3%<br>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%<br>High school=32.4%<br>College=26.9%<br>> 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)<br>Female=84.5%<br>(N=548-Independent/cross-validation "non-dementia" sample) | Spouse=44%<br>Adult child=38%<br>Child-in-Law=10%<br>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)<br>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<br>Mean: 62.3 (SD=13.6) | White=56.3%<br>Black=24.0%<br>Hispanic=18.9%<br>Other=0.8% | N=1,225<br>Female=81.4% | Spouse=48.0%<br>Adult child=44.3%<br>Sibling=2.3%<br>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%<br>High school diploma=24.4%<br>> high school=56.4% |
| Gaugler *et al.* (2004)[42] | **Percieved Unmet Need (PUN)** | Mean: 61.17 (SD=13.24) | White=98.4%<br>Other=1.6% | N=694<br>Female=70.9% | Spouse=37.3%<br>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)<br>(1=No junior high diploma, 2=No high school diploma, 3=High school diploma, 4=Some college, 5=Associate |

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| | | | | | | | | | degree, 6=College degree, 7=Some graduate, 8=Graduate degree) |
| Tarlow *et al.* (2004)[43] | **The Positive Aspects of Caregiving (PAC)** | Range: 22-95<br>Mean: 62.2 | White=57%<br>Black=22.3%<br>Hispanic=19.8%<br>Other=1% | N=1,229<br>Female=81.4% | Husband=12.4%<br>Wife=36.4%<br>Adult child=46.2%<br>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%<br>White=47% | N=177<br>Female=71.8% | Spouse=68.4%<br>Adult child=23.2%<br>Other relative=8.5% | Family caregivers recruited for this study were enrolled in the Miami 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%<br>High school education=19.8%<br>> high school=62.7% |
| Gitlin *et al.* (2005)[45] | **Caregiver Assessment of Function and Upset (CAFU)** | Mean: 61.9 (SD=13.5) | Black=43%<br>White=53%<br>Mixed=4% | N=640<br>Female=77% | Adult child=41.9%<br>Spouse=45%<br>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.<br>(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.<br>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<br>Mean: 62 | Not reported | N=153<br>Female=61% | Spouse=24%<br>Adult child=60%<br>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:<br>Mean: 44.4 (SD=15.44)<br>(*Caregivers*:<br>Range: 25-83<br>Mean: 54.3 (SD=15.3)) | Overall:<br>Not reported<br>(Caregivers:<br>White=95.5%<br>Non-White=4.5%) | N=121<br>Female=66.4%<br>(Caregivers:<br>N=45<br>Female=73.3%)<br>Note: Discrimination and difficulty indexes for the KAML-C test were calculated with the sample of caregivers and experts (N=82). | Overall:<br>Not reported<br>(Caregivers:<br>Adult child=57.8%<br>Spouse=28.9%<br>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:<br>care receivers were early-stage AD) | Not reported | *(Caregivers:*<br>High school graduate=13.3%<br>Some college =35.6%<br>College graduate=28.9%<br>Advanced degree=22.2%)<br>*(Experts:*<br>Mean: 18.7 (SD=2.1))<br>(Students:<br>Mean: 19.9 (SD=0.6)) |
| Gitlin *et al.* (2006)[51] | **Perceived Change Index (PCI)** | Mean: 61.06 (SD=14.31) | Black=47.8%<br>White=48.2%<br>Other=4.0% | N=255<br>Female=74.5% | Non-Spouse=61.2%<br>Spouse=38.8% | Family caregivers recruited for this study were enrolled in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project. | Medical diagnosis of probable AD or a MMSE < 24. | Mean=4.25 years of caring (SD=3.77) | Mean=12.23 years of education |

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| | | | | | | REACH participants were enrolled via community sites, health and social service agencies, primary care clinics, and physicians' offices. | | | (SD=2.62) |
| Reilly *et al.* (2006)[52] | **Partner-Patient Questionnaire for Shared Activities (PPQSA)** | Mean: 66.4 | Not reported | N=100<br>Female=64% | Spouse=71%<br>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<br>Mean: 68<br>(SD=11.5) | Not reported | N=232<br>Female=65.1% | Spouse=65.9%<br>Adult child=24.6%<br>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<br>(SD=13.25) | Basque, Spanish | N=135<br>Female=77% | Spouse=44.4%<br>Adult child=46.7%<br>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<br>Mean: 63.8<br>(SD=13.3) | Not reported | N=125<br>Female=64.8% | Spouse=41.6%<br>Adult child=44.8%<br>Other relative=9.6%<br>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<br>(SD= 13.87) | White=63%<br>Black=37% | N=217<br>Female=79% | Spouses=57%<br>Adult child (natural or in-law)=31%<br>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%<br>Black=24.5%<br>Asian=2.6% | N=229<br>Female=90% | Adult child=49.3%<br>Spouse=29.3%<br>Friend=7.9%<br>Grandchild=5.2%<br>In-law=3.9%<br>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):**<br>**Scale 1:**<br>***S-PSSS Family (SSfa)***<br>(Family support among AD CGs)<br>**Scale 2:**<br>***S-PSSS Friends (SSfr)***<br>(Friends support among AD CGs) | Range: 18-72<br>Mean: 44.8<br>(SD=13.12)<br>(Demographically, the two subsamples: N=115 (Scale 1) and N=114 (Scale 2) were reasonably homogenous. | White=72.8%<br>Black=24.6%<br>Asian=2.6%<br>(Demographically, the two subsamples were reasonably homogenous.) | N=115<br>Female=89.9% | Adult child=48.6%<br>Spouse=29.7%<br>Friend=8.1%<br>Grandchild=5.4%<br>In-law=4.1%<br>Other=4.1%<br>(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**<br>Mean: 35.11<br>(SD=21.90)<br>**Dementia Caregivers**<br>Mean: 62.48<br>(SD=12.33) | **Overall**<br>American Indian/Alaskan=1.2%<br>Asian/Pacific Is=13.7%<br>Black/African American=6.1%<br>White=59.0%<br>Multiracial=9.2%<br>Hispanic=10.8% | Overall:<br>N=763<br>Female=70.2%<br>(Caregivers:<br>N=54<br>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.<br>The study uses a mixed sample composed of the following five groups:<br>Students (N=484); General public-Older adults | Dementia | Not reported | Not reported |

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| | | | **Dementia Caregivers**<br>American Indian/Alaskan=3.4%<br>Asian/Pacific Is=12.1%<br>Black/African American=20.7%<br>White=46.6%<br>Multiracial=5.2%<br>Hispanic=12.1% | | | (N=89); Senior center staff (N=61); Dementia Caregivers (N=54); and Dementia professionals (N=75) | | | |
| Czaja *et al.* (2009)[67] | **REACH Risk Appraisal Measure (RAM)** | Range: 22 to 89<br>Mean: 60.57 (SD=13.32) | Hispanic=33.0%<br>Black=32.9%<br>White=34.1% | N=642<br>Female=82.9% | Spouse=42.4%<br>Adult child=47.8%<br>Sibling=2.8%<br>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%<br>High school=22.6%<br>> High school=57.8%<br>Missing=7.8% |
| Montorio *et al.* (2009)[68] | **Dysfunctional Thoughts about Caregiving Questionnaire (DTCQ)** | Mean: 58 years (SD=14.1) | Not reported | N=227<br>Female=75.3% | Spouse=44.1%<br>Adult child=45.8%<br>Child-in-Law=4.8%<br>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%<br>1-4 years=39.6%<br>>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%<br>Black=9%<br>Asian=7%<br>Hispanic=18%<br>Other=1% | N=200<br>Female=79% | Spouse=45.5%<br>Adult child/Child-in-Law=42.5%<br>Sibling/Sibling-in-Law=3.5%<br>Niece/Nephew=1%<br>Grandchild=1.5%<br>Friend=4%<br>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<br>Dementia Severity:<br>Mild=17%<br>Intermediate=60%<br>Advanced=23% | <1 year of care=11%<br>1-2 years of care=14%<br>2-3 years of care=14%<br>3-5 years of care=21%<br>>5 years of care=42% | ≤ 8 years=3%<br>Some high school=3%<br>High school graduate=8%<br>Some college=33%<br>College graduate=29%<br>> College=24% |
| Epstein-Lubow *et al.* (2010)[71] | **Caregiver Self-Assessment Questionnaire (CSAQ)** | Not reported | White=97.2%<br>Other=2.8% | N=106<br>Female=66% | Spouse=39.0%<br>Adult child=50.5%<br>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%<br>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%<br>White=85.9%<br>Hispanic=0.7%<br>Multiethnic=0.3% | N=304<br>Female=76% | Spouse=43.1%<br>Adult child=38.8%<br>Friend=4.3%<br>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<br>Mean: 59.63 (SD=12.60) | Spaniards=100% | N=288<br>Female=79.2% | Spouse=37.2%<br>Parent=57.6%<br>Other relative=5.2% | Participants were recruited from social and health care centers in Madrid, Spain. | AD=58.4%<br>Other dementias=41.6% | Range: 3-312 months<br>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<br>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%<br>Vascular dementia=35.7%<br>Mixed dementia=7.1%<br>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%<br>Indian=2.9%<br>Eurasian=1.3%<br>Other=0.4% | N=238<br>Female=68.1% | Spouse=7.6%<br>Adult child=81.5%<br>Child-in-Law=5.9%<br>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%<br>Moderate Stage=47.9%<br>Severe Stage=27.7% | <1 year of caregiving=12.6%<br>1-3 years of caregiving=33.8%<br>>3 years of caregiving=53.6% | Primary=1.7%<br>High school=39.5%<br>Tertiary=58.8% |
| Savundranayagam *et al.* | **Montgomery Borgatta Caregiver** | Spouses*:*<br>Range: 24-91 | Spouses*:*<br>White: 91.0% | Spouses:<br>N=280 | Spouse=53%<br>Adult child=47% | All participants were part of the League of Experienced Family Caregivers, a registry of | Cognitive or memory problems or a diagnosis | Spouses:<br><6 months of | Spouses*:*<br>< High school |

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| (2011)[78] | **Burden Scale (MB-CBS)** | Mean: 63<br>Adult Child:<br>Range: 23-71<br>Mean: 52 | Black: 4.0%<br>Hispanic: 3.0%<br>Other 3.0%<br>Adult child:<br>White: 77.0%<br>Black: 8.0%<br>Hispanic: 5.0%<br>Other: 9.0% | Female=76.4%<br>Adult child:<br>N=243<br>Female=87.9% | | 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. | of probable AD or dementia. (Proportions not reported.) | caregiving=1.1%<br>6-12 months=6.5%<br>13-24 months=9.0%<br>25 months to 5 years=30.7%<br>>=5 years=52.7%<br>Adult child:<br><6 months of caregiving=5.4%<br>6-12 months=11.3%<br>13-24 months=14.6%<br>25 months to 5 years=32.6%<br>>=5 years=36.0% | (HS)=0.4%<br>Some HS=3.9%<br>HS graduate=13.6%<br>Some college=33.9%<br>College graduate=27.1%<br>Graduate degree=21.1%<br>Adult child:<br>< HS=0.0%<br>Some HS=0.8%<br>HS graduate=11.6%<br>Some college=31.0%<br>College graduate=33.5%<br>Graduate degree=23.1% |
| Werner *et al.* (2011)[80] | **Family Stigma in Alzheimer's Disease Scale (FS-ADS):**<br>**Scale 1: Family Stigma**<br>**Scale 2: Lay persons' stigma**<br>**Scale 3: Structural stigma** | Mean: 52.7 (SD=8.8) | Place of Birth:<br>Israel=75.7%<br>Europe/America=17.3%<br>Asia/Africa=5.9%<br>Other=1.1% | N=185<br>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):**<br>**Scale 1: Caregivers' Assessment of the Patient (CAP)**<br>**Scale 2: Caregivers' Assessment of Themselves (CAT)** | Range: 18 to 93<br>Mean=58.2 (SD=15.6) | Not reported | N=676<br>Female=71% | Adult child=39%<br>Spouse=37%<br>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<br>Mean: 65.5 (SD=13.1) | White=92.8%<br>Black=2%<br>Asian=1.7%<br>Mixed=0.9% | N=361<br>Female=65.3% | Adult child=30.1%<br>Spouse/Partner=4%<br>Sibling=1.6%<br>Parent=14.3%<br>Friends=1.6%<br>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<br>Mean: 71.6 (SD=7.8) | White=92%<br>Other=8% | N=84<br>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%<br>Other=4.5% | N=155<br>Female=59.5% | Spouse, Sibling, or Adult child=83.9%<br>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 |

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| Tebb et al (2013)[85] | **The Caregiver Well-Being Scale: Short Form Rapid Assessment:**<br><br>**Scale 1:**<br>**Basic Needs Scale**<br>**Scale 2:**<br>**Activities of Daily Living Scale** | Range: 29-82<br>Mean: 53.50<br>(SD=7.90) | White=87%<br>Black=11%<br>Hispanic=1%<br>Asian=1% | N=486<br>Female=96.1% | Spouse=13.6%<br>Adult child=69.2%<br>Child-in-Law=8.3%<br>Other relative=2.0%<br>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%<br>Other diseases or conditions=76% | Range: 4 months-30 years<br>Mean: 5 years of caregiving | Not reported |
| Bekhet & Zauszniewski (2013)[86] | **Depressive Cognition Scale (DPS)** | Range: 22-87<br>Mean: 57.5<br>(SD=15.6) | White=56.3%<br>Black=35%<br>Hispanic, Asian, or other=8% | N=80<br>Female=90% | Parent=15%<br>Adult child=26.3%<br>Spouse=20%<br>Sibling=3.8%<br>Other relative=35% | Participants were recruited from Alzheimer's Association early stage programs. | Dementia | Not reported | High school=25%<br>Associate or some college=30%<br>College degree=20%<br>Graduate/Professional=25% |
| Orgeta *et al.* (2013)[88] | **Warwick–Edinburgh Mental Well-Being Scale (WEMWBS)** | Range: 24-88<br>Mean: 62.42<br>(SD=11.22) | White=92.5%<br>Other=7.5% | N=170<br>Female=81.2% | Spouse=52.6%<br>Adult child=29.3%<br>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%<br>2-4 years of caregiving=22.6%<br>4-6 years of caregiving=23.3%<br>>=6 years of caregiving=38.3% | Left school before 14 years old=2.45%<br>Left school at 14 years old=48.4%<br>Left school at 18 years old=49.2% |
| Wilks *et al.*(2013)[89] | **Spiritual Support Scale (SSS)** | Mean: 61 | White=62%<br>Black=36%<br>Other=1.3%<br>Hispanic=0.9% | N=691<br>Female=79.8% | Adult child=51.5%<br>Other=16.9%<br>Spouse/partner=16.8%<br>Grandchild=6.6%<br>Sibling=4.4%<br>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:<br>Early stage=22.3%<br>Middle stage=36.1%<br>Late stage=41.5% | Not reported | Not reported |
| Crellin *et al.* (2014)[90] | **Caregiver Efficacy Scale (CES)** | Mean: 66.39<br>(SD=13.06) | White (British/Irish/other)=92.6%<br>Black (African/Caribbean/other)=2.9<br>Asian/Indian/other=4.5%<br>Other=0.8% | N=245<br>Female=70.6% | Spouse/partner=62.1%<br>Adult child=28.6%<br>Family= 6.9%<br>Other=2.4% | Recruited through primary and secondary healthcare, health professionals, voluntary organizations, and social services. | Dementia severity:<br>Mild=62.6%<br>Moderate=27.5%<br>Severe=9.9% | Not reported | School leaver (14–18 yrs.)=72.2%<br>Higher education=27.8% |
| Cole *et al.* (2014)[92] | **Impact of Alzheimer's Disease on Caregiver Questionnaire (IADCQ)** | 18-29 years=11%,<br>30-49 years=39.5%,<br>50-69 years=47%,<br>70+ years=2.5% | White=84.5%<br>Black=7%<br>Asian=4.5%<br>Native American=1%<br>Other=3% | N=200<br>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%<br>6-12 months= 22.5%<br>13-24 months= 25.5%<br>>2 years= 42% | Not reported |
| Gillanders *et al.* (2014)[93] | **Cognitive Fusion Questionnaire (CFQ)** | Range: 31 to 95<br>Mean: 68.6<br>(SD=11.5) | Not reported | N=219<br>Female=66% | Spouse=87%<br>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<br>Mean: 52<br>(SD = 10.29 ) | Not reported | N=183<br>Female=57.4% | Spouse=13.1%<br>Son/daughter=65%<br>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<br>(SD=5.81) | ≤ Primary school=10.9%<br>Junior high school=14.8%<br>High school=30.6%<br>≥ College=43.7% |

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| Losada *et al.* (2014)[95] | **Experiential Avoidance in Caregiving Questionnaire (EACQ)** | Mean: 61.37<br>(SD=14.84) | Not reported | N=263<br>Female=78.3% | Sons/daughters=49.5%<br>Spouses=41.8%<br>Other=8.7% | All recruited through social and healthcare centers in Madrid and advertisements in the media. | AD=60.2%<br>Other dementias=39.8% | Mean: 3.8 years (SD=3.05)<br>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<br>(SD=9.60) | Not reported | N=45<br>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.* (2014)[97] | **Dementia Knowledge Assessment Tool (DKAT2)** | Family Caregivers:<br>Mean: 55<br>Care workers:<br>Mean: 45 | Not reported | Family Caregivers:<br>N=34<br>Female=Not reported<br>Care workers:<br>N=70<br>Female=Not reported | Family Caregivers:<br>Adult child= 59%<br>Other family=41% | Sample was recruited from four residential aged 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.) | Dementia and Meeting criteria for moderate to very severe cognitive decline | At least 3 months | Not reported |
| Kraijo *et al.* (2014)[98] | **The Perseverance Time (Pt)** | Range: 29-93<br>Mean: 66.4<br>(SD = 13.4) | Not reported | N=223<br>Female=65.5% | Partner=54.3%<br>Parent (in-law)=38.6%<br>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<br>Mean: 3.1 years (SD=2.1) | Low=12.6%<br>Middle=58.7%<br>High =28.7% |
| Sadak et al. (2015)[100] | **Partnering for Better Health-Living with Chronic Illness: Dementia (PBH-LCI:D)** | Mean: 65.9<br>(SD=11.1) | White=91%<br>Asian=4%<br>Black=4%<br>Native American=1% | N=130<br>Female=80% | Spouse or partner=63%<br>Adult child=25%<br>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%<br>College graduate=77% |
| Chang *et al.* (2016)[101] | **Affiliate Stigma Scale** | Mean: 52.8<br>(SD=12.18) | Chinese=100% | N=271<br>Female=53.1% | Adult child= 61.6%<br>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%<br>High school=31.7%<br>Some college=34.3% |
| Powers & Whitlach (2016)[103] | **Cultural Justifications for Caregiving Scale (CJCS)** | Mean: 64.74<br>(SD=12.56) | African American=35%<br>White=65% | N=202<br>Female=79% | Spouse=56.4%<br>Adult child=35.6%<br>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)<br>(Mean: 3.17 years) | No high school=0.5%<br>Some high school=6.8%<br>High school graduate=19.9%<br>Some college=36.6%<br>College graduate=16.2%<br>Post graduate degree=19.9% |
| Piersol *et al.* (2016)[106] | **Functional Capacity Card Sort (FCCS)** | Mean: 65.8<br>(SD=12.2) | Non-White=22.7%<br>White=77.3% | N=88<br>Female=88.6% | Spouse=55.7%<br>Non-spouse=44.3% | Convenience sample recruited from mailings, physician offices, and media advertisements. | Dementia | Range: 0.5 to 22 years<br>Mean: 5.1 years (SD=3.5) | High school=2.3%<br>More than High School=97.7% |
| Kiriake & Moriyama (2016)[107] | **The Partnership Scale (PS)** | Mean: 60.398<br>(SD=11.35) | Japanese=100% | N=261<br>Female=76.5% | Spouse=23.4%<br>Adult child=46.7%<br>Daughter/Son-in-law=25.3%<br>Sibling=1.1% | Caregivers were recruited from five different facilities in a particular prefecture in Japan | Suspected dementia=2.3%<br>Light dementia=6.1%<br>Moderate dementia=30.3% | Less than 6 months=6.2%<br>6 months-1 year=8.2%<br>1-3 years=28.8% | Not reported |

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| | | | | | Other=3.4% | | Severe dementia=61.3% | 3-5 years=23.0%<br>5-9 years=21.0%<br>9-12 years=7.0%<br>12 years or more=5.8% | |
| Maneewat *et al.* (2016)[108] | **Caregiver resilience scale (CRS)** | Range: 20 to 60 | Thai=100% | N=150<br>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 caregivers who provided care for older persons with dementia, (2) aged 20 to 60 years, (3) able to speak and understand the Thai language. | Mild to moderate dementia or any subtypes of dementia | Not reported | Not reported |
| Sullivan *et al.* (2016)[109] | **The Thoughts Questionnaire (TQ)** | Range: 36–85<br>Mean: 64.30<br>(SD = 10.65) | Caucasian =94.3%<br>non-Caucasian=5.7% | N=35<br>Female=86% | Spouses=68.6%<br>Non-spousal family=31.4% | Participants recruited by snowball sampling beginning with flyers distributed to community-support agencies. | AD=34.3%<br>Mixed type =5.7%<br>FTD=5.7%<br>Early onset AD=31.4%<br>Vascular dementia=5.7%<br>Lewy bodies=5.7%<br>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<br>(SD=12.3) | White=98%<br>Non-White=2% | N=205<br>Female=75% | Spouse=62%<br>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%<br>Other=3% |
| Piggott *et al.* (2017)[112] | **Caregiver Confidence in Sign/Symptom Management (CCSM) Scale** | Range: 23-90<br>Mean: 62 | White=79%<br>Black/African American=18%<br>Asian=3% | N=194<br>Female=83% | Spouse=41%<br>Daughter=43%<br>Daughter-in-law=6%<br>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<br>Mean: 60.97<br>(SD=14.34) | Not reported | N=253<br>Female=76.7% | Spouse=41.4%<br>Son/daughter=50.2%<br>Other (e.g., mother-in-law)=8.4% | Recruited from social and health care centers in Madrid, Spain | AD=70.4%<br>Other dementia=29.6% | Range: 0.5–20 years<br>Mean: 3.76 years (SD = 3.08) | Not reported |
| Stott *et al.* (2017)[115] | **Hospital Anxiety and Depression Scale (HADS)** | Mean: 68<br>(SD=19) | White=93%<br>Black and minority ethnicity=7% | N=284<br>Female=68% | Spouse, sibling (same generation)=63.4%<br>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%<br>Vascular dementia=17.3%<br>Other dementia=36.6% | Mean: 31.46 months<br>(SD=7.37) | School dropout=69.7%<br>Higher/further education=30.3% |
| Losada *et al.* (2017)[117] | **The Caregiving Ambivalence Scale (CAS)** | Mean: 60.9<br>(SD=13.77) | Spanish | N=401<br>Female=77.1% | Adult child=51.4%<br>Spouses=41.1%<br>Other=7.5% | Recruited from social and health care centers in Madrid, Spain | AD=67.5%<br>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<br>Mean: 51.5<br>(SD=12.4) | Not reported | N=132<br>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.)<br>Total years providing care was not reported. | Illiterate or primary school (age 7-11 years)= 16.67%<br>Guidance school (age 12-14 years)= 11.36%<br>High school (age 15-18 years)= 36.36%<br>Associate or bachelor's degree= 31.82%<br>Master's degree |

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| Fabà & Villar (2017)[120] | **Gains Associated with Caregiving (GAC) scale** | Mean: 63.0 (SD=12.30) | Not reported | N=260<br>Female=66.5% (final field study)<br>(An initial EFA study was conducted in an independent sample of N=152 participants) | Partner=48.8%<br>Adult child=47.4%<br>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%<br>Primary education=37.3%<br>Secondary education=38.1%<br>Higher education=16.9% |
| Weisman de Mamani *et al.* (2018)[121] | **Stigma Impact Scale (SIS)** | Range: 25–83<br>Mean: 50.73 (SD = 12.73) | White=53.8%<br>Black=28.3%<br>Hispanic=6.6%<br>Asian-American=1.9%<br>Other=9.4% | N=106<br>Female=81.1% | Adult child=51.9%<br>Spouses=14.2%<br>Grandchildren=17.9%<br>Nieces/nephews=8.5%<br>Children in-law=5.7%<br>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%<br>College degree=38.7%<br>Some college=37.7%<br>High school=2.8%<br>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<br>Mean: 61.8 (SD = 11.7) | Sami=7%<br>Other=93% | N=430<br>Female=68.9% | Spouses=28.8%<br>Adult child=60.7%<br>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%<br>Afro-Caribbean=1.1 %<br>Asian=1.1%<br>Other ethnic group=0.6% | N=182<br>Female=64.6% | Spouses=80.1%<br>Son/daughter=16%<br>Other=0.6%<br>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%<br>1 to 3 years=44.2%<br>4 to 6 years=34.3%<br>7 to 10 years=9.9%<br>10+ years=9.4% | Not reported |
| Peipert *et al.* (2018)[126] | **Dementia Burden Scale – Caregiver (DBS-CG)** | Range: 22-99<br>Mean: 63 (SD=14) | Race:<br>White=44%<br>Black=6%<br>Asian=5%<br>Other=5%<br>Missing=39%<br>Ethnicity:<br>Hispanic=10%<br>Not Hispanic=50%<br>Missing=40% | N=1,091<br>Female=67% | Adult child= 49%<br>Spouse/partner= 35%<br>Friend= 2%<br>**Paid or hired caregiver= 3%**<br>Other= 10% | Caregivers were recruited from UCLA Alzheimer's disease Center programs. | Dementia type not specified=43%<br>AD=38%<br>Mixed dementia=8%<br>Vascular dementia=4%<br>Other dementia=6% | Not reported | High school graduate=9%<br>Some college=16%<br>College graduate=40% |
| Stansfeld *et al.* (2019)[127] | **Sense of Coherence Scale-13 (SOC-13)** | Range: 18–89<br>Mean: 59.5 (SD=12.3) | White British or Irish=94.2%<br>Mixed British=0.7%<br>Indian/British Indian=0.7%<br>Black Caribbean/African=0.7%<br>Other=3.7% | N=583<br>Female=80.3% | Spouse/partner= 30.1%<br>Son/daughter= 58.9%<br>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%<br>Vascular dementia=18.9%<br>Lewy Bodies=7.2%<br>FTD=23.3% | Not reported | Primary education or less=0.5%<br>Secondary education=23.7%<br>Further education=71.3%<br>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%<br>African American=21.2%<br>Hispanic=2.4%<br>Other=4.6% | N=170<br>Female=69.4% | Spouse=12.4%<br>Adult child=54.7%<br>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.* | **Center for** | Mean: 53.0 | Chinese=86.6% | N=394 | Spouses= 13.7% | Caregivers caring for community-dwelling people | Dementia: | Mean= 6.8 years | |

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| (2019)[130] | **Epidemiological Studies Depression Scale (CES-D)** | (SD: 10.7) | Malay=6.3%<br>Indian=4.6%<br>Other=2.5% | Female=59.9% | Adult child=86.3% | 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. | Mild=15.7%<br>Moderate=41.4%<br>Severe=42.9% | (SD=6.7) | Primary or no formal=10.4%<br>Secondary=57.9%<br>Tertiary =31.7 |
| Barello *et al.* (2019)[131] | **Caregiving Health Engagement Scale (CHE-s)** | Mean: 53.3<br>(SD=12.5) | Italian=100% | N=198<br>Female=76.5% | Parent=56.1%<br>Adult child=13.6%<br>Spouse/Partner=24.7%<br>Other=5.6% | 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 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. | Pulmonary disease=8.4%<br>**ADRD=12.6%**<br>Diabetes=7.1%<br>Cystic fibrosis=7.1%<br>Other (various)=34.8% | At least six months | Not reported |
| Brown *et al.* (2019)[132] | **Carer Dementia Quality of Life (C-DEMQOL)** | Range: 21-90<br>Median: 62 | White British=84.9%<br>White Other=8.7%<br>Black/African/ Caribbean=3%<br>Mixed Ethnic Background=1.7%<br>Indian/Bangladeshi=0.7%<br>Arab=0.3%<br>Other=0.7% | N=300<br>Female=72.9% | Adult child=49.5%<br>Spouse/long-term partner=42.8%<br>Family friend=1.3%<br>Sibling=1.0%<br>Other family member=0.7%<br>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%<br>Mixed=19%<br>Vascular dementia=13.1%<br>FTD=3.6%<br>Lewy bodies=2.2%<br>Other dementia=4.0% | Not reported | Not reported |
| Cheng *et al.* (2019)[133] | **Caregiver Grief Questionnaire (CGQ)** | Range: 36-84<br>Mean: 58.27<br>(SD=10.42) | Chinese=100% | N=173<br>Female=84% | Spouse= 32%<br>Sibling= 1%<br>Adult child= 59%<br>Child-in-law= 7%<br>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%<br>Secondary= 51%<br>Tertiary= 25%<br>None= 6% |
| McCaffrey *et al.* (2020)[135] | **Carer Experience Scale (CES)** | Mean: 52<br>(SD=14) | Not reported | N=500<br>Female=79.1% | Adult child=32%<br>Partner=25%<br>Parent=31%<br>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%<br>Mental health problems=34%<br>Other=23% | ≤ 24 months=26%<br>> 24 months=74% | ≤ 11 years=17%<br>12 years=9%<br>Diploma=27%<br>Undergraduate=26%<br>Postgraduate=18%<br>Other=1% |
| Wynn & Carpenter (2020)[137] | **The Frontotemporal Dementia Knowledge Scale (FTDKS)** | Mean: 51.5<br>(SD=15.7) | White=90.2% | N=174<br>Female=76.4% | **Caregivers of people with FTD**=58.6%<br>(*Spouses, Adult children, Relatives, and Friends)*<br>**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:<br>Never been involved=9.8%<br>Helped arrange=2.0%<br>Assisted in caregiving=15.7%<br>Primary caregiver=72.5% | High school=4.9%<br>Some college=16.7%<br>Associate's degree=3.9%<br>Bachelor's degree=40.2%<br>Master's degree=25.5%<br>Doctoral degree8.8% |
| Van Houtven *et al.* (2020)[138] | **Caregiver Perceptions About Communication with Clinical Team Members (CAPACITY) Instrument** | Mean: 70.3<br>(SD=9.6) | White=95.8% | N=1,746<br>Female=67.7% | Spouse/Significant Other=89.1%<br>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**.<br>The IDEAS Study recruited Medicare beneficiaries aged 65 years and older with progressive MCI and/or dementia of uncertain cause from 592 | MCI=72.4%<br>Dementia=27.6% | Time providing care for the patient (hours)<br>5 hours or fewer a week (wk) =29.8%<br>6–19 hours a | High school graduate or less=14.1%<br>Some college=28.8%<br>Bachelor's |

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| | | | | | | 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. | | wk=13.8%<br>20–39 hours a wk=5.6%<br>40 or more hours a wk=4.7%<br>Not providing care or don't know =46.0% | degree=27.4%<br>Graduate degree=29.8% |
| Doherty *et al.* (2020)[139] | **Consumer Access, Appraisal and Application of Services and Information for Dementia (CAAASI-Dem)** | Mean: 46.1 (SD=14.2) | Not reported | N=3,146<br>Female=86.1% | Relationship of the family CG to care 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%) | Participants were volunteers who had enrolled the Understanding Dementia Massive Open Online Course (UDMOOC) and who consented to participate in the CAAASI-Dem study. | Dementia | Not reported | Primary school=0.2%<br>Secondary school (years 11–12)=7.9%<br>Secondary school (years 7–10)=4.7%<br>Certificate or apprenticeship=18.6%<br>Associate degree=20.6%<br>Bachelor's=26.9%<br>Higher University degree(Grad, Masters, PhD)=17%<br>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<br>Female=75.8% | Spouse= 29.8%<br>Sibling= 1.7%<br>Adult child/child-in-law= 60.1%<br>Grandchild= 2.8%<br>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%<br>High school=39.9%<br>Junior college/technical school=28.7%<br>College=21.9%<br>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<br>Female=68.4% | Spouse=45.1%<br>Daughter-/son-in-law=48.7%<br>Other=4.3%<br>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%<br>Lewy bodies=11.8%<br>Vascular dementia=4.6%<br>FTD=3.6%<br>Unknown=15.1%<br>Missing=5.3% | ≤ 1 year=15.1%<br>> 1–5 years=44.0%<br>> 5–10 years=27.0%<br>> 10 years=8.9%<br>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%<br>Hispanic=8% | N=253<br>Female=62.7% | Spouses= 68.6%<br>Adult child= 18.8%<br>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%<br>MCI=31.2%<br>AD=15.0%<br>Lewy bodies= 32.0%<br>Vascular dementia= 4.7%<br>FTD=2.4% | Not reported | Mean=16 years (SD=2.6) |
| Losada *et al.* (2020)[143] | **Revised Familism Scale (RFS)** | Range: 29-87<br>Mean: 59.6 (SD=13.10) | Not reported | N=119<br>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%<br>Other dementia=42.9% | Range: 3-312 months<br>Mean: 54.44 months (SD=46.50) | Not reported |
| Maltby *et al.* (2020)[146] | **Adult Carers for Older Adults** | **United States**:<br>Mean: 37.77 | **United States**:<br>White=75.6% | **United States:**<br>N=164 | Relationship of the family CG to care | The samples were recruited via online survey data recruitment platforms including Mturk | **United States:**<br>**Dementia (including** | United States:<br>0 to 40 hours per | Not reported |

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| | **Quality of Life Questionnaire** | (SD=12.00)<br>**China**:<br>Mean: 32.71<br>(SD=7.57) | Black=10.4%<br>Asian=6.7%<br>Hispanic=6.1% | Female=58.5%<br>**China:**<br>N=131<br>Female=54.9% | recipient is not reported. | (USA) and Wenjuanxing (China). | **AD)=30.5%**<br>Diabetes=23.2%<br>Heart disease=21.3%<br>Stroke=5.5%<br>**China:**<br>**Dementia (including AD)=14.5%**<br>Diabetes=40.5%<br>Heart disease=45.8%<br>Stroke=6.9% | week= 82.3%<br>China:<br>0 to 40 hours per week= 95.6%% | |
| 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<br>(SD=9.6) | Not reported | N=116<br>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<br>(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<br>Mean: 66.42<br>(SD=13.23) | Not reported | N=451<br>Female=66.4% | Spouse/partner=63.9%<br>Son/daughter-in-law=31.9%<br>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**:<br>Less than 4 hours=48.5%<br>4 hours or more=51.5% | Education<br>Range: 0-24 years<br>Mean: 11.91 years<br>(SD: 4.42) |
| Teresi *et al.* (2020)[153] | **Perceived Stress Scale (PSS)** | Range: 19-92<br>Mean: 58.4 (SD = 11.2) | Hispanic=100% (Dominican, Puerto Rican, and Mexican) | N=453<br>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)<br>High school graduate=55%<br>≥High School=45% |
| Thompson *et al.* (2020)[154] | **Fear of Incompetence—Dementia Scale (FOI-D)** | Range: 18–80<br>Mean: 36.44<br>(SD=11.29) | Caucasian=79% | N=636<br>Female=65.2% | Grandchildren= 54%<br>Adult child= 21%<br>Niece/nephew= 15%<br>Great-grandchild= 2%<br>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<br>Mean: 3.94 years | Not reported |
| Voormolen *et al.* (2021)[155] | **The Care-Related Quality of Life (CarerQol) questionnaire** | Mean: 66.2<br>(SD=13.4) | Not reported | N=433<br>Female=66.0% | Spouse or partner=63%<br>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%<br>13 years=43.7% |
| Rose *et al.* (2021)[157] | **Family Quality of Life in Dementia (FQOL-D) scale.** | Mean: 52<br>(SD=2.0) | White=74.2%<br>African American=21.3%<br>Native American/Asian/Pacific Islander/Other=4.5% | N=244<br>Female=56.6% | Spouse/partner=45.5%<br>Daughter=27%<br>Son=4.5%<br>Other relative=13.1%<br>Friend/neighbor=5.3%<br>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%<br>High school graduate=28.3%<br>13–15 years=25.0%<br>College graduate=29.1%<br>17–18 years=7.0%<br>>18 years=8.6% |
| Clemmensen *et al.* (2021)[158] | **Dementia Carer Assessment of Support Needs Tool (DeCANT)** | Mean: 61.7<br>(SD=13.68) | Not reported | N=301<br>Female=78.4% | Spouse/partner=53.7%<br>Adult child=41%<br>Sibling=0.7% | 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 | AD=67.35%<br>FTD=5.78%<br>Lewy bodies=4.76%<br>Vascular dementia=4.42% | Not reported | Elementary education=7.22%<br>Secondary education=38.49% |

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| | | | | | Other=4.7% | 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. | Mixed dementia diagnosis=4.76%<br>Other=7.82%<br>Do not know=5.10% | | Higher education=47.77%<br>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%<br>Black=0.8%<br>Southeast Asian=1.5%<br>East Asian=1.5%<br>Latin American=0.8%<br>Indigenous=2.3% | N=134<br>Female=78.2% | Spouse=23.9%<br>Adult child or child-in-law=69.4%<br>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%<br>Vascular dementia=13.5%<br>Mixed =9.8%<br>Lewy bodies =6.8%<br>FTD=3.0v<br>Korsakoff's =1.5v<br>Unknown =19.5%<br>Other =5.3% | Not reported | Less than high school=2.3%<br>High school=13.5%<br>College or university=64.7%<br>Graduate school=19.5% |
| Wuttke-Linnemann *et al.* (2021)[160] | **Resilience and Strain Questionnaire (ResQ-Care)** | Mean: 56.60 (SD=10.63) | Not reported | N=291<br>Female=84.5% | Adult child=51.4%<br>Spouse=33.8%<br>Parents taking care of child=9.7%<br>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%<br>**Dementia diagnosis=47.6%**<br><u>Note:</u> Mixed sample of carers; patients had AD or other physical disabilities. | Hours (h) spent caregiving:<br><20 h/week=33.0%<br>20–40 h/week=33.0%<br>>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)**<br>**<u>Scale 1:</u>** <u>Care Receiver</u> (ITGDCQ-CR)<br>**<u>Scale 2:</u>**<br>Other Relatives (ITGDCQ-OR) | Mean: 62.7 (SD=12.9) | Not reported | N=201<br>Female=66.2% | Spouse=46.3%<br>Adult child=50.1%<br>Other=3.6% | Recruited through health and adult day care centers in Madrid. | AD=61.2%<br>Mild cognitively impaired=26.4%<br>Other dementia=1.5% | Mean=49.7 months (SD=45.2)<br>(Daily hours of care, Mean=14.5 hours (SD=8.9) | Low= 15.4%<br>Medium= 58.2%<br>High=26.4% |
| Horton *et al.* (2021)[162] | **Impact of DEmentia on CARers (SIDECAR) Battery:**<br>**<u>SIDECAR-D</u>:** *Direct Impact on Carers*<br>**<u>SIDECAR-I</u>:** *Indirect Impact on Carers*<br>**<u>SIDECAR-S</u>:** *Support and Information* | Range: 34-92<br>Median age: 70 | White=97%<br>Other=3% | N=570<br>Female=72.3% | Spouse or partner=74.4%<br>Son or daughter=18.9%<br>Son-in-law or daughter-in-law=1.9%<br>Other (relative/ friend)=3.4%<br>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:<br>Mild=36.7%<br>Moderate=47.5%<br>Severe=13.0%<br>Missing=2.8% | Not reported | Not reported |
| Schlomann et al (2021)[163] | **Berlin Inventory of Caregiver Stress-Dementia (BICS-D)**<br><br>(Inventory comprising 25 subscales) | Mean=60<br>SD=11.4 | Not reported | N=594<br>Female=79% | Daughter/son=42%<br>Daughter-in-law=9%<br>Female partner=28%<br>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:<br>Mild=4%<br>Moderate=42%<br>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<br>Female=78.7% | Spouse=65.7%<br>Son=6.1%<br>Daughter=19.8%<br>Daughter-in-law=5.2%<br>Sibling=1.7<br>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 | Dementia | Mean=4.55 years (SD=3.36)<br>(average care time per day was 11.30 hours (SD=5.47) | Less than elementary=2.0%<br>Elementary=19.6%<br>Junior high=17.6%<br>Senior High=37.6%<br>College and above=23.3% |

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| | | | | | | to withdraw consent from the study. | | | |
| Wawrziczny *et al.* (2022)[165] | **Control and Stimulation in Dementia Caregiving (CSDC-13) Scale** | Mean: 59.43 (SD=12.54) | Not reported | N=282<br>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<br>Female=68.6% | Adult child=54.3%<br>Spouse=41.9%<br>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<br>Mean: 60.20 (SD=10.75) | Non-Hispanic White=95.3%<br>African American=1.4%<br>Asian=0.6%<br>Native American=0.4%<br>Pacific Islander=0.3% | N=699<br>Female=88.7% | Spouse=56.8%<br>Adult child=37%<br>Other family=2.9%<br>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:**<br>Lewy bodies= 65.8%<br>AD= 11.4%<br>Parkinson's disease dementia= 10.9%<br>Other dementias= 8.9%<br>**Disease stage:**<br>Mild= 6.7%<br>Moderate= 55.4%<br>Severe= 34.6% | Not reported | Post-college=34.9%<br>Less than 7 years=0.3%<br>Partial high school=0.7%<br>High school=9.0%<br>Partial college=22.7%<br>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<br>Female=43.9% | Spouse/partner=62.8%<br>Son/daughter=30.6%<br>Other family member=5.2%<br>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<br>Mean: 60 (SD=13.19) | White=93% (n=65)<br>Black/African/Caribbean=1% (n=1)<br>Mixed multiple=1% (n=1)<br>Other ethnic group=3% (n=2)<br>Not disclosed=1% (n=1) | N=70<br>Female=76% | Spouse/partner= 34%<br>Adult child/child-in-law= 54%<br>Other=10%<br>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%<br>Vascular dementia= 18.6%<br>FTD= 11.4%<br>Lewy bodies= 2.9%<br>Mixed= 24.3%<br>Not disclosed/unknown= 5.7% | Not reported | Not reported |
| Cartwright *et al.* (2022)[173] | **Multidimensional scale of perceived social support (MSPSS)** | Range: 20-92<br>Mean: 60.5 (SD=14.40) | White (British)=92.2% (n=249)<br>White (other)=4.8% (n=13)<br>Black=0.7% (n=2)<br>Asian= 0.7% (n=2)<br>Mixed=1.1% (n=3)<br>Other=0.4% (n=1) | N=270<br>Female=65.6% | Husband=21.9%<br>Wife=15.9%<br>Son=9.6%<br>Daughter=40.7%<br>Son-in-law=1.9%<br>Daughter-in-law=1.9%<br>Granddaughter=3.7%<br>Grandson=0.4%<br>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%<br>Vascular dementia=12.2%<br>Dementia with Lewy bodies=2.2%<br>Parkinson's dementia=1.9%<br>FTD=4.8%<br>Mixed dementia=22.6%<br>Dementia (subtype unknown)=4.8%<br>Other=3.3% | 0–1 year=5.9%<br>1–2 years=14.8%<br>3–4 years=31.9%<br>5–8 years=28.1%<br>9 years or more=9.3% | Postgraduate degree =27.0%<br>University degree (or equivalent)=30.4%<br>Higher education (or equivalent)=16.3%<br>A level (or equivalent)=10% )<br>GCSE grades A*-C (or equivalent=8.9%<br>Other or no qualifications=7.4% |

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| Kim *et al.* (2022)[175] | **Dementia Public Stigma Scale (DePSS)** | Mean: 46.2<br>(SD=15.4) | Not reported | N=3,250<br>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<br>(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%<br>Secondary school=5.5%<br>Certificate/apprenticeship=17.8%<br>Associate degree=16.5%<br>Bachelor's=28.6%<br>Higher university degree=20.4% |
| Hosseini *et al.* (2022)[176]<br>(The following studies used the same validation sample.)<br>Sharif-Nia *et al.* (2022)[178]<br>Sharif-Nia *et al.* (2023)[179] | **Family Caregivers' Hardiness Scale (FCHS)**<br>**The Care Challenge Scale (CCS)**<br>**Care Stress Management Scale (CSMS)** | Mean: 50.26<br>(SD=13.24) | Not reported | N=435<br>Female=50.6% | Daughter=52.9%<br>Son=13.1%<br>Wife=8.5%<br>Husband=4.6%<br>Friend=7.8%<br>Relative=13.1% | Convenience sample of family/informal caregivers willing to participate in the study and who were able to use social networks such as Telegram and WhatsApp. | AD | Care hours per day: Mean=7.51 hours (SD=5.51) | Illiterate=2.5%<br>Less than diploma=6.9%<br>Diploma=46%<br>Academic=44.6% |
| Kuzmik *et al.* (2023)[180] | **Modified Caregiver Strain Index (MCSI)** | Mean: 61.9<br>(SD=14.0) | Non-Hispanic White=66% (n=279)<br>Non-Hispanic Black=34% (n=144) | N=423<br>Female=72.3% | Adult child=52%<br>Spouse=29%<br>Nephew/niece=4%<br>Sibling=4%<br>Granddaughter/son=3%<br>Goddaughter=1%<br>Friend=2%<br>Daughter-in-law=2%<br>Partner=1%<br>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),<br>AD8 Dementia Screening Interview (≥2),<br>Clinical Dementia Rating Scale (Range: 0.5-2.0),<br>Functional Activities Questionnaire (≥9).} | Not reported | Less than high school=8%<br>High school graduate=25%<br>Some college or technical school=30%<br>College graduate=21%<br>Graduate or professional school=14% |
| Olthof-Nefkens *et al.* (2023)[183] | **Experienced Communication in Dementia Questionnaire-Caregiver (ECD-C)** | Range: 41-86<br>Mean=65<br>(SD=11.4) | Not reported | N=57<br>Female=68%<br>(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).<br>AD=87.7%<br>FTD=1.8%<br>Lewy bodies=1.8%<br>Progressive aphasia=1.8%<br>Mixed=7% | Not reported | Not reported |
| Potter *et al.* (2023)[184] | **The Long-Term Conditions Questionnaire for Carers (LTCQ-Carer)** | Range: 41-90<br>Mean:67 | Quantitative (Phase 2):<br>White British (94%)<br>Non-white (3%) | Quantitative:<br>N=107<br>Female=63%<br>(plus 10 cognitive "think aloud" interviews with carers -completed in Phase 1 qualitative study) | Qualitative Phase 1: (think aloud):<br>Spouse (70%)<br>Adult child (30%)<br>Quantitative (Phase 2): Family member=94%<br>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<br>(SD=11.1) | Not reported | N=322<br>Female=80% | Spouse= 59%<br>Adult child= 39.8%<br>Other= 1.2% | Caregivers were recruited by numerous public relation methods (regional and national newspapers, television and radio interviews, project homepage) and cooperation partners | Care recipients were diagnosed as having dementia, or at least fit criteria for MCI. | Mean: 4.9 years<br>(SD= 3.7) | Primary or other =3.1%<br>Secondary: Level 2 =50.9% |

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|  |  |  |  |  |  | (clinics, practices, home support services). | AD=44.1%<br>Vascular dementia=10.2%<br>FTD=5.3%<br>Other/unknown=40.3% |  | Secondary: Levels 3 & 4 =12.4%<br>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<br>Female=75.7% | Spouses=30.5%<br>Adult child/in-law=59.5%<br>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%**<br>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 Outcome Measure-Carer Version (PPOM-C)** | Range: 20-92<br>Mean: 60.51 (SD=14.37) | White British (96.6%) | N=267<br>Female=65.2% | Daughter=40.4%<br>Husband=21.7%<br>Wife=16.1%<br>Son=9.7%<br>Granddaughter=3.7 %<br>Other=4.1%<br>Daughter-in-law=1.9%<br>Son-in-law=1.9%<br>Grandson=0.4% | Unpaid family carer for a person living with dementia. They must have been over 18 years 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. | AD=47.6%<br>Dementia of mixed etiology=22.5%<br>Vascular dementia=11.6%<br>FTD=5.6%<br>Other=7.1%<br>Lewy bodies=2.2%<br>Posterior cortical atrophy=1.9%<br>Parkinson's Dementia=0.5% | 0–12 months=5.6%<br>1–2 years=15%<br>3–4 years=31.5%<br>5–6 years=19.9%<br>7–8 years=8.6%<br>9–10 years=7.1%<br>10 years+ =12.4% | Undergraduate=31.1%<br>Postgraduate=26.6 %<br>Higher education=15.7%<br>a-level= 10.5%<br>GCSE's= 8.6%<br>Other= 3.4% |
| Suganuma *et al.* (2024)[190] | **Caregiving Competence Scale for Dementia (CCSD)** | Mean: 68.4 (SD=9.5) | Japanese | N=150<br>Female=63.3% | Spouse=61.3%<br>Son or daughter =28.7%<br>Son or daughter in-law=6.0%<br>Sibling=2.7%<br>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%<br>Vascular dementia=6.0%<br>Lewy bodies=6.0%<br>FTD=2.7%<br>Young onset AD=12.7%<br>Mixed-type dementia=6.7%<br>MCI=7.3%<br>Unknown=10.0% | Mean: 60 months (SD=51.3) | ≤ Ninth grade=4%<br>10–12=36%<br>≥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.