					haracteristics of the	Caregiver Sample Used in Tool Validation Process	i		
Reference	Name of the Scale(s)	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
Ü	The Cost of Care Index (CCI)	Mean: 66	Not reported	N=127 Female=64%	Spouses=68% Other relatives=32%	Participants were recruited through the cooperation of local AD supports groups in the area. Caregivers were interviewed in their homes by trained personnel.	AD	Not reported	Not reported
(1991) ⁷	Scale 1: Perceived Social Support for Caregiving (PSSC) Scale 2: Social Conflict (SC)	Mean: 62	Not reported	N=206 Female=69.2%		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
	Anticipatory Grief Scale (AGS)	Range: 59-76 Mean: 68.1	Not reported	N=27 Female=100%	Spouse=100%	Clinic at the Veterans Administration Medical Center	Diagnosed with ADRD using DSM-III-R criteria; all had progressive deterioration	Not reported	Range=1-6 years beyond high school Mean=2.48 years beyond high school
(1991) ⁹	The Screen for Caregiver Burden (SCB)	Mean: 67.4 (SD=7.4)	Not reported	N=79 Female=68.4%	Spouse=100%	Spouse caregivers and care recipients were recruited in western Washington State. No further details are provided.	Diagnosis of possible/probable Primary Degenerative Dementia	Not reported	Mean: 13.4 years (SD=2.8)
	Caregiver Reaction Assessment (CRA)		Not reported	N=377 Female=81.4%	,	health agencies (physically impaired, N=267) and eight chapters of the Alzheimer's Association (N=110)	ADRD=29.2% Physically impaired=70.8%	Mean=5.0 years of caring (SD=5.7)	At least some college=59.2%
•	Family Conflicts Scales (FCS)	Mean: 62.2	Unknown=64% White=30% Black=4% Asian=1% Hispanic=1%	N=555 Female=26%	Spouse=58.7% Adult child=39.8% Child-in-Law=%1.4	Recruited from local Alzheimer's Association contact records of self-described primary caregivers of a noninstitutionalized spouse or parent (including parent-in-law) with AD or similar dementia.	AD or similar dementia from caregiver reports	Unknown=64% 0-1 year=9% 1-2 years=13% 3-5 years=11% 6+ years= 3%	Unknown=64% <high college="" graduate="6%" high="" school="10%" some="">College=6%</high>
(1992) ¹²	The Revised Memory and Behavior Problem Checklist (RMPBC)	Mean: 54 (SD=13.4)	Not reported	N=201 Female=61%	Spouse=46% Adult child=41% Other relative=10% Friend=3%	The sample recruitment pool consisted of all new patients participating in a comprehensive assessment for cognitive impairment at a geriatric clinic. Most patients were referred by family member or primary care physician because of concern about cognitive changes or mood disturbances.	Dementia=85% Depression=10% Other=5% Note: Because the sample represented a consecutive series of patients in a hospital clinic, the study included carers of patients with and without dementia.	Not reported	< Grade school=1% Grade school=3% High School=47% College=27% Graduate Degree=15% Unknown=7%
	Caregiver Burden Scale (CBS)	Mean: 61	Black=24% Non-Black=76%	N=82 Female=84%	Spouse=54% Other relative=46%	Potential participants were contacted through support groups and the Statewide AD Registry.	Moderate to severe AD	Mean: 63 months of caregiving	Not reported
Gerritsen <i>et al.</i> (1994) ¹⁴	Care-Giving Burden Scale (C-GBS)	Mean: 60.1	Not reported	N=89 Female=75%	Spouse=49% Adult child=27% Other=24%	Eligible caregivers were referred by general practitioners to geriatric outpatient clinic of a psycho-geriatric nursing home.	AD=37% Amnestic disorder=15% Organic psycho- syndrome=20% Multi-infarct dementia=7% Unknown=21%	Not reported	Not reported
		Mean=61.7 (SD=14.19)	Not reported	N=298 Female=Not reported	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=87.6% Non-dementia=12.4%	Not reported	Not reported

						dementia were also given the quiz.			
Niederehe (1994) ¹⁶	Management	Range: 25-93 Mean: 59.6 (SD=14)	Not reported	N=152 Female=70.4%	Spouse=36.1% Adult child=58.6% Other=5.3%	Participants were recruited from medical, psychiatric, neurologic, and specialized dementia evaluation clinics, and a social service program.	Dementia Note: The MMSE mean for the patient sample was 9.2 (SD=7.5), indicating significant cognitive impairment.	Not reported	Not reported
(1996) ¹⁸	Caregiver Reciprocity Scale (CRS)	Range: 51-60	Black=7.6% Hispanic=1.0% White=91.1%	N=303 Female=83.8%	Adult child=100%	A convenience sample was recruited through letters sent to retired teachers, employees of a state university, and employees of a regional hospital. Caregivers also asked others to participate.	Dementia=36.3% Arthritis=58.7% Hypertension=46.2% Heart Disease=42.9%	Not reported	Not reported
(1996) ¹⁹	Behavioral and instrumental stressors in Dementia (BISID)	Not reported	Not reported	<u>Sample 1:</u> N=205 Female=Not reported <u>Sample 2</u> : N=264 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
Dassen <i>et al.</i> (1996) ²⁰	Sense of Competence Questionnaire (SCQ)	Mean: 63	Not reported		or in-law)=28% Sons (natural or in- law)=8% 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% Moderate Dementia=58% Severe Dementia=29%	Not reported	Not reported
		Range: 34-83 Mean: 66.5 (SD=13.1),	Not reported	Female=67%		Recruited from the patients (and their caregivers; at two Alzheimer's Disease Research Centers: the University of Washington and the Mount Sinai School of Medicine in New York		Not reported	Not reported
(1997) ²³	Rewards Scale	Range: 28-82 Mean: 58.9 (SD=12.1)	Black=100%	N=83 Female=100%	Adult child=60.2% Child-in-Law=3.6% Spouse=13.3% Sibling=6.0% Other=16.9%	Recruited from a variety of community agencies that served an aging population and from written media.	Medical diagnosis of ADRD or identified by agency as probably demented or a history of confusion in the past 6 months.	·	Some High school=35% High school graduate=49% College graduate=16%
al. (1997) ²⁴	instrument to assess the experience of	Range: 15-80 <35 =12% 35-49 =39% 50-64 =31% >64 =18%	Not reported	N=976 Female=78%	Parent=20.4% Adult child=39.3% Spouse=23.0% 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.	and disabilities=80% (Other long-term illnesses and disabilities included: physical impairments, cancer, stroke, diabetes,	care=15%	<10 years=32% 10-11 years=35% >11 years=33%
Kaufer <i>et al.</i> (1998) ²⁵	The Neuropsychiatric	Range: 40-89 Mean: 64.2 (SD=13.0)	Not reported		Spouse=63.5% Adult child=32.9% Child-in-Law=3.5%	Recruitment targeted caregivers of patients enrolled in the memory disorder clinics at the University of California at Los Angeles and the	Possible AD=30.6% Probable AD=69.4% <u>Note</u> : Measured by	Not reported	Not reported

	Caregiver Distress (NPI-D) Scale						National Institute of Neurological and Communicative Disorders and Stroke -Alzheimer's Disease and Related Disorders Association Work Group criteria.		
(1999) ²⁶	Caregiver Self-	Range: 30-85 , Mean: 59.5 (SD= 11.3)	Not reported	Female=83%	Spouse=53% Adult child=45% Other=2%	two psycho-educational classes designed to	Cognitive deficits, in particular, AD=53% No cognitive impairment=47%	Not reported	Not reported
(1999) ²⁷	Through Caregiving Scale (FMTCS)	(SD=8.54)	Black=35.8% White=64.2%	Female=63.7%	Spouse=100%	Alzheimer's clinics, Veterans Administration hospital programs, community home-care programs, and adult day care centers in a large metropolitan area which provided services to persons with presumed medical diagnoses of possible dementia. Five participants were recruited from African American churches who were caring for a spouse who had trouble remembering the time, things that were told them, and recognizing people they knew, or were confused about everyday life.			Mean=13.1 years of education
	Subjective Burden Scale (SBS)	Mean: 55.0 (SD=9.9)	Japanese	Female=Not reported		patient registry at a private geriatric hospital. The		Not reported	Not reported
					Other=3.1%	remaining 42 participants were recruited from psychiatric outpatient clinics.			

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.