				С	haracteristics of the	Caregiver Sample Used in Tool Validation Process	s		
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
Greene <i>et al.</i> (1982) ¹ Scotland	Scale 1: Behavioral and Mood Disturbance Scale (BMDS) Scale 2: Relatives' Stress Scale (RSS)	Not reported	Not reported	N=38 Female=Not reported	Daughters=42.1% Spouses=39.5% 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. 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
Novak & Guest (1989) ⁴ Canada	Caregiver Burden Inventory (CBI)	Range: 25-87 Mean: 60.13 (SD=13.06)	Not reported	N=171 Female=73.8%	and in-law)=48.8%	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
Gerritsen <i>et al.</i> (1994) ¹⁴ The Netherlands	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
Gilleard <i>et al.</i> (1994) ¹⁵ United Kingdom	Dementia Quiz (DQ)	Mean=61.7 (SD=14.19)	Not reported	N=298 Female=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.		Not reported	Not reported
(1996) ¹⁹	Behavioral and instrumental stressors in Dementia (BISID)	Not reported	Not reported	Sample 1: N=205 Female=Not reported Sample 2: 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
Vernooij-Dassen et al. (1996) ²⁰ The Netherlands	Sense of Competence Questionnaire (SCQ)	Mean: 63	Not reported	N=141 Female=67%	or in-law)=28% Sons (natural or in- law)=8%	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
Schoefield <i>et al.</i> (1997) ²⁴ Australia	Comprehensive instrument to assess the experience of caregiving: A battery of scales Scale 1:	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 computerassisted 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,	1-2 years of care=15%	<10 years=32% 10-11 years=35% >11 years=33%

	T	1	1	1	1		T	ı	
	Scale 2:						cardiovascular disease,	>=10 years of	
	Family						cerebral palsy, Down	care=26%	
	environment						syndrome, etc.)		
	Scale 3:						-, -, -,		
	Caring role								
	Scale 4:								
	Help Needed by								
	Recipient								
	Scale 5:								
	<u>Scale 5:</u> Behavior Problem								
		14000 FE O	1	N=255	Spouse=12.2%	Destining anto (NI=212) ware recruited from a	Dantia	Mint reported	Matronortod
	Subjective Burden Scale (SBS)		Japanese			Participants (N=213) were recruited from a	Dementia	Not reported	Not reported
(1999) ²⁸	Scale (SRS)	(SD=9.9)		Female=Not reported		patient registry at a private geriatric hospital. The remaining 42 participants were recruited from			
Japan						psychiatric outpatient clinics.			
	Zarit Burden	Mean: 61.7	Not reported	N=312		Participants were recruited as part of the	Dementia	Not reported	Not reported
(2000) ³⁰	Interview (ZBI)	(SD=13.4)				Canadian Study of Health and Aging (CSHA). The			
						CSHA sampled 9,008 community dwelling elderly			
Canada						people across Canada. Researchers screened this	•		
						sample and identified individuals with mild,	severe according to the		
					Friend=8.9%	moderate or severe dementia using DSM-III	DSM-III R.		
						criteria and a modified MMSE score < 78.			
						Informal caregivers of these individuals were			
						invited to participate in the validation study.			
Guberman <i>et al.</i>	The Caregiver Risk	Range: 24-89	Not Reported	N=76	Spouse=27.6%	Researchers chose a purposive sample from	Cognitive	Range: 2 months	Not reported
(2001) ³¹	Screen (CRS)	Mean: 60		Female=82%	Mother=36.8%	seven home care agency sites in Quebec (N=4)	impairment=57%	to 32 years	
					Other (fathers,	and Nova Scotia (N=3). Assessors within each	Other health	-	
Canada					mothers/fathers in	research site selected known family caregivers	conditions=43%		
					law, sisters in law,	and invited them to participate in the study. Over			
						half of the respondents were giving care to			
					neighbors)=35.6%	cognitively-impaired family members (57%) and			
						the rest were not (43%).			
Suwa (2003) ³⁶	Assessment Scale	Mean: 51.4	Japanese=100%	N=90	Spouse=23.3%	The study recruited a convenience sample of	AD=71.1%	Not reported	Mean: 11.6 years of
, ,	for Caregiver's	(SD=11.3)		Female=72.2%	•	caregivers to outpatients of a Senile Dementia	Vascular dementia=18.9%		education (SD=2.8)
	Experience with	(-			Child-in-Law=36.7%		Mixed type of		,
	Dementia (ASCED)				Other=1.1%	Server magain	dementia=8.9%		
	,						Other dementia=1.1%		
Goolieb &	RIS Eldercare Self-	Range: 31-88	Not reported	N=146	Spouse=37%	Caregivers were recruited into the study with the		Mean: 5.4 years	< High
Rooney (2003) ³⁸		Mean: 61	Trot reported	Female=73%	Adult child=60.3%	help of two urban geriatric agencies that		of care (SD= 16.1)	
Rooney (2003)	cificacy scale	(SD=13.4)		i cinalc=7570		provided community services to the caregivers or	aisoraei	or care (3D= 10.1)	High school=32.4%
Canada		(30-13.4)				registered the patient for possible future			College=26.9%
Callaua						placement in long-term care.			> College=26.9%
Gräßel et el	Durdon Coole fo:	Moan: EQ	Not reported	N=1 1/2 (Domontic		placement in long-term care. BSFC questionnaires were distributed by the staff	Domontia=1000/		
		Mean: 58	Not reported	N=1,143 (Dementia					Not reported
, ,	Family Caregivers	(2D=11.9)		sample)		of three cooperating support services from the	(Dementia caregivers	of caregiving	
	(BSFC)			Female=84.5%		city of Erlangen, Germany or via the regional	sample)	(SD=1.4)	
C In				(N. 540		branch of the Society for Alzheimer's sufferers	NI-1- 450/ -5:1 "		
Canada				(N=548-		and their caregivers.	Note: 45% of the "non-		
				Independent/cross-			dementia caregivers		
				validation "non-			sample" were caring for		
				dementia" sample)			elderly people with		
							relatively unimpaired		
							cognitive performance		
							and the remaining 55%		
							were carers of individuals		
							with neurological		
							disorders.		
Andrén &	Carers'	Range: 27–90	Not reported			Subjects 70 or older and receiving any form of	Dementia per DSM-IV	Not reported	Not reported
	Assessment of	Mean: 62	,				diagnostic criteria and		'
	Satisfactions Index						MMSE < 24.		
	(CASI)					replying to the letter were telephoned, screened			
Sweden	<u> </u>					for cognitive decline, and diagnosed for dementia			
L		1				, , , , , , , , , , , , , , , , , , , ,	i		

						·			
	1					by a physician. The person with dementia was			
		1				asked to <u>nominate</u> the relative who had the main			
						responsibility for their care (i.e., the relative who looked after the person the most).			
al. (2007) ⁵³		Mean: 68	Not reported	N=232 Female=65.1%	Adult child=24.6%	and Costs of Caring (BECCA) trial. Recruitment	Primary progressive dementia	Not reported	Not reported
	Index (CADI)	(SD=11.5)				took place through primary, secondary, and			
United Kingdom		1				voluntary sector care with some self-referrals			
		1				following media publicity and word of mouth.			
		1				Inclusion criteria for the trial limited participation			
		1				to those carers providing 20 or more hours of assistance per week to a community-dwelling			
						relative with primary progressive dementia.			
Losada <i>et al.</i>	Revised Familism	Mean: 59.97	Basque, Spanish	N=135			Dementia	Mean: > 3 hours	Mean=10.1
		(SD=13.25)			·	services centers.		per week of	(SD=4.49) years of
Spain		<u> </u>			Other relative=8.9%				formal education
			Not reported	N=125			DSM-IV diagnoses of	0 0	Not reported
` '		Mean: 63.8		Female=64.8%			dementia and	4 hours a week	
		(SD=13.3)			Other relative=9.6%	Purposefully chosen to be representative in	standardized diagnoses of		
United Kingdom	Experienced (Brief-COPE)	1				terms of dementia severity as part of the London and South-East Region Alzheimer's Disease	AD		
	(Brief-COFL)					(LASER-AD) Study.			
Montorio <i>et al.</i>	Dysfunctional	Mean: 58 years	Not reported	N=227			Dementia	<1 year=28.4%	
(2009)68	•	(SD=14.1)		Female=75.3%		were contacted by the researchers to obtain		1-4 years=39.6%	Mean: 8.7 years
	Caregiving	ĺ			Child-in-Law=4.8%	their support and to ask caregivers to participate			(SD=5.1)
Spain	Questionnaire				Other relative=5.3%	in the study.			ĺ
	(DTCQ)	<u> </u>			<u> </u>				
	_		Spaniards=100%		·	Participants were recruited from social and	AD=58.4%	•	Not reported
		Mean: 59.63		Female=79.2%		health care centers in Madrid, Spain.	Other dementias=41.6%	months	
	(CGQ)	(SD=12.60)			Other relative=5.2%			Mean: 53.15 months	
Spain					'			(SD=46.10)	
Wimo et al.	Resource	Not reported	Not reported	N=14	Spouse=100%	Participants were recruited from a health center.	AD=35.7%	'	Not reported
(2010) ⁷⁵	Utilization in	100.000.	1001000000	Female=85.7%	· ·	Eligibility for recruitment required the caregiver	Vascular dementia=35.7%	·	1101.350.132
	Dementia (RUD)	1					Mixed dementia=7.1%		
Sweden					'	day with the dementia patient.	Other cognitive		
		<u> </u>	<u> </u>	<u> </u>	<u> </u> '		problems=21.4%	<u> </u>	
1 '		Mean: 50.1	Chinese=95.4%	N=238		Participants were recruited from two sources:	Early-Stage	<1 year of	
, ,		(SD=10.1)	Indian=2.9%	Female=68.1%		,	Dementia=24.4%	caregiving=12.6%	
	(GAIN)		Eurasian=1.3% Other=0.4%			, ,	Moderate Stage=47.9% Severe Stage=27.7%	1-3 years of caregiving=33.8%	High school=39.5%
Singapore		1	Other=0.4%		Other=5.0%	local Alzheimer's association.		>3 years of	Tertial y=50.0%
					'			caregiving=53.6%	
Werner <i>et al.</i>	Family Stigma in	Mean: 52.7	Place of Birth:	N=185	Adult child=100%	Participants were a convenience sample of 185	AD	Mean: 5.4 years	
(2011)80		(SD=8.8)	Israel=75.7%	Female=74.6%		children of persons with AD recruited from		(SD=4.1)	Mean years of
	Disease Scale (FS-		Europe/America=17.3%			support groups organized by the Israeli			education: 15 years
	ADS):		Asia/Africa=5.9%			Alzheimer's Association (N=41), from			(SD=2.6)
	Scale 1: Family	1	Other=1.1%			psychogeriatric clinics (central and northern parts	3		
	Stigma	1				of Israel, N=91), and by snowball sampling			
	Scale 2: Lay persons' stigma	1				(N=53). Interviews with participants were conducted face to face.			
	Scale 3: Structural	1				conducted race to race.			
	stigma				'				
		Range: 26-102	White=92.8%	N=361	Adult child=30.1%	Recruited from local health services	Care receivers were	Not reported	Not reported
	being and Support		Black=2%				diagnosed with dementia		
			Asian=1.7%		-	associations, and training courses run by these	or a mental health		
United Kingdom	questionnaire		Mixed=0.9%		Parent=14.3%	associations.	problem.		
					Friends=1.6%				
		56.00	1		Other=2.1%				
Riley <i>et al.</i>	Birmingham	Range: 56-88	White=92%	N=84	Spouse=100%	Recruited through various agencies providing	Dementia, AD, and	Not reported	Not reported

(2013)83	Relationship	Mean: 71.6	Other=8%	Female=69%		support for poople with domentia and their	Vascular Dementia.		
United Kingdom	Continuity Measure (BRCM)	(SD=7.8)				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.			
(2013) ⁸⁵ Canada	The Caregiver Well-Being Scale: Short Form Rapid Assessment: Scale 1: Basic Needs Scale Scale 2: Activities of Daily Living Scale			Female=96.1%	Adult child=69.2% Child-in-Law=8.3% Other relative=2.0% Other=7.0%	previously-conducted studies with caregivers. Participants in the original studies were recruited	cognitive	Range: 4 months- 30 years Mean: 5 years of caregiving	Not reported
(2013) ⁸⁸ United Kingdom	Edinburgh Mental Well-Being Scale (WEMWBS)	(SD=11.22)	Other=7.5%	Female=81.2%	Other=18.1%	contacted by voluntary sector organizations offering support services to carers of people with dementia.		2-4 years of caregiving=22.6% 4-6 years of caregiving=23.3% >=6 years of caregiving=38.3%	years old=48.4% Left school at 18 years old=49.2%
		(SD=13.06)	White (British/Irish/other)=92.6% Black (African/Caribbean/ other)=2.9 Asian/Indian/other=4.5% Other=0.8%	Female=70.6%		healthcare, health professionals, voluntary organizations, and social services.	Dementia severity: Mild=62.6% Moderate=27.5% Severe=9.9%		School leaver (14– 18 yrs.)=72.2% Higher education=27.8%
(2014) ⁹³	Questionnaire (CFQ)	Range: 31 to 95 Mean: 68.6 (SD=11.5)			Spouse=87% Adult child=13%	The Caregiver sample was recruited as part of a larger study on caregiver distress. Recruitment occurred through a postal survey sent to caregivers enrolled on the Scottish Dementia Clinical Research Network research register, advertisements placed in a local Carers' Centre newsletter and presentations given at local Alzheimer Scotland caregiver meetings.	ADRD	Not reported	Not reported
		Range: 28–85 Mean: 52 (SD = 10.29)	Not reported	Female=57.4%	Daughter-in-	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		≤ Primary school=10.9% Junior high school=14.8% High school=30.6% ≥ College=43.7%
(2014) ⁹⁵ Spain	•	Mean: 61.37 (SD=14.84)		Female=78.3%	5%	9	Other dementias=39.8%	Mean: 3.8 years (SD=3.05) Mean: 14.04 hours per day spent on caregiving duties	Not reported
(2014) ⁹⁷ Australia	Knowledge Assessment Tool (DKAT2)	Family Caregivers: Mean: 55 Care workers: Mean: 45		N=34 Female=Not reported Care workers: N=70 Female=Not reported	Adult child= 59% Other family=41%	members involved in the care or support of residents with dementia for at least three months. (The study also recruited all available workers providing care for residents with dementia.)	Meeting criteria for moderate to very severe cognitive decline	At least 3 months	Not reported
	The Perseverance Time (Pt)	Range: 29-93 Mean: 66.4				Informal carers participating in this study were recruited in cooperation with regional	Dementia	Range: 0.5–16 years	Low=12.6%

-		(CD 42.4)		ı	1-) 20 60/	L			MA: J. J
The Netherlands		(SD = 13.4)			law)=38.6% Other (family) relationship=7.2%	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			Middle=58.7% High =28.7%
_	Affiliate Stigma Scale	Mean: 52.8 (SD=12.18)	Chinese=100%	N=271 Female=53.1%	Adult child= 61.6% Other=38.4%	their registry diagnosed with dementia. Caregivers of outpatients at a local general hospital volunteered to take part in the study. Each participant had at least one family member	and vascular dementia)	Mean: 2.45 years (SD=2.43)	Junior high school or less=33.9%
Taiwan							criteria from the Diagnostic and Statistical Manual of Mental Disorders, 4th Ed.		High school=31.7% Some college=34.3%
	The Partnership Scale (PS)	Mean: 60.398 (SD=11.35)	Japanese=100%		Spouse=23.4% Adult child=46.7% Daughter/Son-in- law=25.3% Sibling=1.1% Other=3.4%			Less than 6 months=6.2% 6 months-1 year=8.2% 1-3 years=28.8% 3-5 years=23.0% 5-9 years=21.0% 9-12 years or more=5.8%	Not reported
Maneewat <i>et al.</i> (2016) ¹⁰⁸ Tailand	Caregiver resilience scale (CRS)	Range: 20 to 60	Thai=100%	Female=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
(2016) ¹⁰⁹	The Thoughts Questionnaire (TQ)	Range: 36–85 Mean: 64.30 (SD = 10.65)	Caucasian =94.3% non-Caucasian=5.7%	Female=86%	Spouses=68.6% Non-spousal family=31.4%	Participants recruited by snowball sampling beginning with flyers distributed to community-support agencies.		Mean: 4.45 years (SD = 4.12)	Not reported
Moreno <i>et al.</i> (2017) ¹¹³ Spain	Valued Living Questionnaire Adapted to Caregiving (VLQAC)	Range: 21–89 Mean: 60.97 (SD=14.34)	Not reported		Spouse=41.4% Son/daughter=50.2 % Other (e.g., mother- in-law)=8.4%		AD=70.4% Other dementia=29.6%	Range: 0.5–20 years Mean: 3.76 years (SD = 3.08)	Not reported
(2017)115	Hospital Anxiety and Depression Scale (HADS)	Mean: 68 (SD=19)	White=93% Black and minority ethnicity=7%		Spouse, sibling (same generation)=63.4% Adult child, niece, nephew (generation below)=35.6%	Participants were drawn from previous randomized trials of people with dementia and their CGs.	Other dementia=36.6%	(SD=7.37)	School dropout=69.7% Higher/further education=30.3%
(2017) ¹¹⁷	The Caregiving Ambivalence Scale (CAS)	Mean: 60.9 (SD=13.77)	Spanish	Female=77.1%	Adult child=51.4% Spouses=41.1% Other=7.5%	Recruited from social and health care centers in Madrid, Spain		Caregivers provided at least 1 hour of care daily, and at least 3 consecutive months of care.	Not reported
al. (2017) ¹¹⁹	Positive Aspects of Caregiving Questionnaire (PACQ)	Range: 19-81 Mean: 51.5 (SD=12.4)	Not reported	Female=84.7%	family CG to care	The study used the Iran Alzheimer Association and Roozbeh Memory Clinic of Tehran University of Medical Sciences as the sampling frame.		(Caregivers spent at least 6 hours per day for patient's care.)	Illiterate or primary school (age 7-11 years)= 16.67% Guidance school (age 12-14 years)=

		1	T	1	1			T	
								providing care was not	11.36% High school (age 15-
									18 years)= 36.36%
									Associate or
									bachelor's degree= 31.82%
									Master's degree
									and higher= 0.79%
	Gains Associated	Mean: 63.0	Not reported	N=260	Partner=48.8%	Participants were recruited from a list of	Dementia		No formal
'	with Caregiving	(SD=12.30)		,	Adult child=47.4%	caregivers provided by health professionals and		least 6 months.	schooling=7.7%
	(GAC) scale			field study)	Other=3.8%	over 20 organizations advocating for dementia			Primary
Spain				(An initial EFA study was conducted in an		patients and caregivers (e.g., Alzheimer's associations, adult day care centers).			education=37.3% Secondary
				independent sample		associations, addit day care certers,.			education=38.1%
				of N=152					Higher
				participants)					education=16.9%
		Range: 29–95	Sami=7%	N=430	Spouses=28.8%	Dementia caregivers in 32 community care	Dementia	Not reported	Not reported
'	•	Mean: 61.8 (SD = 11.7)	Other=93%	Female=68.9%	Adult child=60.7% Other=10.5%	agencies in Northern Norway were invited to participate in the study.			
	(Scale validation	(30 - 11.7)			Offici -10.570	participate in the study.			
,	with family carers								
	of people with								
	dementia-Norway)		144 : 00 404	1. 100	00.10/				
	Dementia Quality of Life Scale for	Mean: 72.15 (SD = 8.31)	White=96.1% Afro-Caribbean=1.1 %		Spouses=80.1% Son/daughter=16%	Participants were recruited from voluntary organizations (Alzheimer's Society, Carers Trust,	Dementia	Less than 1 year=2.2%	Not reported
	Older Family	(3D = 0.31)	Asian=1.1%		Other=0.6%	Carers Federation) and community-based carers'		year – 2.2% 1 to 3	
	Carers (DQoL-OC)		Other ethnic group=0.6%		Missing=3.3%	groups. Information about the study was also		years=44.2%	
United Kingdom					_	publicized in public areas and online		4 to 6	
						advertisements were placed on social media (e.g.		years=34.3%	
						Facebook, Twitter, and blogs from Alzheimer's		7 to 10	
						Society).		years=9.9% 10+ years=9.4%	
Stansfeld <i>et al.</i>	Sense of	Range: 18–89	White British or	N=583	Spouse/partner=	Recruitment into the study occurred through a)	AD=50.5%	Not reported	
(2019) ¹²⁷		Mean: 59.5	Irish=94.2%	Female=80.3%	30.1%	an online database of people with dementia and	Vascular dementia=18.9%	·	Primary education
	13 (SOC-13)	(SD=12.3)	Mixed British=0.7%		Son/daughter=	, ,	Lewy Bodies=7.2%		or less=0.5%
United Kinndon			Indian/British Indian=0.7%		58.9%	interest in taking part in research, b) from	FTD=23.3%		Secondary
United Kingdom			Black Caribbean/African=0.7%		Other= 11%	relevant charitable organizations for older people, c) people with dementia and their family			education=23.7% Further
			Other=3.7%			caregivers. Caregivers who expressed an interest			education=71.3%
			St.16. 51775			in the study were emailed or contacted by phone			Other general
						with a link to the online version of the survey and			education=3.5%
						offered a paper copy with a freepost envelope to			
Visa stat	C1	14 52.0	Chi 06 60/	N. 204	C	return the completed survey as an option.	D		
"		Mean: 53.0 (SD: 10.7)	Chinese=86.6% Malay=6.3%	N=394 Female=59.9%	Spouses= 13.7% Adult child=86.3%	Caregivers caring for community-dwelling people with dementia were recruited from the two	Dementia: Mild=15.7%	Mean= 6.8 years (SD=6.7)	Primary or no
, ,	Studies	(30. 10.7)	Indian=4.6%	emale=35.570	Addit cilid=80.570		Moderate=41.4%	(3D=0.7)	formal=10.4%
	Depression Scale		Other=2.5%			and also from the inpatient wards of the geriatric			Secondary=57.9%
	(CES-D)					psychiatry unit at the Institute of Mental Health.			Tertiary =31.7
						A consecutive sampling method was used to			
Danalla at al	Cii 1114h	Mann. 52.2	Italian=100%	N. 100	Parent=56.1%	achieve a desirable response rate. Convenience sample of family caregivers of	Pulmonary disease=8.4%	A+ I+ -:	Niet verenduted
	Caregiving Health Engagement Scale		italian=100%	N=198 Female=76.5%		convenience sample of family caregivers of patients with complex health care needs.	ADRD=12.6%	At least six months	Not reported
	(CHE-s)	(35-12.3)					Diabetes=7.1%	months	
Italy					7%	who met selection criteria provided to the	Cystic fibrosis=7.1%		
					Other=5.6%		Other (various)=34.8%		
						participants included caregivers with diverse			
						demographic backgrounds and with different experience of caregiving across different disease			
						conditions including Alzheimer's disease and			
						dementia.			

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(2019) ¹³² United Kingdom	Quality of Life (C- DEMQOL)		White British=84.9% White Other=8.7% Black/African/ Caribbean=3% Mixed Ethnic Background=1.7% Indian/Bangladeshi=0.7% Arab=0.3% Other=0.7%	N=300 Female=72.9%	partner=42.8% Family friend=1.3% Sibling=1.0% Other family member=0.7% Other=4.7%	Family carers of people with a clinical diagnosis of dementia were recruited from Sussex and North London. Carers were visited in their own homes, where researcher-administered interviews took place.	AD=58% Mixed=19% Vascular dementia=13.1% FTD=3.6% Lewy bodies=2.2% Other dementia=4.0%		Not reported
(2019) ¹³³ China	Questionnaire (CGQ)	Range: 36-84 Mean: 58.27 (SD=10.42)	Chinese=100%	N=173 Female=84%	Spouse= 32% Sibling= 1% Adult child= 59% Child-in-law= 7% Grandchild= 1%	Recruited from psychogeriatric clinics in China and a list of those agreeing to be contacted for research participation.	diagnosis of AD or meeting the NINCDS- ADRDA criteria for possible AD.		· · · · · · · · · · · · · · · · · · ·
		Mean: 52 (SD=14)	Not reported	N=500 Female=79.1%	Adult child=32% Partner=25% Parent=31% Other (friend, family, or neighbor)=12%	The study recruited a mixed sample of informal/family caregivers of persons with different disease conditions including carers of dementia, aging-related or neurological problems. The participants were recruited through a statewide non-profit organization representing and providing support to carers to improve their health and wellbeing. Persons age 18 and over who self-identified as primary, informal carer were invited to participate in an online survey.	Dementia, memory, aging, or neurological problems=43% Mental health problems=34% Other=23%	> 24	≤ 11 years=17% 12 years=9% Diploma=27% Undergraduate=26 % Postgraduate=18% Other=1%
(2020) ¹³⁹ Australia	Consumer Access, Appraisal and Application of Services and Information for Dementia (CAAASI-Dem)	Mean: 46.1 (SD=14.2)	Not reported	N=3,146 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		Primary school=0.2% Secondary school (years 11–12)=7.9% Secondary school (years 7–10)=4.7% Certificate or apprenticeship=18. 6% Associate degree=20.6% Bachelor's=26.9% Higher University degree(Grad, Masters, PhD)=17% Not indicated=4.0%
Greiner (2020) ¹⁴⁰	Social Capital Scale for Caregivers of People with Dementia	Mean: 63.7 (SD=12.1)	Japanese	N=178 Female=75.8%	Spouse= 29.8% Sibling= 1.7% Adult child/child-in- law= 60.1% Grandchild= 2.8% Other= 5.6%	Randomly selected 1,373 facilities (community general support centers, daycare centers, Alzheimer's cafes, home-visit nursing stations, and federations for families with dementia) to distribute questionnaires to 2,825 primary caregivers.	Dementia	Mean=5.5 years (SD=4.2)	Junior high school=8.4% High school=39.9% Junior college/technical school=28.7% College=21.9% Graduate school=1.1%
Fujita (2020) ¹⁴¹ Japan	The Empowerment Scale for Family Caregivers of Community- dwelling People with Dementia (EFCD)	Mean: 65.27 (SD=12.06)	Japanese	N=304 Female=68.4%	Spouse=45.1% Daughter-/son-in- law=48.7% Other=4.3% Missing=2%	A convenience sample was recruited from users of the outpatient unit of a university hospital, five homecare support clinics, and 13 homecare facilities in 17 prefectures in Japan. Participants from 22 self-help groups in 17 prefectures were also approached for recruitment. Questionnaires were mailed to participants.	Lewy bodies=11.8% Vascular dementia=4.6% FTD=3.6% Unknown=15.1% Missing=5.3%		Not reported

(2020) ¹⁴³ Spain	` ,	Mean: 59.6 (SD=13.10)	·	Female=77.9%	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.	Other dementia=42.9%	months Mean: 54.44 months (SD=46.50)	Not reported
(2020) ¹⁴⁶ United Kingdom	Older Adults Quality of Life Questionnaire	China: Mean: 32.71 (SD=7.57)	White=75.6% Black=10.4% Asian=6.7% Hispanic=6.1%	N=164 Female=58.5% China: N=131 Female=54.9%	Relationship of the family CG to care recipient is not reported.	(USA) and Wenjuanxing (China).	United States: Dementia (including AD)=30.5% Diabetes=23.2% Heart disease=21.3% Stroke=5.5% China: Dementia (including AD)=14.5% Diabetes=40.5% Heart disease=45.8% Stroke=6.9%	0 to 40 hours per week= 82.3% China: 0 to 40 hours per week= 95.6%%	Not reported
(2020) ¹⁴⁹ United Kingdom	Patient Partners Life Impact Questionnaire (APPLIQue) (Questionnaire specific to spousal caregivers of people with AD)		Not reported	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	(SD=9)	Not reported
et al. (2020) ¹⁵⁰ Germany; Ireland; Italy; The Netherlands; Norway; Portugal; Sweden; United Kingdom	Choice Experiments for the Preferences of Older People Capability-based measure of general quality of life: the ICEPOP Capability (ICECAP-O) instrument.		Not reported	Female=66.4%	Spouse/partner=63. 9% Son/daughter-in- law=31.9% Other=4.2%	Data were collected in eight European countries in the context of the Actifcare project: Germany, Ireland, Italy, the Netherlands, Norway, Portugal, Sweden and the UK. Care receivers meeting eligibility criteria and their informal carers were invited to complete the questionnaires, available in seven different languages.	of dementia (i.e., CDR scores 1 or 2) or scores on the MMSE ≤ 24.	day: Less than 4	Education Range: 0-24 years Mean: 11.91 years (SD: 4.42)
al. (2021) ¹⁵⁵ The Netherlands; Germany; Ireland; United Kingdom; Sweden; Norway; Italy;Portugal	Quality of Life (CarerQol) questionnaire	Mean: 66.2 (SD=13.4)	·	Female=66.0%	Spouse or partner=63% Other=37%	Caregivers of individuals with dementia were recruited from the Access to Timely Formal Care (Actifcare) project.	Dementia		<13 years=56.3% 13 years=43.7%
		Mean: 61.7 (SD=13.68)		Female=78.4%	7% Adult child=41%	were recruited from (1) nine municipalities in	AD=67.35% FTD=5.78% Lewy bodies=4.76% Vascular dementia=4.42% Mixed dementia diagnosis=4.76% Other=7.82%	·	Elementary education=7.22% Secondary education=38.49% Higher education=47.77% Other=6.53%

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(2021) ¹⁵⁹ Canada Wuttke- Linnemann <i>et</i>	Preparing for End- of-Life with Dementia Questionnaire Resilience and	Mean: 61.7 (SD=11.43) Mean: 56.60 (SD=10.63)	White=93.2% Black=0.8% Southeast Asian=1.5% East Asian=1.5% Latin American=0.8% Indigenous=2.3%	N=291 Female=84.5%	in-law=69.4% Other=6.7% Adult child=51.4% Spouse=33.8%	and (3) social media. 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. Recruitment for the online survey was performed by distributing the link on various websites. The printed version of the survey, along with the	Vascular dementia=13.5% Mixed =9.8% Lewy bodies =6.8% FTD=3.0v Korsakoff's =1.5v Unknown =19.5% Other =5.3%	Hours (h) spent caregiving:	Less than high school=2.3% High school=13.5% College or university=64.7% Graduate school=19.5% Medium-track secondary school
Germany	(ResQ-Care)	Mann (2.7	Not and ordered		of child=9.7% Other=5.1%	prepaid envelopes, was sent to registered physicians, outpatient clinics, care support offices, and welfare organizations, among others.	diagnosis=47.6% Note: Mixed sample of carers; patients had AD or other physical disabilities.	h/week=33.0% 20–40 h/week=33.0% >40 h/week=34.0%	diploma or lower (46.4%)
et al. (2021) ¹⁶¹ Spain	The Interpersonal Triggers of Guilt in Dementia Caregiving Questionnaire (ITGDCQ) Scale 1: Care Receiver (ITGDCQ-CR) Scale 2: Other Relatives (ITGDCQ-OR)	(SD=12.9)	Not reported		Spouse=46.3% Adult child=50.1% Other=3.6%	centers in Madrid.	AD=61.2% Mild cognitively impaired=26.4% Other dementia=1.5%	(Daily hours of care, Mean=14.5 hours (SD=8.9)	Low= 15.4% Medium= 58.2% High=26.4%
United Kingdom	DEmentia on CARers (SIDECAR) Battery: SIDECAR-D: Direct Impact on Carers SIDECAR-I: Indirect Impact on Carers SIDECAR-S: SIDECAR-S: Support and Information	Median age: 70	White=97% Other=3%		Spouse or partner=74.4% Son or daughter=18.9% Son-in-law or daughter-in-law=1.9% Other (relative/friend)=3.4% Missing=1.4%	health and social care services.	Dementia severity: Mild=36.7% Moderate=47.5% Severe=13.0% Missing=2.8%	Not reported	Not reported
(2021) ¹⁶³ Germany	Berlin Inventory of Caregiver Stress- Dementia (BICS-D) (Inventory comprising 25 subscales)	SD=11.4	Not reported	N=594 Female=79%	Daughter-in-law=9% Female partner=28%	Caregiving relatives from across Germany were recruited through newspaper announcements and articles in pharmacy magazines. Following a telephone screening interview, respondents were sent a refined version of the inventory and other outcome measures by postal mail including a return envelope with paid postal fees.	Dementia severity: Mild=4% Moderate=42% Severe=54%	Mean=41.1 months (SD=32.4)	Not reported
(2022) ¹⁶⁴ Korea	The Competence Scale in Managing Behavioral and Psychological Symptoms of Dementia (CS- MBPSD)		Not reported		Spouse=65.7% Son=6.1% Daughter=19.8% Daughter-in- law=5.2% Sibling=1.7 Other=1.5	Participants were recruited from local dementia centers in 21 out of the 25 districts in the city of Seoul after gaining permission to collect data from the heads of the centers. Participants were recruited through posted announcements or notification about the study from center staff. Researchers went to the local dementia centers and directly explained to the recruited participants the purpose and contents of the study, how to participate in the study, and how to withdraw consent from the study.		time per day was 11.30 hours (SD=5.47)	Less than elementary=2.0% Elementary=19.6% Junior high=17.6% Senior High=37.6% College and above=23.3%

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<i>al.</i> (2022) ¹⁶⁵ France		Mean: 59.43 (SD=12.54)		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
, ,	Caregiving Compassion Scale (CCS)		Not reported	Female=68.6%	Spouse=41.9% Other relatives=3.8%	Recruitment was conducted through different health and adult day care centers in Madrid, Spain. Nursing homes were excluded. Study inclusion criteria included: older than 18 years old; primary caregiver of the relative with dementia; performing caregiving tasks at least one hour per day during the last three months, and not being under psychiatric and/or psychological treatment.	Dementia	A criterion for participation was performing caregiving tasks during at least one hour per day during the last three months.	Not reported
United States United Kingdom Australia	Caregiver Interview for	Not reported.	Not reported.	Female=43.9%	8% Son/daughter=30.6 %	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
(2022)171	Instrument (FAMSI)	Mean: 60 (SD=13.19)	White=93% (n=65) Black/African/Caribbean=1 % (n=1) Mixed multiple=1% (n=1) Other ethnic group=3% (n=2) Not disclosed=1% (n=1)	Female=76%	34% Adult child/child-in- law= 54% Other=10% Not disclosed=1%	Participants were a convenience sample in South-East England, UK. They were recruited via the Join Dementia Research database and through social media, community advertising or researcher outreach activities where the study was presented to carers' groups (e.g. Alzheimer's Society groups).	18.6% FTD= 11.4% Lewy bodies= 2.9%	Not reported	Not reported
(2022) ¹⁷³		Mean: 60.5 (SD=14.40)	, ,	Female=65.6%	Wife=15.9% Son=9.6% Daughter=40.7% Son-in-law=1.9% Daughter-in- law=1.9%	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.	Vascular dementia=12.2% Dementia with Lewy bodies=2.2% Parkinson's	1–2 years=14.8% 3–4 years=31.9% 5–8 years=28.1% 9 years or more=9.3%	University degree
(2022) ¹⁷⁵		Mean: 46.2 (SD=15.4)		Female=87.5%	recipient is not	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	Dementia (73.4% of the sample reported knowing someone living with dementia and almost half		Primary school=0.2% Secondary school=5.5% Certificate/apprenti

						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.	(49%) indicated they provided care for a person living with dementia.)		ceship=17.8% Associate degree=16.5% Bachelor's=28.6% Higher university degree=20.4%
(2022)176	(FCHS)	Mean: 50.26 (SD=13.24)	Not reported	Female=50.6%	Daughter=52.9% Son=13.1% Wife=8.5% Husband=4.6% Friend=7.8% 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		Illiterate=2.5% Less than diploma=6.9% Diploma=46% Academic=44.6%
(2022) ¹⁷⁸ Sharif-Nia <i>et al.</i> (2023) ¹⁷⁹	The Care Challenge Scale (CCS) Care Stress Management Scale (CSMS)								
Olthof-Nefkens et al. (2023) ¹⁸³ The	Experienced Communication in	Range: 41-86 Mean=65 (SD=11.4)		Female=68%	All CGs were either partners, relatives, or close friends (no percentages are reported).	Participants were recruited from the Geriatrics Department of the Radboud University in The Netherlands, visiting between September 2015 and January 2016.	Diagnosed by a geriatrician as having mild to moderate dementia (Clinical Dementia Rating score between 0.5 and 2). AD=87.7% FTD=1.8% Lewy bodies=1.8% Progressive aphasia=1.8% Mixed=7%	Not reported	Not reported
(2023) ¹⁸⁴ United Kingdom	Conditions Questionnaire for	Range: 41-90 Mean:67	Quantitative (Phase 2): White British (94%) Non-white (3%)	N=107 Female=63% (plus 10 cognitive "think aloud" interviews with carers -completed in <u>Phase</u>	(think aloud): Spouse (70%) Adult child (30%) Quantitative (Phase	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
(2023) ¹⁸⁵ Germany	Thoughts Scale (CTS)	Mean: 63 (SD=11.1)	Not reported	Female=80%	Spouse= 59% Adult child= 39.8% Other= 1.2%	Caregivers were recruited by numerous public relation methods (regional and national newspapers, television and radio interviews, project homepage) and cooperation partners (clinics, practices, home support services).	Care recipients were diagnosed as having dementia, or at least fit criteria for MCI. AD=44.1% Vascular dementia=10.2% FTD=5.3% Other/unknown=40.3%	(SD= 3.7)	Primary or other =3.1% Secondary: Level 2 =50.9% Secondary: Levels 3 & 4 =12.4% Tertiary: Levels 5 & 6 =33.2%
al. (2023) ¹⁸⁷	(BBCS)	(SD=12.6)	Not reported	Female=75.7%	Spouses=30.5% Adult child/in- law=59.5% Other carers (e.g., aunts, uncles, nieces, nephews) =10%	Care assessors from the Medical Service of the Bavarian Health Insurance distributed self-report questionnaires to statutorily insured informal caregivers.	to ADL and IADL needs requiring family caregiving= 62.1%	Mean: 48.45 months (SD=78.72)	Not reported
(2023) ¹⁸⁸ United Kingdom	Psychology Outcome	Range: 20-92 Mean: 60.51 (SD=14.37)	White British (96.6%)		Daughter=40.4% Husband=21.7% Wife=16.1% Son=9.7% Granddaughter=3.7 %	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		3–4 years=31.5% 5–6 years=19.9%	

					Alzheimer's Society.	9–10 years=7.1% 10 years+ =12.4%	
) í	Caregiving Competence Scale for Dementia (CCSD)	Japanese	Female=63.3%	Son or daughter =28.7% Son or daughter in- law=6.0% Sibling=2.7% Others=1.3%	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.	(SD=51.3)	≤ Ninth grade=4% 10–12=36% ≥13 years of schooling=60%

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