

Study	Population (as described by author)*	Description of severity or recruitment criteria	Proxy type	N dyads	QOL instrument	Proxy Effect examined using**	Rater agreement
Arlt et al. (2008)	Dementia	"Mild to Moderate" MMSE ≥ 11	Family caregivers	100	SF-12 HS, EUROHIS QOL	Group comparison	Weak Pearson's correlation
Arons et al. (2013)	Dementia	"Very mild to moderate"	Informal caregivers	175	EQ-5D, QOL-AD	Descriptive statistics	Poor-moderate ICC over multiple timepoints
Bruvik et al. (2012)	Dementia	MMSE ≥ 15	Family caregivers	230	QOL-AD	Group comparison ^a	NA
Huang et al. (2008)	Dementia		Family caregivers	120	QOL-AD	Group comparison	Low Cronbach's Alpha for whole group and across severity subgroups
Jacob et al. (2017)	Dementia		Family caregivers	718	QOL-AD	Group comparison	NA
Römhild et al. (2018)	Dementia (64.2% community dwelling, ≥ 65 years)	MMSE ≤ 24	Family vs paid carers, dependent on setting. Of the family ones (adult children (45.1%))	1330	QOL-AD	T-test ^a	Poor agreement as per Bland-Altman plot Limits of Agreement.
Wu et al. (2020)	Dementia (including FTLD)	MMSE ≥ 15	Informal caregivers	1283	QOL-AD	Descriptive statistics & Bland Altman plot ^b	Poor agreement as per Bland-Altman Limits of Agreement ^c
Bosboom et al. (2012)	Alzheimer's Disease	"Mild to Moderate"	Family caregivers (rated twice)	80	QOL-AD	Group comparison	^d
Conde Sala et al. (2010)	Alzheimer's Disease	MMSE 10-28	Family caregivers (spouses vs children)	251	QOL-AD	Group comparison & effect size ^a	NA
Logsdon et al. (2002)	Alzheimer's Disease	"An actively involved caregiver" ^e		177	QOL-AD	NA	Poor ICC
Ready et al. (2004)	Alzheimer's Disease or MCI	"Very mild to mild" Alzheimer's	"Reliable informant"	79	DQol	NA	Moderate Pearson's correlation

Vogel et al. (2006)	Alzheimer's (age >60 years)	"Very early Alzheimer's" MMSE ≤ 20	Family caregivers	48	QOL-AD, EQ-5D	NA	NA
Bakker et al. (2014)	Young Onset Dementia (including FTLD)		Informal caregivers	152	QOL-AD	Group comparison	NA
Cruise et al. (2005)	Stroke Aphasia	Reliable Yes/No response; moderate comprehension ($\leq 5/10$ on WAB Comp)	Main regular contact	30	Four measures ^f	Global QOL rating on t-test and effect size	Moderate ICC agreement for QOL item of Dartmouth COOP and Overall score on Well-Being Scale
Hilari et al. (2007)	Stroke Aphasia	Score $>7/15$ on the receptive subtest of Frenchay Aphasia Screening Test (FAST) which is the cut-off score for self-completion of SAQOL-39	Significant other who saw them ≤ 2 /week	50	SAQOL-39	T-test (small effect size & large SD)	Excellent ICC for overall QOL
Ignatiou et al. (2012)	Stroke Aphasia			23	SAQOL-39 (Greek version)		

*Community dwelling unless otherwise specified

**Some studies had multiple participant subgroups. This column is concerned with whether a proxy effect was found between the community dwelling group with the condition (IE not in institutional care)

and their informal carer / communication partner (ie not a health professional)

a) Additional differences reported depending on subgroup of caregiver

b) Wu et al. (2020) do not report the confidence interval for the mean and therefore it was impossible to know if the line of equality was inside the confidence interval window (necessary for Bland Altman plot interpretation, see Giavarina, 2015). However, as the 1.96SD Limits of Agreement were reported, we were able to calculate the confidence interval (based on Mean=3.3, SD=6.38, n=1283 dyads) to be 95%CI=2.95-3.65. Therefore a significant bias is occurring.

- c) Our analysis as no a priori limits set by authors
- d) Bosboom et al. (2012) claimed acceptable agreement of raters based on their BA plot, however, we have omitted this finding due to our observation (also noted by Römhild et al., 2018) that the interpretation of what limits of agreement represent is incorrect.
- e) an actively involved caregiver who lived with them or spent every day with them. 80% of caregivers were spouses, 9% were adult children, and 11% were other close relatives or friends who lived with and cared for the patient
- f) Four QOL measures: A global rating designed for the study, the Short-Form-36 Health Survey (Ware & Sherbourne, 1992), Dartmouth COOP Charts (Nelson et al., 1987) and the 'How I feel about myself' wellbeing scale (Ryff, 1989). Only total or overall scores are considered in this table, rather than subscales.

Notes:

NA: refers to cases where no test has been reported

FTLD : Fronto-temporal Lobar Degeneration (Coyle Gilchrist et al., 2016)

DQol : Dementia Quality of life Instrument (Brod et al., 1999)

EUROHIS QOL : European health interview surveys quality of life index (Schmidt, 2006)

EQ-5D : A measure of health status from the EuroQol Group (Rabin & De Charro, 2001)

QOL-AD : Quality of Life in Alzheimer's Disease Scale (Logsdon et al., 1999)

SAQOL-39 : Stroke and Aphasia Quality of Life Scale (Hilari et al., 2003)

SF-12 HS : 36-Item Short Form Survey (Ware, 1996)