

# A comparison of self and proxy quality of life ratings for people with dementia and their carers

Citation for published version (APA):

O'Shea, E., Hopper, L., Marques, M., Goncalves-Pereira, M., Woods, B., Jolley, H., Verhey, F., Kerpershoek, L., Wolfs, C., de Vugt, M., Stephan, A., Bieber, A., Meyer, G., Wimo, A., Michelet, M., Selbaek, G., Portolani, E., Zanetti, O., Irving, K., & ActifCare Consortium (2020). A comparison of self and proxy quality of life ratings for people with dementia and their carers: a European prospective cohort study. *Aging & Mental Health*, 24(1), 162-170. <https://doi.org/10.1080/13607863.2018.1517727>

## Document status and date:

Published: 02/01/2020

## DOI:

[10.1080/13607863.2018.1517727](https://doi.org/10.1080/13607863.2018.1517727)

## Document Version:

Publisher's PDF, also known as Version of record

## Document license:

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## A comparison of self and proxy quality of life ratings for people with dementia and their carers: a European prospective cohort study

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To cite this article: E. O'Shea, L. Hopper, M. Marques, M. Gonçalves-Pereira, B. Woods, H. Jelley, F. Verhey, L. Kerpershoek, C. Wolfs, M. de Vugt, A. Stephan, A. Bieber, G. Meyer, A. Wimo, M. Michelet, G. Selbaek, E. Portolani, O. Zanetti, K. Irving & the Actifcare Consortium (2020) A comparison of self and proxy quality of life ratings for people with dementia and their carers: a European prospective cohort study, *Aging & Mental Health*, 24:1, 162-170, DOI: [10.1080/13607863.2018.1517727](https://doi.org/10.1080/13607863.2018.1517727)

To link to this article: <https://doi.org/10.1080/13607863.2018.1517727>



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## A comparison of self and proxy quality of life ratings for people with dementia and their carers: a European prospective cohort study

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### ABSTRACT

**Objectives:** To identify correlates of self-rated and proxy-rated quality of life (QoL) in people with dementia on (i) a dementia-specific and (ii) a capability-wellbeing QoL measure at baseline and 12-month follow-up, and to consider such factors in the context of QoL intervention development.

**Method:** Prospective clinical and demographic data were collected from 451 community-dwelling dyads (mild-moderate dementia) across eight European countries. QoL was measured using the QOL-AD and the ICECAP-O. Multivariate modelling identified correlates of self- and proxy-rated QoL at baseline and at 12-month follow-up.

**Results:** Carer's proxy-ratings of QoL were significantly lower than self-ratings at all time-points for both measures. Proxy-ratings declined over time, but self-ratings remained stable. Baseline predictors of greater self-rated QoL were education, and greater functional ability and relationship quality. Greater proxy-rated QoL was associated with education and greater functional ability, relationship quality, carer social support and carer QoL, lower carer anxiety/depression and less severe neuropsychiatric symptoms in people with dementia. At follow-up, greater self-rated QoL was predicted by greater functional ability, relationship quality, carer social support and having a spousal carer. Greater proxy-rated QoL at follow-up was associated with the same factors as at baseline; however, the dyad living together was an additional predictive factor.

**Conclusion:** Both proxy-ratings and self-ratings of QoL should be interpreted with caution and in the context of each individual caregiving relationship. Different functional, psychosocial, relational and contextual factors influence self- and proxy-ratings, and both sets of factors should be considered in the context of QoL intervention development for the dyad.

### ARTICLE HISTORY

Received 23 February 2018  
Accepted 24 August 2018

### KEYWORDS

Dementia; carers; quality of life; proxy-rating; intervention development

## Introduction

In the absence of curative treatment for dementia, one of the key outcomes of health and social care service use is the preservation or enhancement of the 'quality of life' (QoL) of the person with dementia as the condition progresses.

Consequently, the reliable and valid measurement of QoL is a critical issue in dementia research, and one which is complicated by factors including heterogeneous conceptualisations and measurement approaches, e.g. disease-specific versus generic and health-related versus multidimensional QoL (Bowling et al., 2014; Matsui et al., 2006). Dementia-specific measures aim to capture specific aspects of QoL related to the dementia condition, making such tools potentially more relevant to the lived experience of dementia. However, by focusing on the effects of one particular condition, such disease-specific measures do not capture the influence of other comorbid conditions or other non-health-related factors on QoL, in the same way that more non-disease-specific and/or multidimensional QoL measures can (Makai,

Becke-bans, van Exel, & Brouwer, 2014), and they do not allow comparisons across different conditions.

Another factor influencing QoL measurement in dementia is whether it is self-reported by the person with dementia, or proxy-reported (e.g. by the primary carer) (Bowling et al., 2014; Orgeta, Orrell, Hounscome, & Woods, 2015). Given the range of cognitive deficits which can impede self-reporting in people with dementia, including poor recall, language impairments, and diminished executive functioning, carers are often asked to complete QoL measures on behalf of the person with dementia. Studies comparing self and proxy ratings have indicated that carers rate the QoL of people with dementia as significantly lower than people with dementia rate their own (Conde-Sala, Garre-Olmo, Turró-Garriga, López-Pousa, & Vilalta-Franch, 2009; Logsdon, Gibbons, McCurry, & Teri, 2002); a reporting discrepancy is unsurprising as QoL is essentially a subjective concept (Bowling et al., 2014), and the carer's perspective may be influenced by different factors. Another common finding is that while self-ratings of QoL remain

stable over time, carer proxy-ratings decrease over time as the condition progresses (Bosboom, Alfonso, & Almeida, 2013; Clare et al., 2014; Conde-Sala, Turró-Garriga, Garre-Olmo, Vilalta-Franch, & Lopez-Pousa, 2014; Dourado et al., 2016).

Factors previously associated with self-rated QoL include education (Huang, Chang, Tang, Chiu, & Weng, 2009; Logsdon, Gibbons, McCurry, & Teri, 1999), awareness of dementia-related deficits (Bosboom, Alfonso, Eaton, & Almeida, 2012; Sousa et al., 2013; Woods et al., 2014), depressed mood (Logsdon et al., 2002; Woods et al., 2014), self-reported health (Orgeta et al., 2015) and pain (Beer et al., 2010; Snow et al., 2005), comorbidity (Buckley et al., 2012), relationship quality (Clare et al., 2014; Woods et al., 2014) and carer 'burden' and depression (Conde-Sala et al., 2009; Logsdon et al., 2002; Snow et al., 2005).

Carer proxy QoL ratings have been associated with the age (Orgeta et al., 2015) and the cognitive and functional ability of the person with dementia (Beer et al., 2010; Bosboom et al., 2012; Gómez-Gallego, Gómez-Amor, & Gómez-García, 2012; Orgeta et al., 2015; Snow et al., 2005) and the presence of neuropsychiatric symptoms (Buckley et al., 2012; Conde-Sala et al., 2009; Nakanishi, Hanihara, Mutai, & Nakaaki, 2011). Carer psychosocial factors also influence carer proxy QoL ratings, e.g. 'carer burden' (Black et al., 2012; Conde-Sala et al., 2009), depression (Karttunen et al., 2011; Logsdon et al., 1999, 2002; Orgeta et al., 2015; Snow et al., 2005), and their own QoL (Conde-Sala et al., 2009) and self-rated health (Orgeta et al., 2015).

There is no consensus on the influence of factors including cognition, activities of daily living, the type of care relationship (e.g. spouse or adult child), and the living situation of the dyad on self and proxy QoL ratings for people with dementia (Buckley et al., 2012; Conde-Sala et al., 2009; Orgeta et al., 2015). It is also not clear how the factors associated with self- and proxy-rated QoL of people with dementia might vary across different types of measures within a sample, and over time. Here we will use the QOL-AD (Logsdon et al., 1999) as a dementia-specific tool and the ICECAP-O (Coast et al., 2008) as a non-disease-specific measure. The conceptual basis of the ICECAP-O is rooted in a capability-wellbeing framework; the tool measures capacity to perform actions and achieve certain states and this is qualitatively distinct from the typical functional approach to generic QoL measurement (Round, Sampson, & Jones, 2014). To date, to our knowledge, the ICECAP-O has not been used with people with dementia to self-report their QoL, although studies using proxy-ratings have been published (Makai et al., 2014; Sarabia-Cobo et al., 2017).

This prospective study, including data from eight European countries, aims to understand the factors associated with (i) self- and (ii) proxy-rated QoL, on a disease-specific and a capability-wellbeing QoL instrument, over a one year period at baseline (T0), six months (T1) and 12 months (T2), and to consider the role of such factors in the context of developing QoL interventions.

## Research questions

1. Do differences exist between the self- and proxy-ratings of the QoL of the person with dementia on disease-specific and capability-wellbeing QoL instruments at T0, T1 and T2?

2. Do differences exist over time (T0, T1, T2) in (i) self-rated and (ii) proxy-rated QoL scores of the person with dementia on a disease-specific and a capability-wellbeing QoL instrument?

3. What factors predict greater (i) self- and (ii) proxy-rated QoL scores of people with dementia on a) a disease-specific QoL measure and on b) a capability-wellbeing QoL instrument at T0 and at T2?

## Method

In this study, we report on data from the Actifcare (Access to Timely Formal Care) study, a 12-month prospective cohort study conducted across eight European countries (Germany, Ireland, Italy, The Netherlands, Norway, Portugal, Sweden and the United Kingdom). The overall aim of Actifcare is to understand why people with dementia and their carers use, or don't use formal services, to inform more timely access to services (Kerpershoek et al., 2016, 2017).

## Participants

Participants were community-dwelling people with mild/moderate dementia (according to DSM-IV-TR criteria) and their informal carers, who were likely to require additional assistance over the coming 12-months, as a result of the dementia, as judged by a clinical professional. Carers had to be in contact with the person with dementia at least once per week. The following constituted exclusion criteria: severe dementia, severe communication difficulties; the receipt of formal services in relation to personal care; alcohol-related dementia; Huntington's disease; learning disabilities; a mental health diagnosis; a terminal diagnosis. This paper reports on data from 451 dyads (people with dementia, their carers) at T0, T1 and T2. At T1 follow-up data was collected for 398 dyads and at T2, for 368 dyads.

## Measures

The participants completed the baseline survey between November 2014 and July 2015, administered by trained data collectors. Participants completed questionnaires on socio-demographic information and a range of clinical measures (see Kerpershoek et al., 2016 for complete list). The measures examined in this study are outlined below.

The Quality of Life- Alzheimer's Disease (QOL-AD) scale is a reliable and valid 13-item disease-specific QoL scale for people with dementia with a Mini Mental State Examination (MMSE) score above 10 (Logsdon et al., 1999); the QOL-AD has a proxy-report version, which was also employed in this study (Logsdon et al., 1999). QOL-AD scores range from 13 to 52. The ICECAP-O is a non-disease-specific QoL instrument with self- and proxy-rating versions for older adults rooted in a conceptual basis of capability and well-being. It measures capabilities with preference-based tariffs applicable in health economic evaluation and scores range between zero and one (Coast et al., 2008). The five domains measured are 'attachment', 'security', 'role', 'enjoyment' and 'control'. We used, whenever available, nationally-validated translations of these tools (Bárrios et al., 2013; Kerpershoek et al., 2016; Makai et al., 2014;

Makai, Brouwer, Koopmanschap, & Nieboer, 2012; Novelli, Rovere, Nitrini, & Caramelli, 2005). Otherwise, we followed the usual procedures to ensure preliminary validity and reliability of the measure, i.e. translation/back translation and pilot tests (Kerpershoek et al., 2016).

Cognitive functioning of the people with dementia was assessed using the MMSE (Folstein, Robins, & Helzer, 1983). Dementia severity was assessed using the Clinical Dementia Rating scale (CDR) (Morris, 1993). The Instrumental Activities of Daily Living (IADL) scale was completed by carers to provide us with specific information on daily living skills, while the Physical Self-Maintenance Scale, also completed by carers, gives information about more basic activities of daily living skills (ADLs; Lawton & Brody, 1970). Neuropsychiatric symptoms in people with dementia were assessed with the Neuropsychiatric Inventory-Questionnaire (NPIQ), as such symptoms are known to significantly influence carer strain (Cummings et al., 1994; Kaufer et al., 2000). Here we will report on the NPIQ 'severity' score. The relationship quality between the person with dementia and the carer was measured using the five-item Positive Affect Index; both members of the dyad completed this from their own perspective (PAI; Bengtson & Schrader, 1982).

Carer QoL was assessed with the carers' self-rated responses on the ICECAP-O (Coast et al., 2008). Carer anxiety and depression was measured with the 14-item Hamilton Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). Carer stress was assessed using the Relative Stress Scale (RSS; Greene, Smith, Gardiner, & Timbury, 1982) and carer social support using the Lubben Social Network Scale (LSNS-6; Lubben & Gironde, 2000).

## Ethics

People with dementia were asked for informed consent but when this was not possible, the legal procedures of the respective country were adhered to. Participants were recruited from general practices and memory clinics, through case managers and community mental health teams, and through advertisements in national and local newspapers. The study protocol was approved by national ethics committees of the eight included EU countries (Kerpershoek et al., 2016, 2017).

## Data analysis

Statistical analyses were conducted using SPSS V23. The data were not normally-distributed. In terms of the handling of missing data, valid percentages and complete case analyses are reported here. Wilcoxon-tests investigated group differences in continuous variables, while Spearman's Rho correlation coefficient assessed the bivariate relationships between continuous variables. Wilcoxon signed-ranks tests examined differences in self- and proxy-ratings of QoL for each measure at T0, T1 and T2. Friedman tests investigated differences in self-ratings and proxy-ratings over time (T0, T1, T2). The Bonferroni correction was applied, as appropriate, to correct for multiple comparisons. The relationships between socio-demographic and clinical variables, and both self- and proxy-rated QoL scores were analysed with multiple regression analyses

**Table 1** Baseline demographic information for people with dementia and carers ( $n = 451$  dyads).

Variable	Person with dementia	Carer
Age, M (SD)	77.77 (7.85)	66.4 (13.26)
Sex, N (%F)	246 (54.5)	299 (66.3)
Years in education, M (SD)	9.82 (4.48)	11.89 (4.42)
MMSE, M (SD)	19 (4.99)	–
Abode of PwD	Own home	–
	Other	–
Lives with person with dementia, N (% Yes)	–	323 (71.6)
Relationship, N (%)	Spouse/partner	–
	Son/daughter	–
	Son/daughter in-law	–
	Sibling	–
	Other	–

**Table 2** Correlations between the self- and proxy-rated QoL measures at baseline.

	QOL-AD (Self)	QOL-AD (Proxy)	ICECAP-O (Self)	ICECAP-O (Proxy)
QOL-AD (Self)	1	.513**	.643**	.361**
QOL-AD (Proxy)	.513**	1	.362**	.583**
ICECAP-O (Self)	.643**	.362**	1	.412**
ICECAP-O (Proxy)	.361**	.583**	.412**	1

\*\* $p < 0.01$ .

(assumptions met), with (i) self- and (ii) proxy-rated QoL scores of people with dementia as the dependent variables. Independent variables were chosen based on the presence of significant bivariate relationships with the dependent variables. The final parsimonious models are reported. The threshold for statistical significance for all analyses was set at  $p < 0.05$ .

## Results

Table 1 displays demographic information for both the people with dementia and the carers in this study.

The bivariate correlations between the self- and proxy-ratings of both QoL measures at baseline can be found in Table 2.

The differences in self- and proxy-QoL ratings were investigated for both QoL measures; proxy-ratings are significantly lower than self-rated QoL for people with dementia across both indices, at all three time points (see Table 3).

The trends in self- and proxy-ratings from T0, to T1 and T2, were investigated for both QoL measures (see Table 4). The results indicate that self-ratings did not change significantly over time on the QOL-AD ( $p = .100$ ) or the ICECAP-O ( $p = .410$ ). Carer's proxy-ratings on the QOL-AD and the ICECAP-O significantly decreased over time ( $p < .001$ ,  $p < .001$ , respectively); post-hoc analyses indicated that for the QOL-AD, proxy-ratings decreased significantly from T0 to T2 ( $r = 0.34$ ,  $p < .001$ ) and from T1 to T2 ( $r = 0.19$ ,  $p = .01$ ), but not from T0 to T1 ( $p = .06$ ). Similarly, with the ICECAP-O, proxy-ratings decreased significantly from T0 to T2 ( $r = 0.2$ ,  $p = .001$ ) and from T1 to T2 ( $r = .13$ ,  $p = .048$ ), but not from T0 to T1 ( $p = .72$ ).

The bivariate relationships between the socio-demographic and clinical variables and the QoL indices were

**Table 3.** Differences between self- and proxy- quality of life measures for the person with dementia at each time point.

Time point	Measure	N (complete cases)	Person with dementia		Carer		Wilcoxon signed ranks	
			Median (IQR)	Median (IQR)	W (Std. Error)	Z	p value	
T0	QOL-AD	437	37 (8)	32 (9)	6655 (1570.21)	-11.01	<.001	
T0	ICECAP-O	409	0.73 (.33)	0.53 (.27)	8063 (1981.1)	-12.42	<.001	
T1	QOL-AD	353	36 (9)	31 (8)	3823.5 (1088.96)	-9.99	<.001	
T1	ICECAP-O	331	0.73 (.32)	0.53 (.27)	6837 (1493.63)	-10.44	<.001	
T2	QOL-AD	304	36 (9)	30 (8)	21,810.5 (957.2)	9.86	<.001	
T2	ICECAP-O	275	0.73 (.27)	0.53 (.27)	3766.5 (1162.47)	-10.58	<.001	

**Table 4** Self and proxy QoL ratings for the person with dementia over time (T0, T1 and T2).

Measure	Person with dementia self-rating over time			Friedman test - $\chi^2$ statistic	N (complete cases)	df	p value
	PwD T0 Mean rank	PwD T1 Mean rank	PwD T2 Mean rank				
QOL-AD	2.10	2.00	1.90	4.61	209	2	0.10
ICECAP-O	2.03	2.03	1.94	1.78	265	2	0.41
Measure	Carer proxy-rating over time			Friedman test - $\chi^2$ statistic	N (complete cases)	df	p value
	Carer T0 Mean rank	Carer T1 Mean rank	Carer T2 Mean rank				
QOL-AD	2.23	2.02	1.75	30.34	237	2	<.001
ICECAP-O	2.12	2.03	1.84	16.44	325	2	<.001

explored at T0 and at T2 (see Table 5) to allow enough time (i.e. 12 months) for changes to occur.

At T0, greater self-rated QoL on both the QOL-AD and the ICECAP-O was significantly associated with younger age and the number of years spent in education for both the person with dementia and for the carer. Greater self-rated QoL (as per the QOL-AD and the ICECAP-O) was also associated with greater ADL, PAI (both self and carer), IADL and LSNS scores, lower HADS scores and greater carer QoL scores.

Greater proxy-rated QoL at T0 was significantly associated with all the same indices as self-rated QoL, and the associations were in the same direction. In addition, greater proxy-rated QoL was significantly associated with greater MMSE and lower NPIQ scores.

At T2, greater self-rated QOL-AD scores were associated with younger age and more years in education for the person with dementia, and having a spousal carer. Both greater self-rated QOL-AD and ICECAP-O scores were associated with lower HADS scores, and greater LSNS, PAI (for people with dementia only, not carers), ADL, IADL and carer ICECAP-O scores. Greater proxy-rated QoL on the QOL-AD at T2 was associated with more years of education for the person with dementia and greater MMSE scores, while greater proxy QOL-AD and ICECAP-O scores were both associated with the dyad living together as opposed to apart, as well as lower NPIQ and HADS scores, and greater LSNS, ADL, IADL and carer self-rated ICECAP-O scores.

The final parsimonious regression models for self- and proxy-rated QoL for both the QOL-AD and the ICECAP-O at T0 and at T2 are presented in Table 6. Greater self-rated QOL-AD T0 scores were predicted by more years in education (person with dementia), greater ADL and PAI (as rated by person with dementia) scores (53% of variance;  $p < .001$ ). Greater ADL and PAI scores (as rated by person with dementia) predicted greater self-rated T0 ICECAP-O scores (44% of variance;  $p < .001$ ).

Greater proxy-rated T0 QOL-AD scores were significantly predicted by more years in education (person with

dementia), greater ADL, LSNS and PAI (as rated by carers) scores, and lower NPIQ and HADS scores (61% of variance;  $p < .001$ ), while greater proxy-rated T0 ICECAP-O scores were independently predicted by greater ADL, PAI (as rated by carers) and ICECAP-O (carer self-rated QoL) scores and lower NPIQ scores (48% of variance;  $p < .001$ ).

At T2, both greater self-rated QOL-AD (52% of variance,  $p < .001$ ) and ICECAP-O (40% of variance,  $p < .001$ ) scores were independently predicted by greater LSNS, PAI (as rated by person with dementia) and ADL scores. Additionally, having a spousal carer was predictive of greater self-rated QOL-AD scores.

Greater proxy-rated T2 QOL-AD scores were significantly associated with more years in education (person with dementia), greater LSNS, PAI (as rated by carers) and IADL scores and lower NPIQ scores (59% of variance,  $p < .001$ ). Greater proxy-rated T2 ICECAP-O scores were associated with greater IADL, PAI (as rated by carers) and ICECAP-O (carer self-rated) scores, lower NPIQ scores and the dyad living together (57% of variance,  $p < .001$ ).

## Discussion

This prospective study compared self- and proxy-rated QoL scores and investigated the demographic and clinical factors associated with them, on both a dementia-specific (QOL-AD) and a capability-wellbeing (ICECAP-O) QoL tool, at baseline, and at six and twelve-month follow-up, and considered these factors in the context of QoL measurement and in terms of QoL intervention development.

The findings indicate that carer proxy ratings are consistently lower than self-rated QoL, across both QoL indices, in line with previous research (Beer et al., 2010; Black et al., 2012; Bosboom et al., 2012; Buckley et al., 2012; Conde-Sala et al., 2009; Jönsson et al., 2006; Logsdon et al., 2002; Nakanishi et al., 2011; Novella et al., 2006; Novella et al., 2001; Sousa et al., 2013; Vogel, Mortensen, Hasselbalch, Andersen, & Waldemar, 2006). While self-rated QoL remained stable over time on the QOL-AD and the ICECAP-O, proxy-rated QoL significantly decreased on both

**Table 5** Demographic and clinical factors and their relationship with self-rated and proxy-rated QoL scores at baseline and at 12 months follow-up.

T0	SELF-RATED		PROXY-RATED	
	QOL-AD	ICECAP-O	QOL-AD	ICECAP-O
Age (PwD)	-0.182, <i>p</i> = .001	-.144, <i>p</i> = .003	-.152, <i>p</i> = .004	-.120, <i>p</i> = .012
Age (Carer)	NS	NS	NS	NS
Sex (PwD)	NS	NS	NS	NS
Sex (Carer)	NS	NS	NS	NS
Education (PwD)	.304, <i>p</i> < .001	.139, <i>p</i> = .004	.247, <i>p</i> < .001	.116, <i>p</i> = .015
Education (Carer)	.236, <i>p</i> < .001	.157, <i>p</i> = .001	.224, <i>p</i> < .001	.106, <i>p</i> = .028
Relationship	NS	NS	NS	NS
Spousal carer (y/n)	NS	NS	NS	NS
Dyad living together	NS	NS	NS	NS
PwD living alone	NS	NS	NS	NS
MMSE	NS	NS	.155, <i>p</i> = .005	.190, <i>p</i> < .001
PAI (PwD-rated)	0.421, <i>p</i> < .001	0.390, <i>p</i> < .001	0.292, <i>p</i> < .001	0.185, <i>p</i> < .001
PAI (Carer-rated)	0.145, <i>p</i> < .001	0.135, <i>p</i> = .006	0.329, <i>p</i> < .001	0.267, <i>p</i> < .001
NPIQ	NS	NS	-.330, <i>p</i> < .001	-.333, <i>p</i> < .001
ADL	.202, <i>p</i> < .001	.213, <i>p</i> < .001	.323, <i>p</i> < .001	.314, <i>p</i> < .001
LSNS	.122, <i>p</i> = .024	.131, <i>p</i> = .008	.210, <i>p</i> < .001	.130, <i>p</i> = .007
RSS	NS	NS	NS	NS
IADL	.160, <i>p</i> = .003	.179, <i>p</i> < .001	.303, <i>p</i> < .001	.271, <i>p</i> < .001
ICECAP-O (CARER)	.188, <i>p</i> = .001	.168, <i>p</i> = .001	.347, <i>p</i> < .001	.329, <i>p</i> < .001
HADS	-.173, <i>p</i> = .002	-.180, <i>p</i> < .001	-.414, <i>p</i> < .001	-.352, <i>p</i> < .001
<b>T2</b>				
Age (PwD)	-.129, <i>p</i> = .038	NS	NS	NS
Age (Carer)	NS	NS	NS	NS
Sex (PwD)	NS	NS	NS	NS
Sex (Carer)	NS	NS	NS	NS
Education (PwD)	.203, <i>p</i> = .001	NS	.229, <i>p</i> < .001	NS
Education (Carer)	NS	NS	NS	NS
Relationship	NS	NS	NS	NS
Spousal carer (y/n)	<i>p</i> = .027	NS	NS	NS
Dyad living together	NS	NS	<i>p</i> = .001	<i>p</i> = .026
PwD living alone	NS	NS	NS	NS
MMSE	NS	NS	.135, <i>p</i> = .042	NS
PAI (PwD-rated)	0.358, <i>p</i> < .001	0.274, <i>p</i> < .001	0.193, <i>p</i> = .001	0.136, <i>p</i> = .021
PAI (Carer-rated)	0.185, <i>p</i> = .001	NS	0.367, <i>p</i> < .002	0.306, <i>p</i> < .001
NPIQ	NS	NS	-.350, <i>p</i> < .001	-.403, <i>p</i> < .001
ADL	.279, <i>p</i> < .001	.237, <i>p</i> < .001	.381, <i>p</i> < .001	.319, <i>p</i> < .001
LSNS	.204, <i>p</i> = .001	.194, <i>p</i> = .001	.280, <i>p</i> < .001	.210, <i>p</i> < .001
RSS	NS	NS	NS	NS
IADL	.186, <i>p</i> = .003	.173, <i>p</i> = .004	.376, <i>p</i> < .001	.304, <i>p</i> < .001
ICECAP-O (CARER)	.140, <i>p</i> = .029	.198, <i>p</i> = .001	.300, <i>p</i> < .001	.405, <i>p</i> < .001
HADS	-.189, <i>p</i> = .004	-.125, <i>p</i> = .042	-.318, <i>p</i> < .001	-.350, <i>p</i> < .001

**Table 6** Final Parsimonious Multivariate Linear Regression Models for the self- and proxy-ratings on the QOL-AD and the ICECAP-O self- at both T0 and at T2.

IV	SELF				PROXY				
	B	Std. Error	Beta	Sig.	IV	B	Std. Error	Beta	Sig.
<b>QOL-AD T0</b>									
Education (PwD)	0.33	0.06	0.24	<.001	Education (PwD)	0.34	0.05	0.25	<.001
ADL	0.52	0.14	0.16	<.001	ADL	0.72	0.14	0.22	<.001
PAI (PwD)	0.60	0.07	0.39	<.001	HADS	-0.18	0.04	-0.20	<.001
					PAI (carer)	0.21	0.06	0.16	<.001
					LSNS	0.13	0.05	0.12	<.001
					NPIQ	-0.20	0.05	-0.18	<.001
<b>ICECAP-O T0</b>									
ADL	0.02	0.01	0.18	<.001	ADL	0.02	0.00	0.18	<.001
PAI (PwD)	0.02	0.00	0.39	<.001	ICECAP-O (Carer)	0.15	0.04	0.16	0.001
					PAI (Carer)	0.01	0.00	0.18	<.001
					NPIQ	-0.01	0.00	-0.19	<.001
<b>QOL-AD T2</b>									
Spousal carer	1.87	0.64	0.15	0.004	Education (PwD)	0.24	0.06	0.18	<.001
LSNS	0.15	0.05	0.16	0.003	LSNS	0.14	0.05	0.14	0.003
ADL	0.87	0.16	0.28	<.001	PAI (Carer)	0.31	0.06	0.24	<.001
PAI (PwD)	0.55	0.09	0.34	<.001	IADL	0.80	0.14	0.27	<.001
					NPIQ	-0.22	0.05	-0.22	<.001
<b>ICECAP-O T2</b>									
LSNS	0.01	0.00	0.17	0.003	IADL	0.02	0.00	0.17	0.001
ADL	0.02	0.01	0.20	0.001	ICECAP-O (Carer)	0.26	0.05	0.28	<.001
PAI (PwD)	0.01	0.00	0.27	<.001	Living together	-0.07	0.02	-0.19	<.001
					PAI (Carer)	0.01	0.00	0.12	0.022
					NPIQ	-0.01	0.00	-0.24	<.001

measures from baseline to 12-month follow-up, and from 6 to 12-month follow-up, supporting previous findings (Bosboom et al., 2013; Clare et al., 2014; Conde-Sala et al.,

2014; Dourado et al., 2016). These findings confirm that there are significant cross-sectional and longitudinal divergences in self- and proxy-rated QoL response patterns,

indicating a need for caution in the interpretation of proxy-rated QoL in the instance where self-rated QoL cannot be obtained.

In terms of correlates, more years in education for the person with dementia were predictive of greater self-rated QoL on the QOL-AD at baseline and greater proxy-rated QoL on the QOL-AD at baseline and follow-up. To date, the evidence in relation to the influence of education on self/proxy-rated QoL is mixed. Many studies have not found an association with either self- or proxy-rated QoL (Dourado et al., 2016; Gómez-Gallego et al., 2012; Matsui et al., 2006; Orgeta et al., 2015; Ready, Ott, & Grace, 2004; Snow et al., 2005; Sousa et al., 2013), while others have found an association with greater self- (Black et al., 2012; Huang et al., 2009; Karttunen et al., 2011; Logsdon et al., 1999) and proxy-rated QoL (Buckley et al., 2012; Logsdon et al., 1999). It is likely that education has complex relationships with extraneous variables that could influence its relationship with QoL, including income, occupation, and the persons' interests/hobbies (Logsdon et al., 1999). This finding also highlights the possible role of education inequality in relation to QoL outcomes in later years for people with dementia in European countries.

Greater functional ability was predictive of greater self-rated QoL at baseline and follow-up (ADLs) and greater proxy-rated QoL at baseline (ADLs) and follow-up (IADLs). This finding is in line with other studies regarding self- (Conde-Sala et al., 2013; Conde-Sala et al., 2009; Logsdon et al., 1999) and proxy-rated QoL (Black et al., 2012; Bosboom et al., 2012; Conde-Sala et al., 2013; Conde-Sala et al., 2014; Conde-Sala et al., 2009; Gómez-Gallego et al., 2012; Karttunen et al., 2011; Logsdon et al., 1999; Orgeta et al., 2015; Snow et al., 2005). However, some studies have reported no such associations (Gómez-Gallego et al., 2012; Matsui et al., 2006; Snow et al., 2005). This could be a result of small samples from distinct populations (Matsui et al., a small, Japanese sample [N = 140 dyads]; Gomez-Gallego et al., a small, Spanish sample [N = 102 dyads], which included those with 'possible' Alzheimer's disease), different measures (Matsui et al., employed the HADL [Hirono, Mori, Yamashita, Tokimasa, & Yamadori, 1997; Hirono, Yamadori, Mori, Yamashita, & Tokimasa, 1995]; Gomez-Gallego employed the Functional Activities Questionnaire [Pfeffer, Kurosaki, Harrah Jr, Chance, & Filos, 1982]), or different treatment of the same measures used here, e.g. Snow et al. (2005) employed the same ADL and the IADL measures (Lawton & Brody, 1970) as were used in the present study, but merged the two scales' scores to create one composite score.

Unsurprisingly, lower levels of neuropsychiatric symptoms in people with dementia were associated with greater proxy-rated QoL at baseline and follow-up on both measures, concurrent with previous research findings (Beer et al., 2010; Black et al., 2012; Bosboom et al., 2012; Buckley et al., 2012; Conde-Sala et al., 2009; Dourado et al., 2016; Gómez-Gallego et al., 2012; Huang et al., 2009; Karttunen et al., 2011; Matsui et al., 2006; Ready et al., 2004; Vogel et al., 2006).

We did *not* find that cognition (MMSE) was a significant predictor of either self- or proxy-rated QoL at baseline or follow-up. This is in contrast with some previous research (Beer et al., 2010; Black et al., 2012; Buckley et al., 2012)

however our findings are in line with the majority of the work in this area employing the QOL-AD (Conde-Sala et al., 2009; Dourado et al., 2016; Gómez-Gallego et al., 2012; Logsdon et al., 1999; Sousa et al., 2013; Vogel et al., 2006; Woods et al., 2014). In light of the findings that awareness is associated with self-rated QoL in 'moderate dementia' (Bosboom et al., 2012; Hurt et al., 2010), but not in the early-stages (Woods et al., 2014), it would be useful for future research to further investigate the role of awareness and other cognitive domains in QoL ratings, using a more comprehensive and reliable assessment tool than the MMSE, e.g. the ADAS-Cog (Rosen, Mohs, & Davis, 1984) or the CAMDEX (Roth et al., 1986).

Relationship quality between the person with dementia and the carer was a significant predictor of both self- and proxy-rated QoL, both from the perspective of the person and of the carer, at baseline and at follow-up. This echoes Clare et al. (2014), in that self-rated relationship quality independently predicts self-rated QoL amongst people with dementia. The finding regarding proxy-rated QoL, however, has not been reported before to our knowledge. Other findings in this study support the notion that relational factors are influential in terms of how both members of the dyad rate the person with dementia's QoL; at T2, having a spousal carer predicted greater self-rated QoL, and the dyad living together predicted greater proxy-rated QoL scores. While these findings regarding QoL and relationship quality were not surprising, it must be noted that relationship quality is a complex construct in itself, involving multiple determinants, which are being considered in another Actifcare study (Marques et al, in preparation).

A range of carer psychosocial factors were also associated with greater proxy-rated QoL, including greater social support (T0, T2; QOL-AD only), carer QoL (T0, T2; ICECAP-O) and lower levels of carer anxiety and depression (T0 only; QOL-AD). Other studies have reported that carer QoL (Dourado et al., 2016; Huang et al., 2009), and anxiety and/or depression (Black et al., 2012; Bosboom et al., 2012; Karttunen et al., 2011; Snow et al., 2005) are significant correlates of proxy-rated QoL for people with dementia. Interestingly, at 12-month follow-up, greater carer social support also predicted greater *self-rated* QoL on the QOL-AD and the ICECAP-O, indicating that carer psychosocial factors significantly impact not only proxy-rated QoL, but the self-rated QoL of the person with dementia also. This suggests that enhancing carer social support might be important for bolstering the QoL of people with dementia, and is worthy of further investigation.

In terms of other factors that might be amenable to intervention, functional ability (ADLs) is another important variable influencing the person with dementia's appraisal of their QoL, on both measures. Proxy-ratings are also associated with modifiable factors including functional ability, neuropsychiatric symptoms, and a range of carer psychosocial variables including carer social support, QoL, anxiety and depression. Importantly, relationship quality was a particularly strong predictor of QoL ratings for both members of the dyad, on both QoL measures, across the time points; this may be a substantial factor in terms of QoL intervention development and is certainly worthy of further research.

In relation to comparing the QoL measures; while the QOL-AD and the ICECAP-O detected many of the same correlates for self- and proxy-rated QoL (ADLs, IADLs, relationship quality, neuropsychiatric symptoms and carer social support), the QOL-AD tended to have slightly stronger relationships with other socio-demographic, clinical and psychosocial variables, particularly in relation to self-ratings. This might indicate that the QOL-AD was more relevant to the person with dementia's experience, or that it was somewhat easier for participants to engage with the questions on the QOL-AD, than the ICECAP-O. However, these findings also demonstrate that the ICECAP-O is a useful tool with a novel conceptual basis given that it is rooted in a capability-wellbeing framework, as opposed to a functional or a deficit model. The ICECAP-O is certainly worthy of further investigation in the context of QoL and dementia.

Taken altogether, these findings indicate that the person with dementia should always be asked about their QoL where possible (i.e. they evidence awareness of their condition and an understanding of the questions they are being asked), and that proxy-ratings of QoL should be interpreted with caution. In the instance where a proxy-rating is necessary, a dementia-specific measure might be more relevant to the caregiving experience of the dyad and might better capture dementia-specific QoL issues. Furthermore, while the mean self-rated QoL of people with dementia tends to remain stable over time, other research findings show that there is actually a degree of individual variation in response patterns over time within samples (Clare et al., 2014), highlighting the value of adopting a more individualised approach to QoL interventions in this population. While interventions should focus on the key predictors identified here, for both the person and the carer, they should also be tailored to the specific needs and preferences of individual dyads, and considered within the context of the caregiving relationship.

In terms of limitations, the findings presented here are not fully representative of people even in the mild to moderate stages of dementia, as the input of a carer was required. The findings are not generalizable to people with more advanced dementia, and those with severe mental or physical health difficulties. It should be noted that we considered looking at cross-country differences, however the samples in each country were not representative of people with dementia in that country, nor were they matched on other key demographic variables, and so we decided this was not appropriate.

The main strengths of this study are the longitudinal design, and the size and variability of the cohort, as it includes 451 dyads from across eight European countries. This is the first study, to our knowledge, to gather self-ratings of people with dementia on the ICECAP-O, and to compare self and proxy rated QoL across (1) a dementia-specific, and (2) a capability-well-being-based non-disease-specific QoL measure.

### Availability of data and materials

The raw data supporting our findings are held at the trial units in each country as paper copies of the questionnaires, and are stored online in a MACRO database via a secure

web-based interface. Data available on application to Professor Frans Verhey.

### Ethics approval and consent to participate

All individual countries have applied for medical ethical approval in their own country. Ethical consideration differs between countries: Medischeethische toetsingscommissie (NL), Wales Research Ethics Committee 5, Bangor (UK), Ethics committee of the Medical Faculty, Martin Luther University Halle-Wittenberg (DE), Regional committee for medical and health research ethics, South-East B (NO), the Regional Ethics Review Board (SW), Dublin City University Research Ethics Committee (IE), Ethics Committee of the Nova Medical School/UNL, Ethics Committee of Centro Hospitalar de Lisboa Ocidental, Ethics Committee of ARSLVT, Ethics Committee of ARSA, Comissão Nacional de Protecção de Dados (PT). Comitato Etico, IRCCS San Giovanni di Dio-Fatebenefratelli (IT). The study protocol complies with the Medical Research Involving Human Subjects Act and codes on 'good use' of clinical data.

### Acknowledgments

This is an EU Joint Programme - Neurodegenerative Disease Research (JPND) project. The project is supported through the following funding organisations under the aegis of JPND - [www.jpnd.eu](http://www.jpnd.eu). Germany, Ministry of Education and Research, Ireland, Health research board, Italy, Ministry of Health, the Netherlands, The Netherlands organization for Health Research and Development, Sweden, The Swedish Research Council for Health, Working Life and Welfare, Norway, The Research Council of Norway, Portugal, Foundation for Science and Technology, United Kingdom, Economic and Social Research Council. The Actifcare Consortium partners are: Coordinator: Maastricht University (NL): Frans Verhey, professor (scientific coordinator, WP1 leader) Consortium members: Maastricht University (NL): Marjolein de Vugt, Claire Wolfs, Ron Handels, Liselot Kerpershoek. Martin-Luther University Halle-Wittenberg (DE): Gabriele Meyer (WP2 leader), Astrid Stephan, Anja Bieber, Anja Broda, Gabriele Bartoszek. Bangor University (UK): Bob Woods (WP3 leader), Hannah Jelley. Nottingham University (UK): Martin Orrell. Karolinska Institutet (SE): Anders Wimo (WP4 leader), Anders Sköldunger, Britt-Marie Sjölund, Oslo University Hospital (NW): Knut Engedal, Geir Selbaek (WP5 leader), Mona Michelet, Janne Rosvik, Siren Eriksen Dublin City University (IE): Kate Irving (WP6 leader), Louise Hopper, Rachael Joyce, CEDOC, Nova Medical School, Faculdade de Ciências Médicas, Universidade Nova de Lisboa (PT): Manuel Gonçalves-Pereira, Maria J. Marques, M. Conceição Balsinha, Helena Bárrios, Ana Machado, on behalf of the Portuguese Actifcare team (FCT-JPNDHC/0001/2012). Alzheimer's Research Unit-Memory Clinic, IRCCS "Centro S.Giovanni di Dio (IT): Orazio Zanetti, Elisa Portolani

### Funding

The project is supported through the following funding organizations under the aegis of JPND - [www.jpnd.eu](http://www.jpnd.eu). Germany, Ministry of Education and Research, Ireland, Health Research Board, Italy, Ministry of Health, the Netherlands, The Netherlands organization for Health Research and Development, Sweden, The Swedish Research Council for Health, Working Life and Welfare, Norway, The Research Council of Norway, Portugal, Foundation for Science and Technology, (Fundação para a Ciência e Tecnologia (FCT - JPND HC/0001/2012), United Kingdom, Economic and Social Research Council. JPND has read and approved of the protocol of the Actifcare study.

### Disclosure statement

The authors report no conflict of interest.

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