

A comparison of self- and proxy-rated quality of life for people with dementia and its relationship to (un)met need in Ireland

Louise Hopper¹, Oonagh O'Sullivan¹, Rachael Joyce¹, Hannah Jelley², Bob Woods², Martin Orrell³, Kate Irving¹, and Frans R. J. Verhey⁴, on behalf of the Actifcare Study Group.

¹School of Nursing and Human Sciences, Dublin City University; ²Dementia Services Development Centre, Bangor University;

³The Institute of Mental Health, University of Nottingham; ⁴Department of Psychiatry and Neuropsychology, Maastricht University

Background

Quality of life (QoL) is a vital outcome of health and social care interventions¹. Health-related QoL refers to an extensive health status that includes physical, cognitive, social, and functional abilities, along with health perceptions. However, a broader multidimensional view of QoL goes beyond health-related or disease-specific QoL. For example, it is widely believed that in later years QoL is based on general life satisfaction and the facets of psychological well-being that can be altered as an individual faces challenges in life². For optimal measurement of QoL, broad health and well-being scales are often used in conjunction with disease-specific measures of cognitive and physical function.

Measuring the QoL of people with dementia (PwD) is challenging due to deficits in recall, time perception, insight and communication. Recent studies indicate that meaningful measurements can be made using subjective and proxy rating on condition-specific measures. As a result, proxy respondents such as health care professionals, spouses, or relatives are often recruited as alternative sources of information^{4, 3}. Yet, self- and proxy ratings can vary significantly and greater understanding is needed as to why this is the case^{4, 12}.

This study, which is part of the JPND-funded Actifcare project, examined self- and proxy (carer) measures of QoL, relationship strength, and (un)met needs for PwD in Ireland.

Method

Design: Data were gathered at baseline, 6-, and 12-months. For this study, baseline demographic, QoL, relationship and (un)met needs are examined.

Participants: 43 PwD (M = 21; F = 22) and carer (M = 10; F = 33) dyads were recruited through GPs, memory clinics, and local adverts. The mean age of PwD was 74.05 (SD = 9.14, min 50, max 92). The mean age of caregivers was 58.12 (SD = 15.05, min 28, max 85).

Materials: QoL was measured using self and proxy versions of the QoL-AD⁵, DEMQOL-U⁶, EQ-5D-5L (VAS)⁷ and ICECAP-O⁸. The PAI⁹ assessed relationship strength; CANE¹⁰ measured un(met) need.

Procedure: Data was collected in interviews (approx. 2 hours long) with the dyads in their own homes. Data was analysed using SPSS.

References

- Bowling, A., Rowe, G., Adams, S., Sands, P., Samsi, K., Crane, M., ... & Manthorpe, J. (2015). Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales. *Aging & mental health*, 19(1), 13-31.
- George, L. K., & Bearon, L. (1980). *Quality of life in older persons: Meaning and measurement*. New York: Human Sciences Press.
- Thorgrimsen, L., Selwood, A., Spector, A., Royan, L., de Madariaga Lopez, M., Woods, R. T., & Orrell, M. (2003). Whose quality of life is it anyway?: The validity and reliability of the Quality of Life-Alzheimer's Disease (QoL-AD) scale. *Alzheimer Disease & Associated Disorders*, 17(4), 201-208.
- Novella, J. L., Jochum, C., Jolly, D., Morrone, I., Ankr, J., Bureau, F., & Blanchard, F. (2001). Agreement between patients' and proxies' reports of quality of life in Alzheimer's disease. *Quality of life research*, 10(5), 443-452.
- Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental Health and Aging*, 5, 21-32.
- Mulhern, B., Rowen, D., Brazier, J., Smith, S., Romeo, R., Tait, R., ... & Lamping, D. (2013). Development of DEMQOL-U and DEMQOL-PROXY-U: generation of preference-based indices from DEMQOL and DEMQOL-PROXY for use in economic evaluation. *Health technology assessment (Winchester, England)*, 17(5).
- Herdman, M., Gudex, C., Lloyd, A., Janssen, M. F., Kind, P., Parkin, D., ... & Badia, X. (2011). Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Quality of life research*, 20(10), 1727-1736.
- Coast, J., et al., Valuing the ICECAP capability index for older people. *Social Science & Medicine*, 2008. 67(5): p. 874-82.
- Bengtson, V. L., & Schrader, S. S. (1982). Parent-child relations. *Research instruments in social gerontology*, 2, 115-186.
- Reynolds, T., Thornicroft, G., Abas, M., Woods, B., Hoe, J., Leese, M., & Orrell, M. Camberwell Assessment of Need for the Elderly (CANE) Development, validity and reliability, 2000. 176:p. 444-452.
- Clare, L., Nelis, S. M., Whitaker, C. J., Martyr, A., Markova, I. S., Roth, I., ... & Morris, R. G. (2012). Marital relationship quality in early-stage dementia: perspectives from people with dementia and their spouses. *Alzheimer Disease & Associated Disorders*, 26(2), 148-158.

Acknowledgements

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 (Germany, Bundesministerium für Bildung und Forschung (BMBF); Ireland, Health Research Board (HRB); Italy, Italian Ministry of Health; Netherlands, The Netherlands Organization for Health Research and Development (ZonMW); Norway, The Research Council of Norway; Portugal, Fundação para a Ciência e a Tecnologia (FCT); Sweden, Swedish Research Council (SRC); United Kingdom, Economic and Social Research Council (ESRC)).

Results

Participant Group Differences

- There were significantly more female carers, even though there were roughly equal numbers of males and females with dementia; $\chi^2 = 12.302$, $df = 1$, $p < .001$.
- Significantly more PwD had a Clinical Dementia Rating (CDR) of 1 ($n=27$) than CDR of 0.5 ($n=5$) or CDR of 2 ($n=11$); $\chi^2 = 18.407$, $df = 2$, $p < .001$.

Self- and Proxy-rated Quality of Life (QoL)

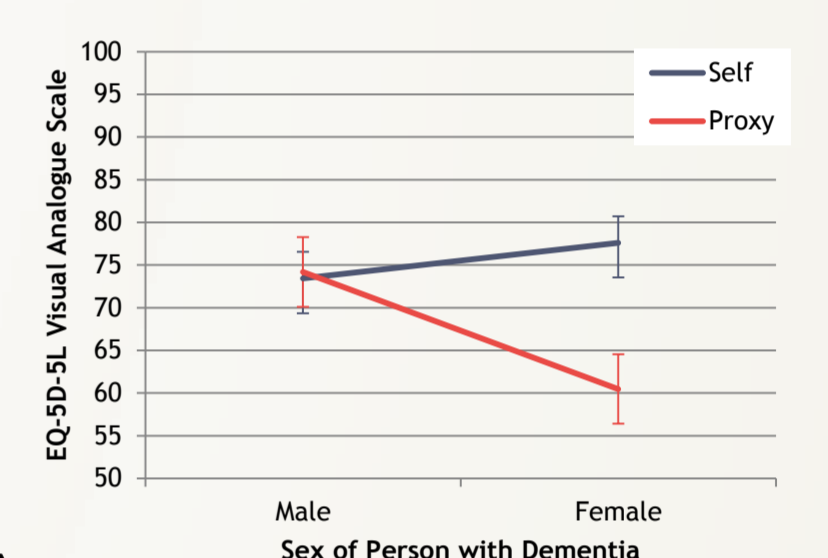
Table 1 Descriptive statistics and within-group differences for self- and proxy-rated QoL measures

Measure	PwD M (SD)	Carer M (SD)	Paired-samples t-test
QoL-AD	38.36 (4.72)	34.75 (5.83)	$t(41) = 4.02$, $p < .001$, $d = 0.64$, $r^2 = 0.28$
EQ-5D-5L VAS	75.52 (14.21)	67.33 (19.71)	$t(41) = 2.48$, $p < .05$, $d = 0.38$, $r^2 = 0.13$
ICECAP-O	17.78 (2.15)	14.88 (2.90)	$t(39) = 5.63$, $p < .001$, $d = 0.89$, $r^2 = 0.45$
Wilcoxon T was used to evaluate DEMQOL-U scores			
DEMQOL-U (positive emotion)	T (N=42) = -4.05, $p < .001$; positive ranks totalled 26, negative ranks totalled 4		
DEMQOL-U (negative emotion)	T (N=42) = -3.83, $p < .001$; positive ranks totalled 24, negative ranks totalled 2		
DEMQOL-U (memory)	No significant difference; positive ranks totalled 8 and negative ranks totalled 12		

- On all but one measure, carers rated the QoL of the person with dementia significantly lower than the ratings given by the person themselves (see Table 1 above).

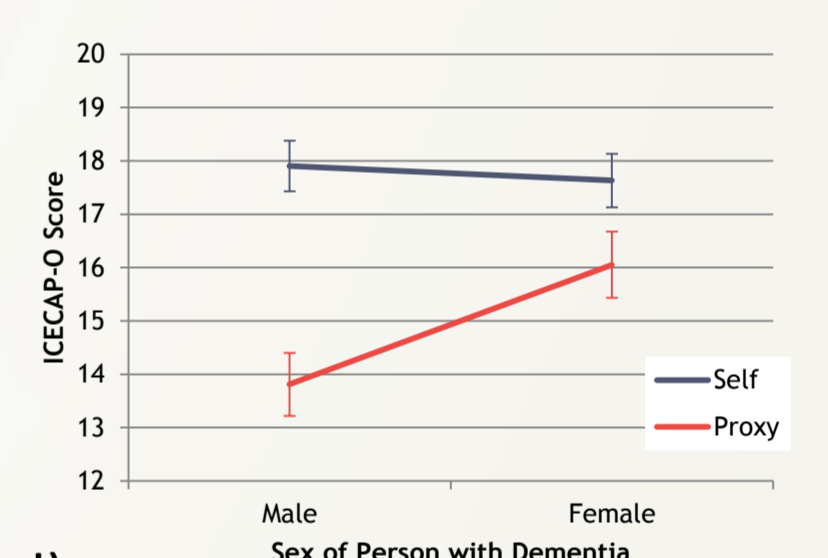
- A 2 (self, proxy) X 2 (male, female) ANOVA for the EQ-5D-5L VAS revealed a significant interaction between rating and PwD Sex; $F(1, 40) = 8.73$, $p < .01$, $\eta_p^2 = 0.18$.

- Post-hoc analysis found a significant difference between self ($M = 77.62$, $SD = 10.56$) and proxy ratings ($M = 60.48$, $SD = 19.36$) for female PwD ($p < .001$). No significant differences were found for male PwD (Bonferroni corrections used).



- A 2 (self, proxy) X 2 (male, female) ANOVA for the ICECAP-O revealed a significant interaction between rating and PwD Sex; $F(1, 38) = 6.85$, $p < .05$, $\eta_p^2 = 0.15$.

- Post-hoc analysis found a significant difference between self ($M = 17.90$, $SD = 2.14$) and proxy ratings ($M = 13.81$, $SD = 3.27$) for male PwD ($p < .001$). No significant differences were found for female PwD (Bonferroni corrections used).

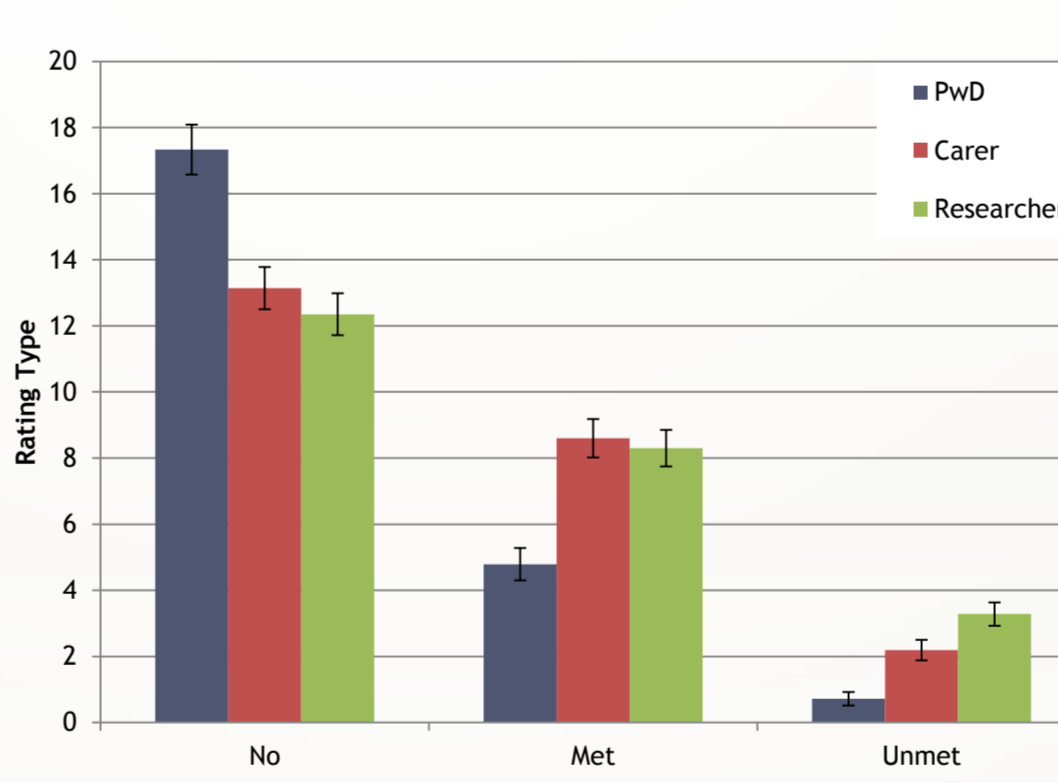


- QoL was also rated significantly lower when severity of dementia (CDR) was higher:

- QoL_AD:** Main Effect of CDR; $F(2,39) = 4.51$, $p < .001$, $\eta_p^2 = .19$; QoL significantly reduced as CDR increased.
- ICECAP-O:** Significant Interaction between rating type and CDR; $F(2, 37) = 8.37$, $p < .001$, $\eta_p^2 = .31$; Proxy QoL significantly reduced as CDR increased but PwD rated QoL decreased at CDR = 1 then rose again at CDR = 2.

Self- and proxy-rated Relationship Strength (Positive Affect index; PAI)

- A paired-samples t-test found a significant difference between PwD and Carer PAI scores; $t(42) = 4.22$, $p < .001$, $d = x$. Relationship quality ratings given by PwD ($M=25.63$, $SD = 4.01$) were significantly higher than those given by carers ($M=22.95$, $SD = 4.59$).



Needs of PwD (Camberwell Needs Assessment, CANE)

- Carers and researchers identified significantly more met and unmet needs than PwD; No need was the most frequently given response in this group.
- The same pattern of results is evident for PwD with a CDR of 1 and 2. No inter-rater differences are found when CDR is 0.5 (Note: sample size is small ($n=5$) in this last group).

- PwD No-Need correlated with QoL-AD ($r = .52^{**}$) and ICECAP-O ($r = .46^{**}$) self ratings. Carer No-, Met and UnMet Need correlated with QoL-AD ($r = .3^*$, $r = -.34^*$, $r = -.45^{**}$) and ICECAP-O ($r = .60^{**}$, $r = -.35^*$, $r = -.50^*$) proxy ratings.

Conclusions

- In line with previous studies, PwD perceive their QoL to be better than their carers do.
 - Interestingly, greater differences were found between self- and proxy-rated health-related QoL for females with dementia in comparison with males, but only for the EQ-5D-5L VAS.
 - In contrast, the opposite pattern was found for the ICECAP-O measure where significant differences between self and proxy ratings were only found for males.
- The finding that PwD view their relationship with their carer in a more positive light than the carers do differs to previous research using the PAI in dementia¹².
- Clear differences were found between self and proxy ratings on each measure. Further research needs to determine why these differences arise and to identify appropriate measures for use with people with dementia, and at different dementia severity levels.