Factors affecting the quality of life of family carers of people with dementia: the role of carer anxiety

Milena Contreras[a], Mizanur Khondoker[a], Eneida Mioshi[a] and Naoko Kishita[a]*

[a]*Faculty of Medicine and Health Sciences, University of East Anglia, Norwich, United Kingdom*

*Corresponding author: Dr Naoko Kishita: School of Health Sciences, Faculty of Medicine and Health Sciences Queens Building, University of East Anglia, Norwich Research Park Norwich, NR4 7TJ (N.Kishita@uea.ac.uk).

Milena Contreras https://orcid.org/0000-0002-5171-0534

Mizanur Khondoker https://orcid.org/0000-0002-1801-1635

Eneida Mioshi https://orcid.org/0000-0002-0066-868X

Naoko Kishita https://orcid.org/0000-0001-8453-2714

Word count: 2977

Factors affecting the quality of life of family carers of people with dementia: the role of carer anxiety

The role of anxiety on the quality of life of family carers of people with dementia is somewhat neglected in the carer literature. The current study aimed to investigate the impact of common risk factors (i.e., care recipient's neuropsychiatric symptoms, carer depression, and burden) and anxiety on QoL. This cross-sectional study recruited eighty-nine family carers. Most of the participants were looking after a spouse with Alzheimer's or mixed dementia. A multiple regression analysis was conducted with carer QoL as a dependent variable. All risk factors (i.e., people with dementia's neuropsychiatric symptoms, carer depression, anxiety, and burden) were entered into the model simultaneously as independent variables. The model's R2 was 33%. The results demonstrated that anxiety was the only significant independent variable of carer QoL ($\beta = -0.34$, $p=0.03$, 95% CI: –0.64 to –0.04). These results indicated that having more symptoms of anxiety was associated with worse QoL as measured by the ICEpop CAPability measure for Older people (ICECAP-O). These findings suggested that improving carer's anxiety may be particularly important in promoting QoL among family carers of people with dementia. Future interventions should target this variable to achieve the desired result of improving carer QoL.

Keywords: informal caregivers, Alzheimer's, QoL, anxiety, depression, neuropsychiatric symptoms.

Introduction

Dementia is one of the major causes of disability and dependency among older people and it affects roughly 50 million people worldwide (WHO, 2017). Due to the great responsibility for care delivery, which family members shoulder, their life is often broadly affected psychologically, physically, and socially (Brodaty & Donkin, 2009). As such, the literature suggests that the quality of life (QoL) of family members is significantly lower than that of non-dementia carers and non-carers (Karg et al., 2018; Schölzel-Dorenbos et al., 2009). Therefore, policies such as the United Kingdom's Carers Action Plan (Department of Health and Social Care, 2018) emphasize the need for understanding how the QoL of family carers is affected to inform interventions that aim to improve carer QoL.

In recent years, there has been an increasing interest in understanding factors affecting carer QoL but, the lack of validated carer-specific QoL measures has led to greater use of generic QoL and health-related QoL instruments. These measures are often criticized for not being sensitive enough for this population (Manthrope & Bowling, 2016; Perry-Duxbury et al., 2020), and several issues need to be considered when measuring QoL in family carers of people with dementia and determining how best to assess this variable.

Firstly, more than one-third of family carers of people with dementia are aged 65 or older worldwide and in some countries, such as Australia, this number can be much greater (i.e., more than half of carers are aged 65+) (Glasby & Thomas, 2019). The use of generic or health-related QoL with such older carers can be problematic as their QoL is often affected by age-related factors, such as changes in physical conditions and levels of independence or loss of social network (Grewal et al., 2006). Indeed, a recent comprehensive systematic review demonstrated that existing carer interventions seem to be more beneficial for younger carers in terms of enhancing QoL compared with older carers (Cheng et al., 2020).

Secondly, family carers are often faced with changed circumstances where they may have limited control (e.g., reduced free time). Finding ways to maintain valued roles and goals in light of losses (e.g., having short calls frequently rather than planning a family holiday to get connected with other family members) may be particularly important for this population (Han et al., 2020).

That is, the key aspect of well-being in older people and family carers is meeting needs rather than how they are met, and function (e.g., physical mobility, size of social network) per se may become less important if the need can be met in another way (Grewal et al., 2006). Therefore, in the current study, we defined carer QoL in terms of an individual's capability to do certain things that are important in life (e.g., doing things that make an individual feel valued) rather than functionality (e.g., physical health) in order to understand factors affecting QoL in family carers of people with dementia.

A recent comprehensive meta-analysis that explored the relationship between various carer- and patient-related factors and QoL, demonstrated that carer depression, carer burden, and people with dementia's neuropsychiatric symptoms were the only factors that had a significant association with QoL in family carers (Contreras et al., 2020). All studies included in this meta-analysis had used generic or health-related QoL measures as their dependent variable, therefore, whether these well-established predictors equally affect QoL when carer QoL is defined as an individual's capability to do things that are important in life is still uncertain.

Moreover, this recent meta-analysis only identified a small number of studies that explored the relationship between carer anxiety and carer QoL, and thus it was not possible to calculate a meaningful effect size. However, considering anxiety is as highly prevalent as depression in this population (Kaddour & Kishita, 2019), providing further evidence on the predictive effect of carer anxiety on carer QoL, in addition to common factors known to have an impact, seems crucial.

Based on the current evidence, this exploratory study will examine predictive effects of potentially modifiable factors, which are considered to have an impact (i.e., carer depression, anxiety and burden, and people with dementia's neuropsychiatric symptoms), on QoL, an individual's capability to do things that are important in life, in family carers of people with dementia.

Methods

Participants

This cross-sectional study collected data from family carers looking after a relative with a clinical diagnosis of dementia that were in a first-degree relationship with the person with dementia (i.e., parent, spouse/partner, sibling, or adult child) and were aged 18 years or older. The dementia diagnosis was based on the self-report of participants. Recruitment took place between July 2017 and February 2020.

A total of 91 participants were recruited from carer support groups, a NHS mental health trust, and from Join Dementia Research, a United Kingdom-based online recruitment tool that allows people with dementia and their carers to register their interest in taking part in research studies. Participants were also recruited through referrals from other ethically approved dementia studies conducted by collaborators. Two participants were excluded from the analyses for having missing data in one of the questionnaires, resulting in 89 participants for the analysis. All questionnaires for data collection were administrated at participants' own homes, the university, or local NHS premises depending on their preference. Full ethical approval was obtained from the NHS Health Research Authority and Research Ethics Committee. Written informed consent was obtained from all participants.

Sample Size Calculation

Prior to the study, the required sample size was calculated using G*Power. This calculation estimated that, based on a linear regression model with four independent variables included in the model, 85 participants would detect a medium effect size (f^2=0.15) at a 5 per cent level of significance with 80 per cent power.

Measures

Anxiety

The Generalised Anxiety Disorder Scale (GAD-7) (Spitzer et al., 2006) was used to measure the severity of anxiety symptoms in family carers. Each item is rated on a 4-point scale: not at all (0), several days (1), more than half the days (2), and nearly every day (3). The sum of scores can indicate anxiety severity of mild (5-9), moderate (10-14), and severe (15-21).

Depression

The Patient Health Questionnaire (PHQ-9) (Kroenke et al., 2001) was used to measure the severity of depressive and anxiety symptoms in family carers. Each item is rated on a 4-point scale: not at all (0), several days (1), more than half the days (2), and nearly every day (3). The sum of scores can indicate depression severity of none (<4), mild (5-9), moderate (10-14), moderately severe (15-19) and severe (20-27).

Burden

Family carer’s burden was assessed by the number of hours devoted to caregiving each week. The following response options were used: 0-2 hours, 3-10 hours, 11-20 hours, 21-40 hours, 41-80 hours, and 81 or more hours.

Neuropsychiatric Symptoms

The Mild Behavioral Impairment Checklist (MBI-C) (Ismail et al., 2017) is a 34-item proxy-informant interview-based measure that assesses the severity of neuropsychiatric symptoms within five domains: motivation, emotional regulation, impulse control, social cognition, and abnormal thoughts/perception. For each item, severity is assessed using a four-point scale: no symptom (0), mild (1), moderate (2), and severe (3). The total score ranges from 0 to 102, with higher scores indicating higher levels of neuropsychiatric symptoms.

Dementia severity

The Frontotemporal Dementia Rating Scale (FRS) (Mioshi et al., 2010) was used to assess dementia severity. The FRS is a 30-item proxy-informant interview-based measure validated in various forms of dementia including Alzheimer's disease. This measure provides logit scores, which are subdivided into six stages of dementia severity: very mild, mild, moderate, severe, very severe, and profound.

Demographics

Information collected included carer age and their level of education, type of relationship with the person with dementia, whether family carers report ongoing health conditions, and if they currently live with the person with dementia in the same household. The type of dementia diagnosed and average years since diagnosis were also recorded.

Carer QoL

The key outcome of this study (i.e., carer QoL) was assessed using the 5-item ICEpop CAPability measure for Older people (ICECAP-O) (Grewal et al., 2006). This instrument defines QoL in a broader sense, rather than health and was specifically designed to assess QoL among older people. Even though this measure is sensitive to changes related to age, it has also been validated in a sample of informal carers of people with dementia that included younger carers (Perry-Duxbury et al., 2020). The scale comprises five attributes: attachment (love and friendship), security (thinking about the future without concern), role (doing things that make you feel valued), enjoyment (enjoyment and pleasure), and control (independence). Each attribute can be scored on four levels (1-4) that range from "not any", "a little", "a lot" to "all" with higher values indicating greater QoL. The ICECAP-O has good psychometric properties with decent evidence about its reliability and validity (Proud et al., 2019).

Statistical Analyses

Descriptive analyses of demographics were performed to characterize the sample.

A multiple regression analysis was conducted to examine to what extent different carer- and patient-related risk factors predicted carer QoL. Neuropsychiatric symptoms of the person with dementia, carer depression, anxiety, and burden were entered into the model as independent variables. The overall model fit was assessed using the F-test and the model's R^2. The standardized coefficients beta (β) were used to assess which of the variables had the strongest impact on the dependent variable (i.e., carer QoL). All statistical analyses were conducted using SPSS version 25 and p-values smaller than 0.05 were considered to be statistically significant.

The Tolerance value and VIF were estimated to check multicollinearity and the Mahalanobis distance to check the presence of outliers. The visualization of residuals against predicted values scatterplot was used to check normality, linearity, and homoscedasticity of residuals.

Results

Sample Characteristics

The demographic characteristics of participants are presented in Table 1. The majority of family carers were female (67.4 per cent), over 65 years old (68.5 per cent), who had at least the secondary school completed (94.3 per cent), and 58.4 per cent reported having ongoing health conditions (e.g., cardiovascular problems, diabetes, arthritis). The majority were looking after a spouse (68.5 per cent) with Alzheimer's disease (44.9 per cent) in the severe stage (46.1 per cent) and 73.1 per cent were living in the same household with the person with dementia. Pearson's correlations and means and standard deviations for all variables are presented in Table 2.

Model-checking

The Tolerance value was higher than 0.33 and the VIF value was below 3.02 for all independent variables in the multiple regression analysis, suggesting that the presence of multicollinearity is less likely to be a concern.

The visualization of the scatterplot of the standard residuals demonstrated that the residuals were distributed with most of the scores plotted on the centre and with a spread pattern. These results suggest that the assumption of normality, linearity, and homoscedasticity of residuals was not violated. The Mahalanobis distance maximum value of 12.73 indicated that there were no extreme outliers present.

Factors affecting family carer QoL

Results of the regression analysis showed that the model with neuropsychiatric symptoms of the person with dementia, carer depression, anxiety, and burden accounted for approximately 33 per cent of the variance in QoL. Carer anxiety was the only variable significantly predicting carer QoL (β = -0.34, p =0.03, 95%CI: −0.64 to -0.04) (See Table 3). These findings suggest that having more symptoms of anxiety can lead to worsening QoL in family carers.

Discussion

This study aimed to explore the impact of carer depression, anxiety, burden and people with dementia's neuropsychiatric symptoms on carer QoL as defined in terms of an individual's capability to do certain things that are important in life. The results demonstrated that carer anxiety was the only significant predictor of QoL.

There is robust evidence that carer depression and burden and neuropsychiatric symptoms of dementia have a negative impact on carer QoL when carer QoL is assessed by generic or health-related QoL instruments (Contreras et al., 2020; Markowitz et al., 2003; Papastavrou et al., 2014). This study suggested that when these well-established predictive factors are included in the same model along with anxiety, they may no longer explain carer QoL, particularly when QoL is focused on an individual's capability rather than functionality. These findings suggest that improving carer's anxiety may be particularly important in promoting their QoL and future interventions should target this key variable to achieve the desired result of improving carer QoL.

To our knowledge, this is the first study to assess the impact of common factors affecting carer QoL, using a measure of QoL that prioritise capability rather than functionality. The literature has shown that QoL does not decrease due to specific factors such as poorer health, but instead QoL decreases because of limitations in what the person can do as a result of poor health (Grewal et al., 2006). In this regard, the ICECAP-O assesses QoL defined in a broader sense, rather than physical health such as the ability to do things that make them feel valued and their subjective sense of independence. This is particularly important for family carers as they often experience high levels of strain and deterioration in subjective well-being, which require to be the main focus of interventions rather than their physical health outcomes (Perry-Duxbury et al., 2020). The ICECAP-O has been validated in informal carers of people with dementia, which is also a strength of this measure (Perry-Duxbury et al., 2020).

Another strength of this study is that carer anxiety was included as one of the potential predictors of carer QoL. Currently, anxiety is fairly neglected compared to depression or burden in the carer literature and older people in general (Contreras et al., 2020; Kaddour & Kishita, 2019). In fact, current national guidelines such as the National Institute for Health and Care Excellence (NICE) guideline for dementia care in the United Kingdom emphasizes that carers of people with dementia are at an increased risk of depression (NICE, 2018). However, the guideline does not refer to the heightened risk of anxiety in this population. Since anxiety is as prevalent as depression in this population (Kaddour & Kishita, 2019), exploring the effect of anxiety on carer QoL seems critical.

Anxiety disorders such as general anxiety disorder (GAD) in family carers of people with dementia, and older people in general, is considered to be hard to treat as a condition such as GAD does not spontaneously remit (Lenze et al., 2005). Current evidence suggests that a conventional psychological approach (e.g. cognitive behaviour therapy) for GAD may be less effective for older adults compared to adults of working age (Kishita & Laidlaw, 2017). The findings of the current study further support the fact that anxiety can have a significant impact on carer's capability to do things that are important to them, and the development of interventions, which can directly target anxiety throughout the dementia journey is critical.

This study also has several limitations that should be taken into account. This study used a measure of objective burden (the number of hours devoted to caring) rather than subjective burden (e.g., the Zarit Burden Interview), which is a commonly used measure in family carers (Chiao et al., 2015). This may have resulted in the contradicting findings between the current study and previous studies that used other types of QoL measures. However, previous literature has shown that the number of hours devoted to caring on a day-to-day basis is one of the most consistent predictors of subjective burden in family carers of people with dementia (Park et al., 2015). This means that, unless objective burden is reduced, subjective burden will not improve and, therefore, objective burden is highly important and modifiable as a target of treatment.

All the independent variables included in this study were selected based on evidence of their association with carer QoL. All these variables are considered to be risk factors, characteristics at the patient, or carer level which could lead to lower levels of QoL. The impact of protective factors was not considered in the current study. A recent systematic review on factors associated with carer QoL suggests that studies that explore the impact of protective factors such as coping strategies, social skills, and interpersonal support are limited (Contreras et al., 2020). Future studies should equally focus on the effect of protective factors that might improve carer QoL to inform future interventions aimed at improving carer QoL.

The use of the ICECAP-O with the carer population has several advantages. However, it is important to acknowledge the existence of other recently developed measures for this population. For example, the C-DEMQOL (Brown et al., 2019) and the Dementia Quality of Life Scale for Older Family Carers (DQoLOC) (Oliveira et al., 2018) that were especially developed for family carers of people with dementia. Although these scales seem promising measures to assess QoL, more studies are needed to evaluate their psychometric properties.

The generalization of the findings may be limited by participants' characteristics. Most of the participants included in this study were female, aged 65 or older, and were looking after a spouse with moderate to severe Alzheimer's disease in a developed country. Future research should replicate the findings of the current study with other types of carers including those with different races and ethnicities.

Finally, it is important to highlight that this was an observational study and thus the results regarding the causality between the variables should be interpreted with caution. Future studies using a longitudinal design are needed to draw conclusions about the direction of effects.

Conclusion

This study found that carer anxiety was the only risk factor affecting carer QoL as assessed by a QoL measure for older adults. Future interventions aiming to improve carer QoL could benefit from targeting anxiety symptoms. It is recommended that future studies continue exploring the underestimated role of anxiety in QoL, especially in carers of less common types of dementia, in the early stages, and from other countries, races and ethnicities.

Funding details

This work presents independent research partly funded by the National Institute for Health Research (NIHR) Applied Research Collaborations (ARC) East of England, at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR, or the Department of Health and Social Care. MC's studentship was also supported by Norfolk and Suffolk Primary and Community Care Research Office and Faculty of Medicine and Health Sciences, University of East Anglia.

Declaration of interest statement

The authors declare that there are no relevant financial or non-financial competing interests to report.

Data availability statement

The data that support the findings of this study are available from the corresponding author, [NK], upon reasonable request.

Acknowledgments

The authors would like to thank Juniper West and Luke Emrich-Mills from Norfolk and Suffolk NHS Foundation Trust for their valuable support in collecting data.

REFERENCES

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia . *Dialogues in Clinical Neuroscience*, *11*(2), 217-228. https://doi.org/10.31887/dcns.2009.11.2/hbrodaty

Brown, A., Page, T. E., Daley, S., Farina, N., Basset, T., Livingston, G., Budgett, J., Gallaher, L., Feeney, Y., Murray, J., Bowling, A., Knapp, M., & Banerjee, S. (2019). Measuring the quality of life of family carers of people with dementia: development and validation of C-DEMQOL. *Quality of Life Research*, *28*(8), 2299-2310. https://doi.org/10.1007/s11136-019-02186-w

Department of Health and Social Care. (2018). *Carers Action Plan 2018-2020 - Supporting carers today*. Department of Health and Social Care. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713781/carers-action-plan-2018-2020.pdf

Cheng, S. T., Li, K. K., Losada, A., Zhang, F., Au, A., Thompson, L. W., & Gallagher-Thompson, D. (2020). The effectiveness of nonpharmacological interventions for informal dementia caregivers: An updated systematic review and meta-analysis. *Psychology and Aging*, *35*(1), 55-77. https://doi.org/10.1037/pag0000401

Chiao, C. Y., Wu, H. S., & Hsiao, C. Y. (2015). Caregiver burden for informal caregivers of patients with dementia: A systematic review. *International Nursing Review*, *62*(3), 340-350. https://doi.org/10.1111/inr.12194

Contreras, M., Mioshi, E., & Kishita, N. (2020). Factors Related to the Quality of Life in Family Carers of People With Dementia: A Meta-Analysis. *Journal of Geriatric*

Psychiatry and Neurology, 0891988720924713. https://doi.org/10.1177/0891988720924713

Glasby, J., & Thomas, S. (2019). *Understanding and Responding to the Needs of Carers of People with Dementia in the UK, US and Beyond*. University of Birmingham, School of Social Policy. https://lx.iriss.org.uk/sites/default/files/carers-of-people-with-dementia.pdf

Grewal, I., Lewis, J., Flynn, T., Brown, J., Bond, J., & Coast, J. (2006). Developing attributes for a generic quality of life measure for older people: Preferences or capabilities? *Social Science & Medicine*, *62*(8), 1891-1901. https://doi.org/10.1016/j.socscimed.2005.08.023

Han, A., Yuen, H. K., Lee, H. Y., & Zhou, X. (2020). Effects of acceptance and commitment therapy on process measures of family caregivers: A systematic review and meta-analysis. *Journal of Contextual Behavioral Science*, *18*, 201-213. https://doi.org/10.1016/j.jcbs.2020.10.004

Ismail, Z., Agüera-Ortiz, L., Brodaty, H., Cieslak, A., Cummings, J., Fischer, C. E., Gauthier, S., Geda, Y. E., Herrmann, N., Kanji, J., Lanctôt, K. L., Miller, D. S., Mortby, M. E., Onyike, C. U., Rosenberg, P. B., Smith, E. E., Smith, G. S., Sultzer, D. L., Lyketsos, C. & NPS Professional Interest Area of the International Society of to Advance Alzheimer’s Research and Treatment (NPS-PIA of ISTAART) . (2017). The Mild Behavioral Impairment Checklist (MBI-C): A Rating Scale for Neuropsychiatric Symptoms in Pre-Dementia Populations. *Journal of Alzheimer's disease : JAD*, *56*(3), 929-938. https://doi.org/10.3233/JAD-160979

Janevic, M. R., & Connell, C. M. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: recent findings. *The Gerontologist*, *41*(3), 334-347. https://doi.org/10.1093/geront/41.3.334

Kaddour, L., & Kishita, N. (2019). Anxiety in Informal Dementia Carers: A Meta-Analysis of Prevalence. *Journal of Geriatric Psychiatry and Neurology*, 891988719868313. https://doi.org/10.1177/0891988719868313

Karg, N., Graessel, E., Randzio, O., & Pendergrass, A. (2018). Dementia as a predictor of care-related quality of life in informal caregivers: a cross-sectional study to investigate differences in health-related outcomes between dementia and non-dementia caregivers. *BMC Geriatrics*, *18*(1), 189. https://doi.org/10.1186/s12877-018-0885-1

Kishita, N., & Laidlaw, K. (2017). Cognitive behaviour therapy for generalized anxiety disorder: Is CBT equally efficacious in adults of working age and older adults? *Clinical Psychology Review*, *52*, 124-136. https://doi.org/10.1016/j.cpr.2017.01.003

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of general internal medicine*, *16*(9), 606-613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x

Lenze, E. J., Mulsant, B. H., Mohlman, J., Shear, M. K., Dew, M. A., Schulz, R., Miller, M. D., Tracey, B., & Reynolds, C. F. (2005). Generalized Anxiety Disorder in Late Life: Lifetime Course and Comorbidity With Major Depressive Disorder. *The American Journal of Geriatric Psychiatry*, *13*(1), 77-80. https://doi.org/10.1097/00019442-200501000-00011

Manthrope, J., & Bowling, A. (2016). Quality of life measures for carers for people with dementia: measurement issues, gaps in research and promising paths. *Research, Policy and Planning*, *31*(3), 15.

Markowitz, J. S., Gutterman, E. M., Sadik, K., & Papadopoulos, G. (2003). Health-related quality of life for caregivers of patients with Alzheimer disease. *Alzheimer Disease & Associated Disorders*, *17*(4), 209-214. https://doi.org/10.1097/00002093-200310000-00003

Mioshi, E., Hsieh, S., Savage, S., Hornberger, M., & Hodges, J. R. (2010). Clinical staging and disease progression in frontotemporal dementia. *Neurology*, *74*(20), 1591-1597. https://doi.org/10.1212/WNL.0b013e3181e04070

NICE. (2018). *Dementia: assessment, management and support for people living with dementia and their carers.* National Institute for Health and Care Excellence.https://www.nice.org.uk/guidance/ng97/resources/dementia-assessment-management-and-support-for-people-living-with-dementia-and-their-carers-pdf-1837760199109

Oliveira, D. C., Vass, C., & Aubeeluck, A. (2018). The development and validation of the Dementia Quality of Life Scale for Older Family Carers (DQoL-OC). *Aging Ment Health*, *22*(5), 709-716. https://doi.org/10.1080/13607863.2017.1293004

Papastavrou, E., Andreou, P., Middleton, N., Papacostas, S., & Georgiou, I. K. (2014). Factors associated with quality of life among family members of patients with dementia in Cyprus. *International Psychogeriatrics*, *26*(3), 443-452. https://doi.org/10.1017/s104161021300224x

Park, M., Sung, M., Kim, S. K., Kim, S., & Lee, D. Y. (2015). Multidimensional determinants of family caregiver burden in Alzheimer's disease. *International Psychogeriatrics*, *27*(8), 1355-1364. https://doi.org/10.1017/S1041610215000460

Perry-Duxbury, M., van Exel, J., Brouwer, W., Sköldunger, A., Gonçalves-Pereira, M., Irving, K., Meyer, G., Selbæk, G., Woods, B., Zanetti, O., Verhey, F., Wimo, A., Handels, R. L. H., & The Actifcare, C. (2020). A validation study of the ICECAP-O in informal carers of people with dementia from eight European Countries. *Quality of Life Research*, *29*(1), 237-251. https://doi.org/10.1007/s11136-019-02317-3

Prince, M., Wimo, A. G. M., Ali, G. C., Wu, Y. T., & Prina, M. (2015). *World Alzheimer Report 2015: the global impact of dementia: an analysis of prevalence, incidence, cost and trends*. Alzheimer's Disease International. https://www.alzint.org/u/WorldAlzheimerReport2015.pdf

Proud, L., McLoughlin, C., & Kinghorn, P. (2019). ICECAP-O, the current state of play: a systematic review of studies reporting the psychometric properties and use of the instrument over the decade since its publication. *Quality of Life Research*, *28*(6), 1429-1439. https://doi.org/10.1007/s11136-019-02114-y

Schölzel-Dorenbos, C. J. M., Draskovic, I., Vernooij-Dassen, M. J., & Olde Rikkert, M. G. M. (2009). Quality of life and burden of spouses of Alzheimer disease patients. *Alzheimer Disease and Associated Disorders*, *23*(2), 171-177. https://doi.org/10.1097/WAD.0b013e318190a260

Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Medicine*, *166*(10), 1092-1097. https://doi.org/10.1001/archinte.166.10.1092

WHO. (2017). *Global action plan on the public health response to dementia.* World Health Organization https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf;jsessionid=45D5FB9484FBFBEED5F84C11E8BC7C0A?sequence=1

Wimo, A., Gauthier, S., & Prince, M. (2018). *Global estimates of informal care*. Alzheimer's. Disease International. https://www.alz.co.uk/adi/pdf/global-estimates-of-informal-care.pdf

Table 1. Demographic characteristics of the sample (N=89).

Family carer characteristics		
Age (in years)	69.1	(± 12.5)
Gender (Female %)	67.4	
Educational Level %		
Unfinished Primary School	1.1	
Primary school	4.5	
Secondary school	40.4	
Vocational diploma	27.0	
Bachelor's degree	20.2	
Master's degree	5.6	
PhD	1.1	
Type of relationship %		
Wife	40.4	
Husband	28.1	
Daughter	25.8	
Son	4.5	
Sister	1.1	
Living with the care recipient (yes %)	73.0	
Ongoing health conditions reported (yes %)	58.4	
Characteristics of people with dementia		
Dementia type		
Alzheimer's %	44.9	
Mixed %	18.0	
Vascular %	14.6	
Frontotemporal %	7.9	
Lewy bodies %	5.6	
Unknown %	6.7	
Other %	2.2	
Years since diagnosis	3.6	(± 2.4)
Dementia Severity %		
Mild	5.6	
Moderate	30.3	
Severe	46.1	
Very severe	18.0	

Table 2. Pearson’s correlations among independent and dependent variables and means and standard deviations (N=89).

Variables	1	2	3	4	*M* (SD)
1 Quality of life (ICECAP-O: 0-1)	-				0.73 (0.16)
2 Carer Depression (PHQ-9: 0-27)	-0.53*	-			19.70 (10.50)
3 Carer Anxiety (GAD-7: 0-21)	-0.55*	0.81*	-		3.28 (0.70)
4 Carer Burden (1-6)	-0.19	0.35*	0.28*		27.86 (8.59)
5 Neuropsychiatric symptoms (MBI-C: 0-102)	-0.22*	0.25*	0.26*	0.26*	1.22 (1.72)

*$P < 0.05$. ICECAP-O high scores denote a better quality of life; PHQ-9 high scores denote more symptoms of depression; GAD-7 high scores denote more symptoms of anxiety; Burden high scores denote more hours devoted to caregiving; MBI-C high scores denote more neuropsychiatric symptoms.

Table 3. Results of multiple regression analysis (N=89).

Predictors	Carer Quality of life			95% CI	
	β	t	P	Lower	Upper
Neuropsychiatric symptoms	-0.08	-0.8	0.43	-0.26	0.11
Carer' depression	-0.25	-1.59	0.12	-0.55	0.06
Carer's objective burden	0.01	0.08	0.93	-0.18	0.20
Carer's anxiety	-0.34	-2.22	0.03	-0.64	-0.04
F	10.45				
d.f.	4				
R^2	0.33				