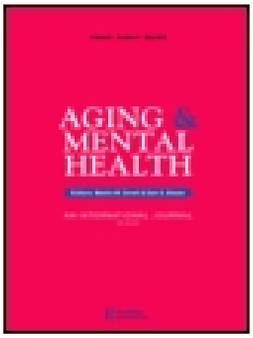
bradscholars

Caregiver influences on 'living well' for people with dementia: Findings from the IDEAL study

Item Type	Article
Authors	Quinn, Catherine;Nelis, S.M.;Martyr, A.;Morris, R.G.;Victor, C.;Clare, L.
Citation	Quinn C, Nelis SM, Martyr A et al (2019) Caregiver influences on 'living well' for people with dementia: Findings from the IDEAL study. Aging and Mental Health. 24(9): 1505-1513.
DOI	https://doi.org/10.1080/13607863.2019.1602590
Rights	© 2019 The Author(s). This is an Open Access article distributed under the Creative Commons CC-BY license (https://creativecommons.org/licenses/by/4.0/)
Download date	2026-03-06 00:33:31
Link to Item	http://hdl.handle.net/10454/17108



Aging & Mental Health

ISSN: 1360-7863 (Print) 1364-6915 (Online) Journal homepage: https://www.tandfonline.com/loi/camh20

Caregiver influences on 'living well' for people with dementia: Findings from the IDEAL study

Catherine Quinn, Sharon M. Nelis, Anthony Martyr, Robin G. Morris, Christina Victor & Linda Clareon behalf of the IDEAL study team

To cite this article: Catherine Quinn, Sharon M. Nelis, Anthony Martyr, Robin G. Morris, Christina Victor & Linda Clareon behalf of the IDEAL study team (2019): Caregiver influences on 'living well' for people with dementia: Findings from the IDEAL study, Aging & Mental Health, DOI: 10.1080/13607863.2019.1602590

To link to this article: https://doi.org/10.1080/13607863.2019.1602590

© 2019 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

Published online: 19 May 2019.

Submit your article to this journal

Article views: 269

View Crossmark data

Full Terms & Conditions of access and use can be found at
https://www.tandfonline.com/action/journalInformation?journalCode=camh20

AGING & MENTAL HEALTH
https://doi.org/10.1080/13607863.2019.1602590

Routledge
Taylor & Francis Group

OPEN ACCESS Check for updates

Caregiver influences on 'living well' for people with dementia: Findings from the IDEAL study

Catherine Quinn[a,b], Sharon M. Nelis[b], Anthony Martyr[b], Robin G. Morris[c], Christina Victor[d] and Linda Clare[b]; on behalf of the IDEAL study team

[a]Centre of Applied Dementia Studies, University of Bradford, Bradford, UK; [b]REACH: The Centre for Research in Ageing and Cognitive Health, University of Exeter Medical School and College of Life and Environmental Sciences, Exeter, UK; [c]Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK; [d]Department of Clinical Sciences, College of Health and Life Sciences, Brunel University London, London, UK

ABSTRACT

Objectives: The capability to 'live well' in people with dementia can be influenced by many factors, including those related to the experiences of their informal caregiver. How caregivers experience their own role can affect not only their well-being but also the way they provide care and hence the experience of the person with dementia. The aim of this study is to identify the potential impact of the caregiver's perception of the caregiving experience on how people with mild to moderate dementia self-rate their QoL, well-being and satisfaction with life.

Method: This study utilised time-point 1 data from 1283 informal caregiver and the 1283 people with dementia whom they provide care from the IDEAL cohort study. Multivariate modelling was used to investigate the associations between measures related to the caregiver's perception of the caregiving experience (caregiving stress, perceived social restrictions, caregiving competence, positive aspects of caregiving, and coping) and the self-ratings of QoL, satisfaction with life, and well-being by the person with dementia.

Results: Lower QoL ratings by the person with dementia were associated with high caregiver stress (−1.98; 95% CI: −2.89, −1.07), high perceived social restrictions (−2.04; 95% CI: −2.94, −1.14) and low caregiving competence (−2.01; 95% CI: −2.95, −1.06). Similar associations were found for satisfaction with life and wellbeing. Positive aspects of caregiving and coping were not associated with outcomes for the person with dementia.

Conclusion: The findings indicate that how the caregiver experiences caregiving can affect the person with dementia. This finding reinforces the importance of providing support to caregivers.

ARTICLE HISTORY
Received 14 December 2018
Accepted 24 March 2019

KEYWORDS
Caregiver stress; competence; satisfaction with life; quality of life; well-being

Informal caregivers are 'the most important resource available for people with dementia' (Department of Health, 2009, p. 12). Recent dementia policy has prioritised enabling people to 'live well' with dementia. To achieve this end the focus has been on improving healthcare and the quality of support offered to people with dementia (e.g. Department of Health, 2009; US Department of Health and Human Services, 2012). However, to provide effective support for people with dementia, it is necessary to identify the factors that can influence people's ability to 'live well'. 'Living well' can be considered a multi-faceted concept; Clare et al. (2014, p. 2) proposed that 'the experience of living well is indexed by positive evaluations of subjective well-being, satisfaction with life, and quality of life (QoL)'. One important aspect of 'living well' is that people with dementia are often cared for by family members or friends (Schulz & Martire, 2004), with caregiving taking place within this social context, where there is a pre-existing relationship between the caregiver and person with dementia (Quinn, Clare, & Woods, 2009). Within this context, it is likely that each member of the dyad will have an influence on the other member's well-being. Indeed, research on people with a chronic illness, including dementia, indicates that 'living well' can be influenced not only by the effects of the condition on the person but also by the effects on caregivers (Institute of Medicine, 2012). Conversely, factors related to the person with dementia have been shown to influence caregivers' well-being (e.g. Farina et al., 2017; Nogueira et al., 2015). This paper will explore the influence of the caregiver's perception of the caregiving experience on how people with dementia self-rate their QoL, satisfaction with life, and well-being.

Dementia changes the dynamics of pre-existing relationships as one member of the dyad takes on the caregiving role and the other member becomes more dependent. Both members of the dyad will be adjusting to the diagnosis of dementia. Conceptual models that have been developed for the dementia field acknowledge that multiple factors can influence a person's capability to 'live well'. Developed for caregivers, the Stress Process Model (SPM; Pearlin, Mullan, Semple, & Skaff, 1990) identifies different aspects of the caregiving experience that could influence outcomes for caregivers. The SPM includes positive self-concepts, including caregiving competence and positive aspects of caregiving, and mediators of the stress process, which involve coping and social support. Whilst the SPM

CONTACT Catherine Quinn c.quinn1@bradford.ac.uk

© 2019 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group
This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

has been a dominant conceptual model in the caregiving field, Judge, Menne, and Whitlatch (2010) identified a dearth of conceptual models to explain the experiences of people with dementia. Judge et al. (2010) adapted the SPM to apply it to people with dementia (SPM-IWD). Research using this model indicates that the different outcomes have unique predictors (Dawson, Powers, Krestar, Yarry, & Judge, 2013). In addition, only a small number of factors included in the model are predictive of the outcomes, indicating that other unidentified factors might influence the well-being and QoL of people with dementia. In particular, although the model acknowledges the role of dyadic strain and the importance of the dyadic relationship, additional factors could be explored such as the potential influence of the caregiver's experience, for example caregiver stress, on the experiences of the person with dementia.

There is some evidence that the caregiver's perception of the caregiving experience can influence how people with dementia rate their capability to 'live well' (e.g. Banerjee et al., 2009; Logsdon, Gibbons, McCurry, & Teri, 2002; Martyr et al., 2018). Most of this research has focused on caregiving burden, with the available evidence indicating that higher caregiver burden is typically associated with lower person with dementia self-rated QoL (e.g. Conde-Sala, Garre-Olmo, Turró-Garriga, López-Pousa, & Vilalta-Franch, 2009; Logsdon et al., 2002); however, other studies have reported non-significant associations (e.g. Gómez-Gallego, Gómez-Amor, & Gómez-García, 2012; Sousa et al., 2013). Little attention has been paid to the influence of other factors relating to caregivers' perception of the caregiving experience. Higher caregiver stress has been associated with lower self-ratings of QoL by the person with dementia (Orgeta, Orrell, Hounsome, Woods, & team, 2015; Woods et al., 2014). Only single studies have explored the influence of either caregiving competence (Logsdon, Gibbons, McCurry, & Teri, 2005) or positive aspects of caregiving (Gitlin, Hodgson, Piersol, Hess, & Hauck, 2014) on the QoL of the person with dementia. In relation to the well-being or satisfaction with life of the person with dementia, no study has explored the influence of caregiving stress, perceived social restrictions, caregiving competence, positive aspects of caregiving, and coping.

In summary, to date no study has explored the combined influence of multiple factors relating to the caregiver's perception of the caregiving experience on how people with dementia self-report their QoL, satisfaction with life, and well-being. In this study we will take a comprehensive look at factors relating specifically to the caregiver's perception of the caregiving experience, drawing on those identified as measuring the caregiving experience in the IDEAL study conceptual model of factors potentially associated with 'living well' (Clare et al., 2014): caregiver stress, perceived social restrictions, caregiver competence, positive aspects of caregiving, and coping. All these factors influence caregiver well-being (e.g.Balducci et al., 2008; Boerner, Schulz, & Horowitz, 2004; Quinn, Clare, & Woods, 2010) and therefore may impact on people with dementia. The aim of this study to identify the potential impact of the caregiver's perception of the caregiving experience on how people with dementia self-report their QoL, well-being and satisfaction with life.

Method

Design

This study utilised data from time-point 1 of the IDEAL cohort study (Clare et al., 2014). IDEAL study participants are people with dementia and their informal caregivers. Data for time-point 1 were collected between July 2014 and August 2016 in 29 National Health Service (NHS) sites within England, Scotland, and Wales (Great Britain). The IDEAL study was approved by the Wales Research Ethics Committee 5 (reference 13/WA/0405), and the Ethics Committee of the School of Psychology, Bangor University (reference 2014 – 11684). The IDEAL study is registered with UKCRN, registration number 16593.

Participants

Participants were people with dementia and their respective informal caregivers. People with dementia were eligible to join the study if they were residing in the community, had a clinical diagnosis of dementia (any sub-type), and a Mini-Mental State Examination score (MMSE; Folstein, Folstein, & McHugh, 1975) of 15 or above, indicating that they were in the mild to moderate stages of dementia. The exclusion criteria for people with dementia were a co-morbid terminal illness, inability to provide informed consent and any potential risks to researchers conducting home visits. If the person with dementia was willing to take part in the study and had an informal caregiver, then the caregiver was approached to take part in the study. The study defined caregiver as the primary caregiver who provides unpaid practical or emotional support. For some people with dementia they did not have an informal caregiving who was willing to participate in the study. In this paper we focus on those cases where the person with dementia participated with an informal caregiver.

Measures

The IDEAL study assessments included an extensive set of measures (for details see Clare et al., 2014). The present study uses a specific sub-set of these measures to address the aims of this specific analysis. Details of the reliability of these measures with this sample are provided in Table 2.

Demographic information

Demographic information was collected from the caregiver on their age, gender, ethnicity, education, kin-relationship to the person with dementia, and numbers of hours per week providing care, and dementia diagnosis. Demographic information was collected from the person with dementia on their age, gender, and education.

Measures completed by the caregiver

Caregiver stress. The 15-item Relatives Stress Scale (Greene, Smith, Gardiner, & Timbury, 1982) is a measure of caregivers' perceived stress resulting from caring for their relatives (example item: Do you ever feel frustrated with your relative/friend?). Items are rated on a 5-point Likert scale ranging from 0 (not at all) to 4 (always/considerably),

with a higher score indicating greater stress. The measure has demonstrated good internal reliability in a sample of caregivers of people with dementia, with a Cronbach's alpha of .85 (Greene et al., 1982).

Perceived social restrictions. Two items were used to explore whether the caregiver felt there was anyone else who could help the caregiver if s/he was ill or needed some respite from caregiving. These items, taken from the social restriction scale, were reported in Balducci et al. (2008) where they were used to measure caregiver role inflexibility. Items are rated on a 3-point scale ranging from 1 (yes, I could find someone quite easily) to 3 (no, there is no one), with lower scores indicating better support. The scale has demonstrated good internal reliability in a sample of caregivers, with a Cronbach's alpha of .89 (Balducci et al., 2008).

Caregiver competence. Competence was measured using the 3-item Caregiving Competence scale (Robertson, Zarit, Duncan, Rovine, & Femia, 2007). This assesses caregivers' perception of the adequacy with which they fulfil their role as a caregiver (example item: How often do you feel that you are doing a good job as a carer?). Items are rated on a 4-point Likert scale ranging from 1 (never) to 4 (all of the time) with higher scores indicating greater competence. The scale has demonstrated good internal reliability in a sample of caregivers of people with dementia, with a Cronbach's alpha of .81 (Robertson et al., 2007).

Positive Aspects of Caregiving. The 9-item Positive Aspects of Caregiving scale (Tarlow et al., 2004) measures the rewards and satisfactions of caregiving (example item: Providing help to my relative/friend has made me feel appreciated). Items are rated on a 5-point Likert scale ranging from 1 (disagree a lot) to 5 (agree a lot), with a higher score indicating more positive appraisals of caregiving. The scale has demonstrated good internal reliability in a sample of caregivers of people with dementia, with a Cronbach's alpha of .89 (Tarlow et al., 2004).

Caregiving coping. Caregiving coping was measured by the single item 'do you feel you cope well as a caregiver?' which was taken from the positive value of caregiving subscale of the Carers of Older People in Europe (COPE) Index (McKee et al., 2003). The item is rated on a 4-point Likert scale ranging from 1 (never) to 4 (always).

Measures of 'living well' completed by the person with dementia (PwD)

'Living well' was measured through ratings of quality of life, satisfaction with life and well-being reported by people with dementia.

Quality of life. The 13-item Quality of Life-Alzheimer's Disease measure (PwD-QoL; Logsdon et al., 2000) is a measure of dementia-specific QoL (example item: How do you feel about your energy level?). Items are rated on a 4-point Likert scale from 1 (poor) to 4 (excellent), with higher scores indicating better QoL. The measure has demonstrated good reliability in a sample of people with dementia, with a Cronbach's alpha of .89 (Thorgrimsen et al., 2003).

Satisfaction with life. The 5-item Satisfaction with Life Scale (PwD-SwLS; Diener, Emmons, Larsen, & Griffin, 1985) elicits a global cognitive judgement about one's life (example item: In most ways my life is close to my ideal). Items are rated on a 7-point scale from 1 (strongly disagree) to 7 (strongly agree), with a higher score indicating better satisfaction with life. The scale has demonstrated good validity and reliability in a sample of older persons (Diener et al., 1985) and in a sample of caregivers of people with dementia (McConaghy & Caltabiano, 2005).

Well-Being. The 5-item World Health Organization-Five Well-Being Index (PwD-WHO-5; Bech, 2004) is a measure of psychological well-being over the last two weeks (example item: I have felt cheerful and in good spirits). Items are rated on a 6-point scale from 0 (at no time) to 5 (all of the time). The scores are summed and transformed into a percentage score, with higher scores indicating better well-being. The scale had moderate internal reliability in a sample of older people (Bonsignore, Barkow, Jessen, & Heun, 2001) and good reliability in a sample of caregivers (Balducci et al., 2008).

Procedure

Participant recruitment and assessment were conducted by researchers from clinical research networks. Participants were recruited from a variety of sources including memory services and Join Dementia Research, a registration service that enables volunteers, including people with dementia, to register their interest in taking part in research (National Institute for Health Research). Potential participants were contacted about the study via telephone and/or postal contact, and those who expressed interest in taking part in the study were visited by a researcher. The researcher completed the eligibility checks and if participants were eligible and agreeable to taking part in the study then the researcher took informed consent and commenced the time-point 1 assessments. People with dementia were administered the assessments whilst caregivers self-completed their assessments. Participants were visited on two further occasions to complete time-point 1 data collection.

Analyses

Preliminary analyses were conducted to test assumptions of normality, linearity, outliers, homoscedasticity, and multicollinearity. As some of the measures were skewed and the distributions deviated from normality, the continuous measures (caregiving stress, perceived social restrictions, caregiving competence, and positive aspects of caregiving) were converted into tertiles. This facilitated comparison between those with high, moderate, and low scores on all the caregiver measures. As only nine participants responded 'never' to the coping question, this category was combined with the 'sometimes' category and re-named as 'low coping'. Similarly, 'often' responses were re-named as 'moderate' coping and 'always' responses were re-named as 'high' coping. Pearson correlations were calculated to explore the associations between the three measures of 'living well'. Since the three measures of 'living well' measures were highly correlated, multivariate modelling was used to investigate differences in self-ratings on measures of 'living well' made by people with dementia across caregiver factors. First, to see if the caregiver factors had individual associations with the measures of 'living well', separate unadjusted models were run for each of the

caregiver factors. These models were then adjusted for covariates relating to the caregiver. These covariates included characteristics of the caregiver (age, gender, caregiver kin-relationship), the caregiving situation (hours per week caregiving) and the dementia diagnosis of the person with dementia. Second, as the caregiver factors of stress, perceived social restrictions, competence, and coping were related to each other, an additional set of multivariate models was applied to investigate whether these factors still had independent relationships with the measures of 'living well' when all these factors were considered together. Caregiving stress, caregiving competence, positive aspects of caregiving, and coping can be considered as factors intrinsic to the caregivers (relating to how they perceive themselves) whilst perceived social restriction is more of an extrinsic factor (relating to how they perceive their situation). All intrinsic factors related to the caregiver were included in one model and then perceived social restriction was added in a further model. Analyses were conducted using Stata 15.1. This study used the IDEAL time-point 1 dataset version 2.

Results

Characteristics of the participating caregivers and people with dementia are shown in Table 1. Of the 1283 caregivers taking part in the study, two-thirds (68.7%) were female and the majority (81%) were spouses/partners. The other types of caregivers (e.g. children, children-in-law, brothers/sisters, grandchildren, nephews/nieces, and step-children) were grouped under 'other family/friends'. Just over half (59.2%) of caregivers provided care for less than 10 hours per week. Of the 1283 people with dementia taking part in the study, just over half were male (58.8%) and the most common diagnosis was Alzheimer's disease (55.7%), followed by mixed Alzheimer's disease and vascular dementia (20.5%). Table 2 reports the participants' scores on the measures. Correlations between the outcome measures indicate that PwD-QoL was strongly correlated with PwD-SwLS ($r = .61$, $n = 1141$ $p < .01$) and PwD-WHO-5 ($r = .69$, $n = 1151$ $p < .01$). PwD-SwLS was strongly correlated with PwD-WHO-5 ($r = .58$, $n = 1237$ $p < .01$).

Table 1. Characteristics of the caregivers and people with dementia.

Demographics	*N*
Caregivers	*n* = 1283
Gender	
Female	881 (68.7%)
Ethnicity	
White British	1228 (96.2%)
Age	369 (28.8%)
<65	
65–69	208 (16.2%)
70–74	267 (20.8%)
75–79	223 (17.4%)
80+	216 (16.8%)
Kin-relationship	
Spouse/partner	1039 (81%)
Other family/friend	244 (19%)
Education[a]	
No qualification	265 (21.5%)
GCSE/equivalent	274 (22.2%)
A level/equivalent	374 (30.4%)
College	319 (25.9%)
Hours of care[b]	
<1 hour	232 (18.8%)
1–10 hours	499 (40.4%)
10+ hours	415 (33.6%)
Other responses	89 (7.2%)
People with dementia	*n* = 1283
Gender	
Female	528 (41.2%)
Age	
<65	103 (8%)
65–69	160 (12.5%)
70–74	232 (18.1%)
75–79	306 (23.9%)
80+	482 (37.6%)
Education[c]	
No qualification	340 (27.2%)
GCSE/equivalent	224 (17.9%)
A level/equivalent	435 (34.8%)
College	252 (20.1%)
MMSE score *M* (*SD*)	23.05 (*SD* = 3.69)
Diagnosis	
Alzheimer's disease	715 (55.7%)
Mixed dementia	263 (20.5%)
Vascular dementia	142 (11.1%)
Frontotemporal dementia	45 (3.5%)
Parkinson's disease dementia	43 (3.4%)
Lewy body dementia	43 (3.4%)
Unspecified/Other dementia	32 (2.5%)

Note. MMSE, Mini-Mental State Examination score; hours of care, hours of care provided on an average day.
[a]Missing data for 51 participants;
[b]Missing data for 48 participants;
[c]Missing data for 32 participants.

Table 3 reports the unadjusted and adjusted associations between the caregiver factors and the measures of 'living well' for the person with dementia. In the unadjusted model there was little difference in scores on the measures of 'living well' in relation to the different levels of both positive aspects of caregiving and coping. For the other measures the main difference in scores occurred between the high and low categories. The observed effect sizes were reduced after adjusting for co-variates; however, the differences between high and low categories for caregiving stress, perceived social restrictions, and caregiving competence remained apparent. Lower PwD-QoL was associated with high caregiving stress (−1.98; 95% CI −2.89, −1.07), high perceived social restrictions (−2.04; 95% CI −2.94, −1.14), and low caregiving competence (−2.01; 95% CI −2.95, −1.06). Lower PwD-SwLS was associated with high caregiving stress (−1.35; 95% CI −2.64, −.44), high perceived social restrictions (−1.77; 95% CI −2.67, −.87), and low caregiving competence (−1.87; 95% CI −2.81, −.92). Lower PwD-WHO-5 was associated with high caregiving stress (−3.84; 95% CI −7.02, −.65), high perceived social restrictions (−2.92; 95% CI −6.09, .24), and low caregiving competence (−4.01; 95% CI −7.34, −.67).

We conducted further adjusted multivariate models were conducted to investigate whether the caregiver factors retained independent relationships with PwD-QoL, PwD-SwL, and PwD-WHO-5 when all the caregiving factors were combined. In the first adjusted model, which contained caregiving stress, caregiving competence, and coping, only caregiving stress and caregiving competence had independent associations with PwD-QoL, PwD-SwL, and PwD-WHO-5, while the effect sizes were considerably attenuated for coping. In the second adjusted model, which contained just caregiving stress and caregiving competence, caregiver stress and competence had independent associations with PwD-QoL, PwD-SwL, and PwD-WHO-5. Building on this model, the third model (reported in Table 4) included perceived social restrictions; the effect sizes of caregiving stress were slightly reduced, but all three

Table 2. Participants' scores on the measures.

Variables	*N* (%)	*M* (*SD*)	Observed range	Cronbach's alpha
Caregiver rated:				
Stress	1198		0–56	.89
Low	427 (35.6)			
Moderate	373 (31.1)			
High	398 (33.2)			
Social restrictions	1233		2–6	.85
Low	592 (48.0)			
Moderate	380 (30.8)			
High	261 (21.2)			
Competence	1238		3–12	.88
Low	297 (24.0)			
Moderate	574 (46.4)			
High	367 (28.6)			
Positive aspects of caregiving	1234		9–45	.91
Low	562 (45.5)			
Moderate	313 (25.4)			
High	359 (29.1)			
Coping	1242		1–4	N/A
Low	313 (25.2)			
Moderate	586 (47.2)			
High	343 (27.6)			
Person with dementia rated				
QoL-AD	1164	36.89 (5.93)	17–52	.81
SwLS	1248	26.50 (5.9)	6–35	.82
WHO-5	1260	61.43 (20.52)	0–100	.79

Note. QoL-AD, Quality of Life in Alzheimer's disease; SwLS, Satisfaction with Life Scale; WHO-5, World Health Organisation - Five Well-being Index.

Table 3. Associations between individual caregiver factors and ratings of quality of life, satisfaction with life and well-being by the person with dementia.

		QoL-AD	SwLS	WHO-5
Unadjusted models		Coefficient (95% CI)	Coefficient (95% CI)	Coefficient (95% CI)
Stress	Low	—	—	—
	Moderate	−1.1 (1.95, −.24)*	−.84 (−1.7, .02)	−3.14 (−6.11, −.16)*
	High	−2.71 (−3.56, −1.86)**	−1.81 (−2.66, −.96)**	−4.88 (−7.83, −1.93)**
Social restrictions	Low	–	–	–
	Moderate	−.35 (−1.15, .46)	−.22 (−1.02, .58)	−.65 (−3.45, 2.15)
	High	−2.15 (−3.06, −1.25)**	−1.83 (−2.73, −.92)**	−3.31 (−6.45, −.16)*
Competence	High	–	–	–
	Moderate	−.84 (−1.65, −.02)*	−.57 (−1.37, .24)	−1.23 (−4.05, 1.6)
	Low	−2.22 (−3.17, −1.26)**	−2.19 (−3.14, −1.24)**	−4.30 (−7.61, −.99)*
Positive aspects of caregiving	High	—	—	—
	Moderate	−.61 (−1.56, .34)	−.69 (−1.63, .25)	−1.96 (−5.23, 1.3)
	Low	−.68 (−1.50, .15)	−1.01 (−1.83, −.19)*	−2.87 (−5.72, −.02)*
Coping	High	–	–	–
	Moderate	−.54 (−1.37, .3)	−.7 (−1.52, .13)	−.61 (−3.49, 2.27)
	Low	−1.41 (−2.38, −.45)**	−1.48 (−2.43, −.53)**	−3.3 (−6.62, .03)
Models adjusted for caregiver gender, caregiver age, kin-relationship, hours per week caregiving, and dementia diagnosis				
Stress	Low	—	—	—
	Moderate	−.64 (−1.51, .24)	−.61 (−1.49, .27)	−2.17 (−5.25, .91)
	High	−1.98 (−2.89, −1.07)**	−1.35 (−2.64, −.44)**	−3.84 (−7.02, −.65)*
Social restrictions	Low	–	–	–
	Moderate	−.18 (−.98, .62)	−.05 (−.85, .74)	−.08 (−2.89, 2.73)
	High	−2.04 (−2.94, −1.14)**	−1.77 (−2.67, −.87)**	−2.92 (−6.09, .24)
Competence	High	–	–	–
	Moderate	−.47 (−1.29, .35)	−.23 (−1.04, .59)	−.25 (−3.13, 2.62)
	Low	−2.01 (−2.95, −1.06)**	−1.87 (−2.81, −.92)**	−4.01 (−7.34, −.67)**
Positive aspects of caregiving	High	—	—	—
	Middle	−.62 (−1.56, .31)	−.84 (−1.78, .1)	−2.41 (−5.7, .87)
	Low	−.76 (−1.59, .07)	−.91 (−1.74, −.08)*	−3.12 (−6.02, −.22)*
Coping	High	–	–	–
	Moderate	−.09 (−.93, .74)	−.28 (−1.11, .55)	.69 (−2.23, 3.61)
	Low	−1.27 (−2.22, −.32)*	−1.26 (−2.20, −.31)*	−3.41 (−6.75, −.07)*

Note. QoL-AD, Quality of Life in Alzheimer's disease; SwLS, Satisfaction with Life Scale; WHO-5, World Health Organisation - Five Well-being Index.
*$p < .05$,
**$p < .001$.

measures were still independently related to PwD-QoL, PwD-SwL, and PwD-WHO-5.

Discussion

This is the first study that we are aware of that has explored the combined influence of multiple factors relating to the caregiving experience on the QoL, satisfaction with life, and well-being of a large cohort of community-dwelling people with mild to moderate dementia. Previously studies that have included caregiver factors have tended to include single factors, with a focus on examining differences between self and informant ratings or on measure validation (e.g. Gómez-Gallego et al., 2012). There has also been a tendency to focus on the self-rated QoL of the person with dementia as an outcome, with little research

Table 4. Fully adjusted model showing associations between stress, competence, and social restriction with ratings of quality of life, satisfaction with life and well-being by the person with dementia.

		QoL-AD Coefficient (95% CI)	SwLS Coefficient (95% CI)	WHO-5 Coefficient (95% CI)
Model adjusted for caregiver gender, caregiver age, kin-relationship, hours per week caregiving, and dementia diagnosis				
Stress	Low	–	–	–
	Moderate	−.18 (−1.08, .72)	−.21 (−1.11, .69)	−1.33 (−4.51, 1.85)
	High	−1.16 (−2.15, −.18)*	−1.53 (−2.56, −.50)*	−2.30 (−5.79, 1.19)
Social restrictions	Low	–	–	–
	Moderate	.17 (−.65, .99)	.20 (−.62, 1.03)	.46 (−2.45, 3.37)
	High	−1.60 (−2.54, −.66)*−	−1.43 (−2.38, −.49)	−2.27 (−5.6, 1.06)
Competence	High	–	–	–
	Moderate	−.19 (−1.04, .65)	−.12 (−.96, .73)	.04 (−2.95, 3.03)
	Low	−1.45 (−2.48, −.43)*	−1.53 (−2.56, −.50)*	−3.25 (−6.87, .38)

Note. QoL-AD: Quality of Life in Alzheimer's disease; SwLS: Satisfaction with Life Scale; WHO-5: World Health Organisation - Five Well-being Index.
*$p < .05$.

using well-being or life satisfaction as outcomes for the person with dementia (Martyr et al., 2018). The findings of this study indicate that caregiving stress, perceived social restrictions, and caregiving competence were associated with outcomes for the person with dementia and all had similar effect sizes. Positive aspects of caregiving and coping were not associated with outcomes for the person with dementia. For caregiving stress, perceived social restrictions, and caregiving competence, the main difference that was observed occurred between caregivers in the high and low categories. In comparison to those reporting low caregiving stress and perceived social restrictions, where caregivers reported high caregiving stress and perceived social restrictions, this was associated with lower self-ratings of QoL, satisfaction with life and well-being by the person with dementia. In comparison to those reporting high caregiving competence, where caregivers reported low caregiver competence, this was associated with lower self-ratings of QoL, satisfaction with life and well-being by the person with dementia.

Research has consistently found that caregivers' perceptions of stress can have a detrimental impact on a caregiver's well-being (e.g. Farina et al., 2017). Models of stress and coping (e.g. Lazarus & Folkman, 1984) identify that stressors and how people appraise these stressors can have an influence on their coping responses, which subsequently have an influence on overall well-being. Extending this, theories of dyadic coping (Bodenmann, 1997) imply that the caregiver's perceptions of stress and subsequent coping responses could influence the responses of the person with dementia. The association between caregiving stress and the outcomes completed by the person with dementia may possibly be due to caregiving stress influencing the caregiver's behaviour. This pattern is seen in the different construct of caregiver burden, which relates to the disruptions in daily routines, relationships and other activities due to caregiving. For example higher caregiving burden has been related to more abusive behaviour and use of a negative or critical emotional tone towards the person with dementia (Cooper et al., 2010; Hinrichsen & Niederehe, 1994). It is likely that the association between caregiving stress and the outcomes for the person with dementia is bi-directional; caring for someone with lower levels of 'living well' may result in increased caregiver stress.

Given that the effect size for caregiving stress was slightly reduced with the inclusion of perceived social restrictions, some of the association between caregiving stress and outcomes for the person with dementia may be linked to perceived social restrictions. If the caregiver's perceptions of stress are the result of the demands of caregiving then it is feasible that having fewer social restrictions, as a result of receiving more support with caregiving, would reduce caregivers' stress levels. There is some evidence to support this association; interventions that incorporate respite use or day care have resulted in reduced burden (Chappell & Reid, 2002). Lack of support with caregiving has also been linked to more negative perceptions of caregiving (Balducci et al., 2008) and so may have an impact on caregivers' well-being and the level of care they provide. Equally, if the caregiver does not receive any additional help with caregiving then the person with dementia is solely reliant on the caregiver for care and is more likely to be affected by the caregiver's well-being and caregiving style. Caregiving competence had an independent association with outcomes for the person with dementia. It is possible that caregivers' level of competence is influencing their caregiving behaviour and in turn influencing the person with dementia. This would be in line with the pathway proposed by Social Cognitive Theory (Bandura, 1986). Equally, there may be a bi-directional relationship; if the person with dementia is not 'living well' this may then lead to feelings of not providing sufficient support and reduced confidence in the caring role for the caregiver.

Perceptions of positive aspects of caregiving were not associated with 'living well'. It has been suggested that caregiving competence and positive aspects of caregiving are related concepts (Carbonneau, Caron, & Desrosiers, 2010) yet the current study highlights differences in terms of their associations with the outcomes for the person with dementia. It may be that identifying positive aspects of caregiving has benefits for caregivers in terms of their own mood and well-being (e.g. Quinn, Clare, McGuinness, & Woods, 2012; Quinn et al., 2010) but that this does not translate to benefits for the person with dementia in terms of his/her ability to live well. It is also possible that the benefits for the person with dementia are in other domains, such as the quality of relationship between the caregiver and person with dementia (Carbonneau et al., 2010). There has been very little research on the influence of the positive aspects of caregiving on outcomes for the person with dementia (Quinn, 2016), and the findings from this study suggest a need for a better understanding how identifying positive aspects of caregiving influences caregivers' behaviour. For instance, Lim, Griva, Goh, Chionh, and Yap (2011) reported that identifying positive aspects of

caregiving was associated with using encouragement as a dementia management style.

In considering the findings of the current study it is important to reflect on the strengths and limitations. This study involved a large cohort of caregivers and people with mild-to-moderate dementia. The study included people with different dementia diagnoses and caregivers who had differing kin-relationships to the person with dementia. The sample was predominantly white British and further research is required to explore the identified associations in a more ethnically diverse sample. This study was a cross-sectional study and thus can only demonstrate associations between variables in this study. However, IDEAL is a longitudinal study and so we will be able to explore how the associations among these factors change over time. In terms of the measures used, caregiving coping was measured by a single item which focused on a global view of coping. Whilst a concise measure was selected due to the large numbers of variables being explored in the IDEAL study, we recognize that there are more substantive measures of coping that can explore coping styles, more context-specific coping or appraisals of coping efficacy (Gignac & Gottlieb, 1996; Kneebone & Martin, 2003). The participants with dementia self-rated their quality of life, satisfaction with life, and well-being. There has been debate on the reliability of subjective ratings made by people with dementia; however, self-reported QoL by people with mild (Woods et al., 2014) and moderate to severe dementia (Hoe, Katona, Roch, & Livingston, 2005) has been shown to be reliable.

This study specifically focused on the influence of caregivers' perceptions of the caregiving experience on the person with dementia. Future studies with IDEAL data will explore the dyadic influence of shared factors on 'living well', using measures that have been administered to both person with dementia and caregivers. We recognize that the caregiving experience will only be one part of the picture and that many factors influence outcomes for the person with dementia. For instance, the conceptual framework of QoL developed by Lawton (1994) identified four main domains that were important to QoL: psychological well-being, behavioural competence, the objective environment, and perceived QoL. Whilst the caregiving experience could be encapsulated under the objective environment (Logsdon et al., 2002), there are other domains that will also influence the person's QoL. However, the findings from the current study imply that selective aspects of the caregiving experience are associated with outcomes for the person with dementia. This finding is important in terms the development of interventions and support services for both people with dementia and caregivers.

Implications

The findings of this study provide preliminary evidence that caregivers' perceptions of stress, social restrictions, and competence can influence the QoL, satisfaction with life and well-being of the people with dementia for whom they provide care. Caregivers' perceptions of stress, social restrictions, and caregiving competence can be considered as modifiable and amenable to change. Thus, it is important to consider the influence of these specific caregiver factors when developing interventions and supportive services aimed at improving the QoL, satisfaction with life and well-being of people with dementia. The findings highlight the need to provide support to caregivers to decrease caregiving stress and enhance feelings of competence, to improve not just caregiver well-being but also the experience of the person with dementia receiving care. Providing effective support to caregivers is important, given findings that poorer caregiver mental health is a unique predictor of mortality people with neurodegenerative disease (Lwi, Ford, Casey, Miller, & Levenson, 2017). There have been some interventions developed to improve caregivers' competence that focus on skills training (e.g. Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001). There have also been interventions developed to reduce caregivers' stress that focus on coping skills (Kajiyama et al., 2013). In addition, improving caregivers' emotional and physical health may also help to alleviate the effects of caregiving stress. This reflects current public health recommendations (Public Health England, 2013) which focuses on improving well-being and opportunities for physical activity. Caregiving may restrict opportunities for engaging in health-related activities and there is evidence that physical activity can reduce burden in caregivers (Orgeta & Miranda-Castillo, 2014). There is less clear evidence about the effectiveness of interventions that focus on reducing social restrictions by improving support with care or even social support (e.g. Chien & Lee, 2011). Support may be formal or informal; it is important to consider not just the amount of support being offered but the quality of support. In terms of formal support, the findings indicate that caregivers would benefit from information about the resources and support services available to them, such as respite care.

Traditionally interventions have been targeted at one member of the dyad, and interventions targeting caregivers can have secondary benefits for the person with dementia by, for instance, improving symptoms (Pinquart & Sörensen, 2006). However, rather than just focusing on the caregiver, our findings highlight the importance of providing support for both members of the dyad. There has been a shift towards the development of more dyadic interventions that aim to support both the caregiver and the person with dementia. Providing interventions to the dyad is considered to be more effective because it is then possible to incorporate the 'synergistic' relationship between the dyad (Laver, Milte, Dyer, & Crotty, 2016). There is some evidence that such approaches can have benefits for both members of the dyad (e.g. Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; Van't Leven et al., 2013). However, the evidence base is primarily from people in the mild to moderate stages and there is less evidence on effectiveness of these types of interventions in people in the late stages of dementia. In selecting a dyadic intervention it is important to consider the difficulties experienced by the dyad and to select the most appropriate type of intervention accordingly (Van't Leven et al., 2013); therefore, there is a need for more tailored interventions.

In conclusion, we believe that this is the first study to explore the combined influence of multiple caregiver factors relating to caregiver's perception of the caregiving experience on the QoL, satisfaction with life, and well-being of community-dwelling people with mild-to-

moderate dementia. The findings demonstrate the influence of caregiving stress, perceived social restrictions, and caregiving competence on the self-rated QoL, well-being and satisfaction with life of the person with dementia. This study contributes new information about factors to include in interventions to improve outcomes for the person with dementia. In particular, this study highlights the need for support services and interventions to take into account the influence of caregiver factors on the outcomes for the person with dementia. Caregiver stress, perceived social restrictions, and caregiving competence are all modifiable factors that could be appropriately targeted through support services and interventions.

Acknowledgements

We would like to acknowledge the support of the following research networks: NIHR Dementias and neurodegeneration specialty (DeNDRoN) in England, the Scottish Dementia Clinical Research Network (SDCRN) and Health and Care Research Wales. We gratefully acknowledge the local principal investigators and researchers involved in participant recruitment and assessment within these networks. We thank the members of the ALWAYs group and the Project Advisory Group for their support with the study. We are extremely grateful to Yu-Tzu Wu and Fiona Matthews for their support with statistical analyses and feedback on drafts of the manuscript.

Author contributions

Authors Quinn, Nelis, Martyr, Morris, Victor, and Clare, were involved in the original conception and design of the project. The lead author Quinn is responsible for the data analysis and interpretation, and for drafting the article. All authors have contributed to the critical revision of the article, and provided final approval of the version to be published.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

The IDEAL study is funded by the Economic and Social Research Council (UK) and the National Institute for Health Research (UK) through grant ES/L001853/2 'Improving the experience of dementia and enhancing active life: living well with dementia' (Investigators: Investigators: L. Clare, I.R. Jones, C. Victor, J.V. Hindle, R.W. Jones, M. Knapp, M. D. Kopelman, R. Litherland, A. Martyr, F. Matthews, R.G. Morris, S.M. Nelis, J. Pickett, C. Quinn, J. Rusted, J. Thom). The support of the ESRC and NIHR is gratefully acknowledged. The IDEAL data will be deposited with the UK Data Archive upon completion of the study. Details on how the data can be accessed will be made available on the project website www.idealproject.org.uk.

ORCID

Catherine Quinn http://orcid.org/0000-0001-9553-853X
Sharon M. Nelis http://orcid.org/0000-0001-9055-3837
Anthony Martyr http://orcid.org/0000-0002-1702-8902
Christina Victor http://orcid.org/0000-0002-4213-3974
Linda Clare http://orcid.org/0000-0003-3989-5318

References

Balducci, C., Mnich, E., McKee, K. J., Lamura, G., Beckmann, A., Krevers, B., … Oberg, B. (2008). Negative impact and positive value in caregiving: Validation of the COPE index in a six-country sample of carers. *The Gerontologist*, *48*(3), 276–286.

Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NJ: Prentice Hall.

Banerjee, S., Samsi, K., Petrie, C. D., Alvir, J., Treglia, M., Schwam, E. M., & del Valle, M. (2009). What do we know about quality of life in dementia? A review of the emerging evidence on the predictive and explanatory value of disease specific measures of health related quality of life in people with dementia. *International Journal of Geriatric Psychiatry*, *24*(1), 15–24.

Bech, P. (2004). Measuring the dimension of psychological general well-being by the WHO-5. *Quality of Life Newsletter*, *32*, 15–16.

Bodenmann, G. (1997). Dyadic coping-a systematic-transactional view of stress and coping among couples: Theory and empirical findings. *European Review of Applied Psychology*, *47*, 137–140.

Boerner, K., Schulz, R., & Horowitz, A. (2004). Positive aspects of caregiving and adaptation to bereavement. *Psychology and Aging*, *19*(4), 668–675.

Bonsignore, M., Barkow, K., Jessen, F., & Heun, R. (2001). Validity of the five-item WHO Well-Being Index (WHO-5) in an elderly population. *European Archives of Psychiatry and Clinical Neuroscience*, *251* (Suppl 2), II27–II31.

Carbonneau, H., Caron, C., & Desrosiers, J. (2010). Development of a conceptual framework of positive aspects of caregiving in dementia. *Dementia*, *9*(3), 327–353.

Chappell, N. L., & Reid, R. C. (2002). Burden and well-being among caregivers: Examining the distinction. *The Gerontologist*, *42*(6), 772–780.

Chien, W. T., & Lee, I. Y. (2011). Randomized controlled trial of a dementia care programme for families of home-resided older people with dementia. *Journal of Advanced Nursing*, *67*(4), 774–787.

Clare, L., Nelis, S. M., Quinn, C., Martyr, A., Henderson, C., Hindle, J. V., … Victor, C. R. (2014). Improving the experience of dementia and enhancing active life-living well with dementia: Study protocol for the IDEAL study. *Health & Quality of Life Outcomes*, *12*(1), 164.

Conde-Sala, J. L., Garre-Olmo, J., Turró-Garriga, O., López-Pousa, S., & Vilalta-Franch, J. (2009). Factors related to perceived quality of life in patients with Alzheimer's disease: The patient's perception compared with that of caregivers. *International Journal of Geriatric Psychiatry*, *24*(6), 585–594.

Cooper, C., Selwood, A., Blanchard, M., Walker, Z., Blizard, R., & Livingston, G. (2010). The determinants of family carers' abusive behaviour to people with dementia: Results of the CARD study. *Journal of Affective Disorders*, *121*(1–2), 136–142.

Dawson, N. T., Powers, S. M., Krestar, M., Yarry, S. J., & Judge, K. S. (2013). Predictors of self-reported psychosocial outcomes in individuals with dementia. *The Gerontologist*, *53*(5), 748–759.

Department of Health. (2009). *Living well with dementia: A national dementia strategy*. London, UK: Department of Health.

Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction With Life Scale. *Journal of Personality Assessment*, *49*(1), 71–75.

Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., … Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimer's & Dementia*, *13*(5), 572–581.

Folstein, M. F., Folstein, F. E., & McHugh, P. R. (1975). "Mini-mental state": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, *12*(3), 189–198. 900265-6

Gignac, M. A., & Gottlieb, B. H. (1996). Caregivers' appraisals of efficacy in coping with dementia. *Psychology and Aging*, *11*(2), 214–225.

Gitlin, L. N., Corcoran, M., Winter, L., Boyce, A., & Hauck, W. W. (2001). A randomized, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia. *The Gerontologist*, *41*(1), 4–14.

Gitlin, L. N., Hodgson, N., Piersol, C. V., Hess, E., & Hauck, W. W. (2014). Correlates of quality of life for individuals with dementia living at home: The role of home environment, caregiver, and patient-related characteristics. *The American Journal of Geriatric Psychiatry*, *22*(6), 587–597.

Gitlin, L. N., Winter, L., Dennis, M. P., Hodgson, N., & Hauck, W. W. (2010). Targeting and managing behavioral symptoms in individuals with dementia: A randomized trial of a nonpharmacological intervention. *Journal of the American Geriatrics Society*, *58*(8), 1465–1474.

Gómez-Gallego, M., Gómez-Amor, J., & Gómez-García, J. (2012). Determinants of quality of life in Alzheimer's disease: Perspective of patients, informal caregivers, and professional caregivers. *International Psychogeriatrics*, *24*(11), 1805–1815.

Greene, J. G., Smith, R., Gardiner, M., & Timbury, G. C. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: A factor analytic study. *Age and Ageing*, *11*(2), 121–126.

Hinrichsen, G. A., & Niederehe, G. (1994). Dementia management strategies and adjustment of family members of older patients. *The Gerontologist*, *34*(1), 95–102.

Hoe, J., Katona, C., Roch, B., & Livingston, G. (2005). Use of the QOL-AD for measuring quality of life in people with severe dementia – The LASER-AD study. *Age and Ageing*, *34*(2), 130–135.

Institute of Medicine. (2012). *Living well with chronic illness: A call for public health action*. Washington, DC: Institute of Medicine.

Judge, K. S., Menne, H. L., & Whitlatch, C. J. (2010). Stress process model for individuals with dementia. *The Gerontologist*, *50*(3), 294–302.

Kajiyama, B., Thompson, L. W., Eto-Iwase, T., Yamashita, M., Di Mario, J., Marian Tzuang, Y., & Gallagher-Thompson, D. (2013). Exploring the effectiveness of an internet-based program for reducing caregiver distress using the iCare Stress Management e-Training Program. *Aging & Mental Health*, *17*(5), 544–554.

Kneebone, I. I., & Martin, P. R. (2003). Coping and caregivers of people with dementia. *British Journal of Health Psychology*, *8*(1), 1–17.

Laver, K., Milte, R., Dyer, S., & Crotty, M. (2016). A systematic review and meta-analysis comparing carer focused and dyadic multicomponent interventions for carers of people with dementia. *Journal of Aging and Health*, *29*, 1308–1349.

Lawton, M. P. (1994). Quality of Life in Alzheimer disease. *Alzheimer Disease & Associated Disorders*, *8* (Suppl 3), 138–150.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York, NY: Springer.

Lim, J., Griva, K., Goh, J., Chionh, H. L., & Yap, P. (2011). Coping strategies influence caregiver outcomes among asian family caregivers of persons with dementia in Singapore. *Alzheimer Disease & Associated Disorders*, *25*(1), 34–41.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2000). Quality of life in Alzheimer's disease: Patient and caregiver reports. In S. M. Albert & R. G. Logsdon (Eds.), *Assessing quality of life in dementia* (pp. 17–30). New York, NY: Springer.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine*, *64*(3), 510–519.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2005). Assessing changes in quality of life in Alzheimer's disease. In B. Vellas, M. Grundman, H. Feldman, L. J. Fitten, B. Winblad, & E. Giacobini (Eds.), *Research and practice in Alzheimer's disease* (Vol. 10, pp. 221–225). Paris, France: Serdi Publisher.

Lwi, S. J., Ford, B. Q., Casey, J. J., Miller, B. L., & Levenson, R. W. (2017). Poor caregiver mental health predicts mortality of patients with neurodegenerative disease. *Proceedings of the National Academy of Sciences*, *114*(28), 7319–7324.

Martyr, A., Nelis, S. M., Quinn, C., Wu, Y.-T., Lamont, R. A., Henderson, C., … Clare, L. (2018). Living well with dementia: A systematic review and correlational meta-analysis of factors associated with quality of life, well-being, and life satisfaction in people with dementia. *Psychological Medicine*, *48*, 2130–2139.

McConaghy, R., & Caltabiano, M. L. (2005). Caring for a person with dementia: Exploring relationships between perceived burden, depression, coping and well-being. *Nursing and Health Sciences*, *7*(2), 81–91.

McKee, K., Philp, I., Lamura, G., Prouskas, C., Öberg, B., Krevers, B., … Nolan, M. (2003). The COPE index-a first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers of older people. *Aging & Mental Health*, *7*(1), 39–52.

National Institute for Health Research. Retrieved from https://www.joindementiaresearch.nihr.ac.uk/

Nogueira, M. M. L., Neto, J. P. S., Sousa, M. F. B., Santos, R. L., Rosa, R. D. L., Belfort, T., … Dourado, M. C. N. (2015). Spouse-caregivers' quality of life in Alzheimer's disease. *International Psychogeriatrics*, *27*(05), 837–845.

Orgeta, V., & Miranda-Castillo, C. (2014). Does physical activity reduce burden in carers of people with dementia? A literature review. *International Journal of Geriatric Psychiatry*, *29*(8), 771–783.

Orgeta, V., Orrell, M., Hounsome, B., Woods, B., & Team, R. (2015). Self and carer perspectives of quality of life in dementia using the QoL-AD. *International Journal of Geriatric Psychiatry*, *30*(1), 97–104.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, *30*(5), 583–594.

Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: Which interventions work and how large are their effects? *International Psychogeriatrics*, *18*(04), 577–595.

Public Health England. (2013). *Introduction to the Public Health England health and well-being directorate*. Retrieved from https://www.gov.uk/government/publications/health-and-wellbeing-introduction-to-the-directorate

Quinn, C. (2016). Positive experiences in dementia caregiving. In C. Clarke & E. Wolverson (Eds.), *Positive psychology approaches to dementia* (pp. 232–252). London, UK: Jessica Kingsley Publishers.

Quinn, C., Clare, L., McGuinness, T., & Woods, R. T. (2012). The impact of relationships, motivations, and meanings on dementia caregiving outcomes. *International Psychogeriatrics*, *24*(11), 1816–1826.

Quinn, C., Clare, L., & Woods, B. (2009). The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging & Mental Health*, *13*(2), 143–154.

Quinn, C., Clare, L., & Woods, R. T. (2010). The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: A systematic review. *International Psychogeriatrics*, *22*(01), 43–55.

Robertson, S. M., Zarit, S. H., Duncan, L. G., Rovine, M. J., & Femia, E. E. (2007). Family caregivers' patterns of positive and negative affect. *Family Relations*, *56*(1), 12–23.

Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry*, *12*(3), 240–249.

Sousa, M. F. B., Santos, R. L., Arcoverde, C., Simões, P., Belfort, T., Adler, I., … Dourado, M. C. N. (2013). Quality of life in dementia: The role of non-cognitive factors in the ratings of people with dementia and family caregivers. *International Psychogeriatrics*, *25*(07), 1097–1105.

Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Rubert, M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving: Contributions of the REACH project to the development of new measures for Alzheimer's caregiving. *Research on Aging*, *26*(4), 429–453.

Thorgrimsen, L., Selwood, A., Spector, A., Royan, L., Lopez, M. D., Woods, R. T., & Orrell, M. (2003). Whose quality of life is it anyway? The validity and reliability of the quality of life-Alzheimers disease (QoL-AD) scale. *Alzheimer Disease & Associated Disorders*, *17*(4), 201–208.

US Department of Health and Human Services. (2012). *National plan to address Alzheimer's disease*. Retrieved from https://aspe.hhs.gov/pdf-document/national-plan-address-alzheimers-disease.

Van't Leven, N., Prick, A. E., Groenewoud, J. G., Roelofs, P. D., de Lange, J., & Pot, A. M. (2013). Dyadic interventions for community-dwelling people with dementia and their family caregivers: A systematic review. *International Psychogeriatrics*, *25*(10), 1581–1603.

Woods, R. T., Nelis, S. M., Martyr, A., Roberts, J., Whitaker, C. J., Markova, I., … Clare, L. (2014). What contributes to a good quality of life in early dementia? Awareness and the QoL-AD: A cross-sectional study. *Health and Quality of Life Outcomes*, *12*(1), 94.