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

Anthony Martyr[1,2], Sharon M. Nelis[1,2], Catherine Quinn[1,2], Yu-Tzu Wu[1,2], Ruth A. Lamont[1,2], Catherine Henderson[3], Rachel Clarke[4,5], John V. Hindle[6,7], Jeanette M. Thom[8], Ian Rees Jones[9], Robin G. Morris[10], Jennifer M. Rusted[4], Christina R. Victor[11] and Linda Clare[1,2,12]

[1]School of Psychology, University of Exeter, EX4 4QG, UK; [2]PenCLAHRC, Institute of Health Research, University of Exeter Medical School, EX1 2LU, UK; [3]Personal Social Services Research Unit, London School of Economics and Political Science, WC2A 2AE, UK; [4]School of Psychology, University of Sussex, BN1 9RH, UK; [5]School of Education and Social Work, University of Sussex, BN1 9RH, UK; [6]School of Psychology, Bangor University, LL57 2AS, UK; [7]Department of Care for the Elderly, Betsi Cadwaladr University Health Board, Llandudno, LL30 1LB, UK; [8]School of Medical Sciences, University of New South Wales, NSW 2052, Australia; [9]Wales Institute of Social and Economic Research, Data and Methods, Cardiff University, CF10 3BB, UK; [10]Department of Psychology, King's College London Institute of Psychiatry, Psychology and Neuroscience, London, SE5 8AF, UK; [11]Department of Clinical Sciences, Brunel University, UB8 3PH, UK and [12]Wellcome Centre for Cultures and Environments of Health, University of Exeter, Exeter, UK

Abstract

Current policy emphasises the importance of 'living well' with dementia, but there has been no comprehensive synthesis of the factors related to quality of life (QoL), subjective well-being or life satisfaction in people with dementia. We examined the available evidence in a systematic review and meta-analysis. We searched electronic databases until 7 January 2016 for observational studies investigating factors associated with QoL, well-being and life satisfaction in people with dementia. Articles had to provide quantitative data and include ⩾75% people with dementia of any type or severity. We included 198 QoL studies taken from 272 articles in the meta-analysis. The analysis focused on 43 factors with sufficient data, relating to 37639 people with dementia. Generally, these factors were significantly associated with QoL, but effect sizes were often small (0.1–0.29) or negligible (<0.09). Factors reflecting relationships, social engagement and functional ability were associated with better QoL. Factors indicative of poorer physical and mental health (including depression and other neuropsychiatric symptoms) and poorer carer well-being were associated with poorer QoL. Longitudinal evidence about predictors of QoL was limited. There was a considerable between-study heterogeneity. The pattern of numerous predominantly small associations with QoL suggests a need to reconsider approaches to understanding and assessing living well with dementia.

Introduction

Dementia refers to a group of progressive brain disorders that result in multiple cognitive and behavioural impairments (Ballard *et al.* 2011). Enabling people with dementia to 'live well' with the condition is a priority for policy and practice (Department of Health, 2009). Living well with chronic illness and disability is viewed by the Institute of Medicine (2012) as 'the best achievable state of health that encompasses all dimensions of physical, mental and social well-being' such that 'to live well takes on a unique and equally important personal meaning, which is defined by a self-perceived level of comfort, function and contentment with life' (p. 32). It is important to gain a clear understanding of the extensive range of factors that may influence ability to live well with dementia in order to identify potential targets for intervention.

In instances where it has been discussed explicitly (e.g. Small, 2007), the concept of 'living well' with dementia has been equated with experiencing a good quality of life (QoL). Living well can however mean more to an individual than current QoL. A sense of subjective well-being can be also associated with living well. Likewise, living well can encompass the experience of a life that is and has been lived well – life satisfaction. The constructs of QoL, subjective well-being and life satisfaction are inter-related but encompass distinct elements (Clare *et al.* 2014a).

Subjective well-being refers to both a positive cognitive appraisal of one's current situation and the experience of an appropriate balance of positive and negative emotions (Diener &

Chan, 2011). In line with this definition, Kitwood's model of personhood (1997) emphasises the way in which interactions and environments contribute to enhancing or detracting from well-being for people with dementia. Subjective perceptions of satisfaction with life reflect the experience of meaning and purpose, the ability to experience continued personal growth, a sense of being in control of one's life, active social participation and happiness (St. John & Montgomery, 2010).

QoL is sometimes conceptualised specifically in relation to health (health-related QoL, HRQoL) (Albert et al. 2001). This is a narrow formulation, however, and given the pervasive effects of dementia, there is likely to be considerable overlap between specific HRQoL and more generic elements of QoL (Wilson & Cleary, 1995). The World Health Organisation (WHO) defines QoL much more broadly as 'an individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by a person's physical health, psychological state, level of independence social relationships and their relationship to salient features of their environment' (p. 1) (World Health Organization, 1995). There is no single accepted theoretical model underlying the conceptualisation and assessment of QoL in dementia, but the most influential formulation is Lawton's dementia-specific framework (1994), which recognises that adequate measurement of QoL requires evaluation of multiple dimensions of a person's life, presenting a broad conceptualisation that accords well with the WHO definition.

Life satisfaction and subjective well-being have not been studied in depth in people with dementia, with a few important exceptions (Zank & Leipold, 2001). QoL has been investigated more substantially, but it has been argued that nevertheless little is known about the QoL of people with dementia, particularly those with more severe conditions (Kane et al. 2003; Banerjee et al. 2009; Cordner et al. 2010), or about whether QoL changes over time as dementia severity increases. In contrast, QoL can be assessed using either generic or dementia-specific measures, of which there are several available (Ready & Ott, 2003; Ettema et al. 2005; Bowling et al. 2015; Algar et al. 2016; Missotten et al. 2016). Although many of these measures share content themes and conceptual underpinnings (Missotten et al. 2016), different measures may yield different results. These methodological limitations and complexities make it difficult to draw clear conclusions about factors associated with aspects of living well with dementia.

While life satisfaction is typically assessed by self-report and well-being is typically assessed by informant ratings, QoL in contrast may be assessed either directly by self-report or by means of informant or proxy ratings made by family or health care professionals. Self-report by people with mild (Woods et al. 2014) and moderate-to-severe dementia (Hoe et al. 2005) has been shown to be reliable, though reliability may depend on which measure is used (Ready & Ott, 2003) and dementia severity. Comparison of self- and informant ratings in situations where both can be obtained indicates that informant ratings are typically more negative than self-ratings (Beer et al. 2010; Moyle & O'Dwyer, 2012; Crespo et al. 2013), and this has implications for how we evaluate informant reports of QoL in people with very severe dementia where only informant or proxy ratings are possible. Furthermore, different informants may have different perspectives; for example, ratings made by family carers and paid/professional carers appear to be associated with different factors (Clare et al. 2014b; Edelman et al. 2005).

Previous reviews have focused on specific aspects of QoL in dementia, including dementia-specific HRQoL (Banerjee et al. 2009), measurement (Ready & Ott, 2003; Ettema et al. 2005; Bowling et al. 2015; Algar et al. 2016; Missotten et al. 2016), residential care (Lawrence et al. 2012; Moyle & O'Dwyer, 2012; Beerens et al. 2013; Robertson et al. 2017), qualitative accounts (O'Rourke et al. 2015a), and a recent narrative overview (Jing et al. 2016). To date, however, there has been no comprehensive systematic review and meta-analysis of factors associated with QoL, well-being and life satisfaction for people with dementia. A careful and comprehensive review is needed to summarise the evidence. In this systematic review and meta-analysis, we examined evidence from quantitative observational studies in order to identify factors associated with QoL, well-being and life satisfaction in people with dementia.

Method

Search strategy

We searched PubMed, CINAHL, Web of Science, PsycNET, AgeInfo, Zetoc, Social Care Online and OpenGrey for English-language publications until 7 January 2016. The search comprised two strings. The first string comprised: (well-being OR wellbeing OR life satisfaction OR quality of life OR *QoL* OR Health Status OR ADRQL OR Apparent Emotion Scale OR BASQID OR CDQLP OR Discomfort Scale OR Duke Health Profile OR DHP OR EQ-5D OR Health Utilities Index OR HUI* OR Nottingham Health Profile OR NHP OR Pleasant Events Schedule-AD OR Progressive Deterioration Scale OR PWB-CIP OR SF-12 OR SF-36 OR ICECAP OR QUALIDEM OR QUALID) AND (dementia OR Alzheimer* OR Parkinson* OR Lewy OR Fronto). The second search string was designed to identify articles in residential care settings that may not mention dementia in the title or abstract and comprised: (well-being OR wellbeing OR life satisfaction OR quality of life OR *QoL* OR health status) AND (nursing home OR long term care OR assisted living OR residential living OR care home OR respite OR day care). Names of specific measures used in the searches were derived from two previous reviews (Ready & Ott, 2003; Ettema et al. 2005). No date restrictions were imposed. We examined reference lists of review articles identified in the searches and searched online for additional publications by first authors of included studies. The review protocol was registered with PROSPERO: CRD42014013633.

Inclusion and exclusion criteria

The population of interest was people with a diagnosis of dementia, irrespective of type, severity, age or living situation. We included observational studies reporting cross-sectional and/or longitudinal associations between specific variables and scores on a standardised questionnaires or rating scales measuring QoL, life satisfaction or well-being. We excluded studies where fewer than 75% of participants had dementia, and intervention studies that did not provide baseline data.

Procedure

Figure 1 shows the article selection process. Title, abstract and full-text screening were conducted by two independent reviewers using a structured proforma, and any disagreements were referred
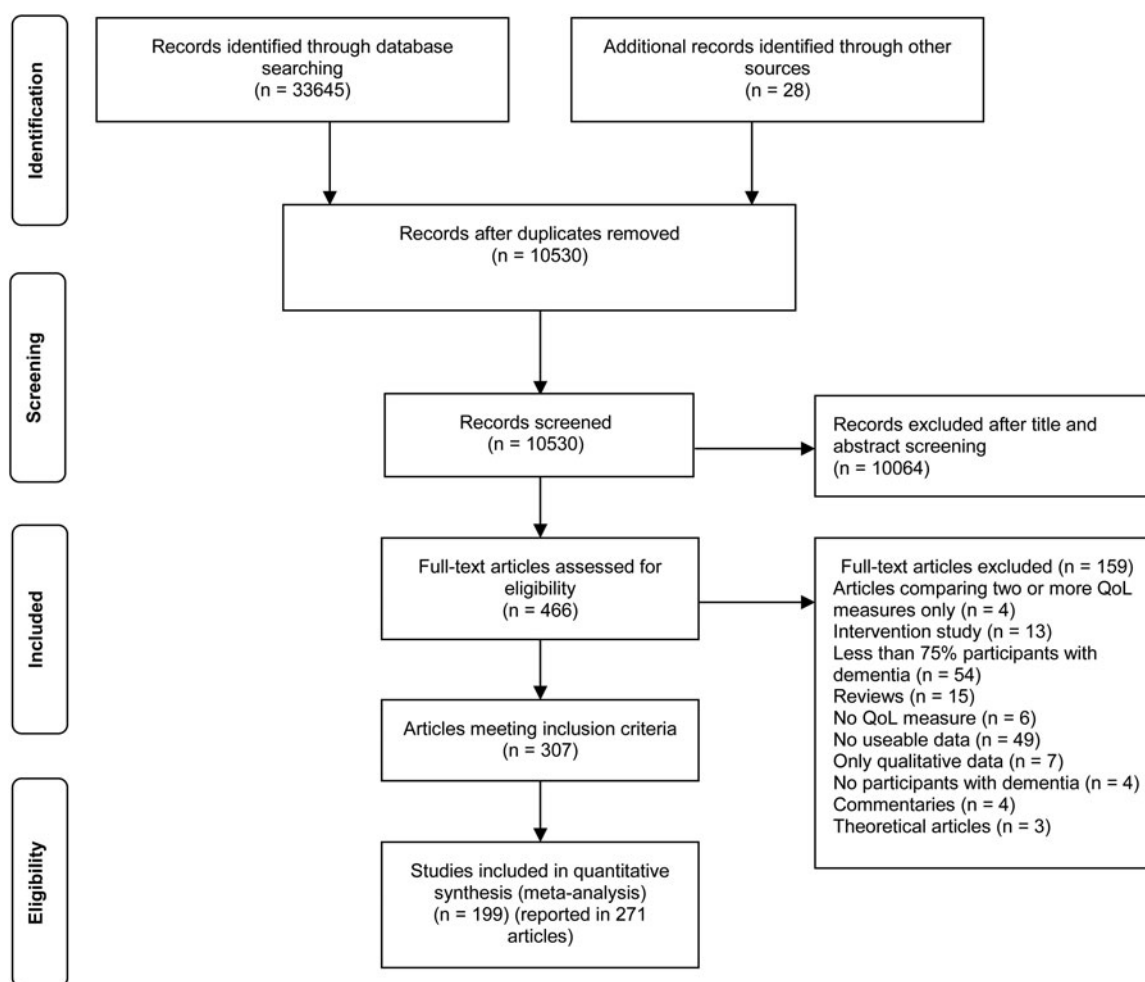
Fig. 1. Flow diagram showing process of study selection.

to a third individual for resolution. Online Supplementary Table S1 provides a list of studies excluded at the full-text screening stage, with reasons. Study quality was assessed by two independent reviewers using a checklist adapted from existing measures (DuRant, 1994; Downs & Black, 1998; Zaza et al. 2000; Sanderson et al. 2007); see online Supplementary Table S2. Scores from the quality assessment of each article were summed; articles that scored 19 or lower were judged to be of poor quality, articles that scored between 20 and 25 were judged to be of satisfactory quality and articles that scored 26 or greater were judged to be of good quality. A structured proforma was used for data extraction.

A description of each outcome measure used in the included studies was taken from either the relevant measure development article or, if this was unavailable, from the most comprehensive description of the measure provided in an included article. Based on this description, each measure was classified as assessing either 'general QoL', 'general HRQoL', 'dementia-specific QoL/HRQoL', 'life satisfaction' or 'subjective well-being'. This process was conducted by three authors working independently, with any disagreements being referred to a fourth individual for resolution.

Where multiple articles reported data from the same study, details for each factor were taken from the article reporting the largest sample size. If an article included data from two sources

[e.g. two different datasets were analysed separately (e.g. Trigg et al. 2007; Li et al. 2013) or data were analysed separately for mild and moderate dementia (e.g. Novelli & Caramelli, 2010)], these were classed as separate studies for the purposes of the analysis. We extracted correlational data provided in study reports or regression data, standardised β (Peterson & Brown, 2005), odds ratios, p values, or t or F statistics converted to correlations, adopting a standardised correlation direction to facilitate comparison (Borenstein et al. 2009).

Statistical analysis

Meta-analysis for each factor was undertaken where comparable data were available from at least five studies. All computations were based on Fisher's z transformations and were conducted using Comprehensive Meta-Analysis 2 (Borenstein et al. 2005) software which calculated average z scores and p values, weighted effect r values and 95% confidence intervals. A two-sided 5% significance level was applied. Multiple within-study correlations were averaged to correct for violations of independence, so that all available data could be included in the analysis. Between-study heterogeneity for each measure was assessed using the I^2 index (Higgins et al. 2003). Estimated effect sizes (subsequently 'effect sizes') $\leqslant 0.09$ were considered negligible, 0.10–0.29 small, 0.30–0.49 moderate and $\geqslant 0.50$ large (Cohen,

1988). A random-effects model (DerSimonian & Laird, 1986) was employed in view of anticipated high heterogeneity across studies.

Where comparisons were described simply as non-significant, the correlation was set at zero. Where *p* values were given as a range, the value used to calculate the correlation was set at the upper limit of the range (e.g. for *p* < 0.05 the value was set at *p* = 0.049).

Separate analyses were conducted for each of the rating methods used in cross-sectional studies: self-rating by the person with dementia, informant rating by a family carer or health care professional (reflecting the informant's appraisal of the person with dementia), proxy rating by a family carer or health care professional (reflecting the appraisal that the proxy thinks the person with dementia would make), and differences between parallel self- and informant ratings. Longitudinal studies were examined separately to identify baseline predictors at follow-up.

Pre-specified sub-group analyses examined whether associations of relevant factors with living well outcomes differed according to the type of rating, type of dementia, living situation of the person with dementia, relationship with the carer or type of measure.

Random-effects meta-regression analyses were used to investigate pre-specified moderating effects of age and cognitive status, indicated by Mini-Mental State Examination (MMSE) scores (Folstein *et al.* 1975), on moderate associations where 10 (Borenstein *et al.* 2009) or more studies were available.

Sensitivity analysis

To examine whether inserting a correlation of 0 for 'non-significant' *p* values influenced the findings, we removed these insertions and repeated the meta-analysis. We also investigated the impact of poor-quality articles on the results. Fourteen articles judged to be of poor quality (seven of which were conference abstracts) were removed from the analysis.

Results

We identified 307 articles for inclusion: 282 journal papers, 16 conference abstracts, three Health Technology Assessment reports, one book chapter and five PhD theses (Fig. 1). These reported findings from 213 individual studies from 36 countries mostly in Europe or North America; online Supplementary Tables S3–S9 provide details and quality ratings. Data on QoL were reported in 205 studies, well-being in five and life satisfaction in three.

Measures of QoL, well-being and life satisfaction

The studies utilised 45 measures of QoL, seven measures of well-being and four measures of life satisfaction (see online Supplementary Table S10). The QoL-AD (Logsdon *et al.* 2000) was the most frequently employed measure of QoL in studies where the focus was self-rated or informant-rated QoL or the difference between self-rated and informant-rated QoL, including longitudinal studies. DEMQOL-Proxy (Smith *et al.* 2005) was the most frequently employed measure of proxy-rated QoL. Distributions of scores on QoL measures are shown in online Supplementary Tables S11–S12c. Self-ratings by people with dementia on the QoL-AD and EQ-5D were higher than the corresponding informant ratings. For all other measures, insufficient data were available to allow a comparison of different rating types.

Studies included in the meta-analysis

In studies of well-being and life satisfaction, there was no overlap in the factors for which associations were examined; each study examined associations with a different set of factors, with the exception of depression which was included in two separate studies of well-being. Consequently it was not possible to conduct meta-analyses of factors associated with well-being and life satisfaction, and meta-analyses were conducted only for studies examining QoL. Data from 37639 people with dementia in 198 studies reported in 272 articles were included (seven studies were excluded due to lack of any data that met criteria for inclusion in the meta-analysis). These studies examined associations of QoL with 159 individual factors relating to the person with dementia and 69 factors relating to the carer. Data on 33 factors relating to the person with dementia and 10 factors relating to the carer were included in the meta-analysis (online Supplementary Tables S13a–S17).

Self-rated QoL

Self-ratings of QoL by the person with dementia were examined in 130 studies reporting associations with 110 factors relating to the person with dementia and 34 factors relating to the carer, of which 28 and eight, respectively, were included in the meta-analysis, based on 129 studies (Fig. 2 and online Supplementary Tables S13a–b).

Informant-rated QoL

Informant ratings made by the carer were examined in 135 studies reporting associations with 114 factors relating to the person with dementia and 56 factors relating to the carer, of which 26 and 10, respectively, were included in the meta-analysis, based on 130 studies (Fig. 3 and online Supplementary Tables S14a–b).

Proxy-rated QoL

Proxy ratings were examined in 27 studies reporting associations of 72 factors relating to the person with dementia and 23 factors relating to the carer, of which nine and one, respectively, were included in the meta-analysis, based on 22 studies (Fig. 4 and online Supplementary Tables S15a–b).

Difference between self- and informant-rated QoL

Scores reflecting differences between self-rated and informant-rated QoL were examined in 23 studies reporting associations with 30 factors relating to the person with dementia and 13 factors relating to the carer, of which 10 and three, respectively, were included in the meta-analysis, based on 22 studies (Fig. 4 and online Supplementary Tables S16a–b).

Comparing self-rated and informant-rated effect sizes

For variables that were assessed in relation to more than one of the different rating methods of self-, informant and proxy ratings or discrepancies between self- and informant ratings, the direction of association was consistent in all cases, although the strength of association varied. Online Supplementary Table S18a–b reports correlations between effect sizes where factors were examined in relation to both self-rated and informant-rated QoL.
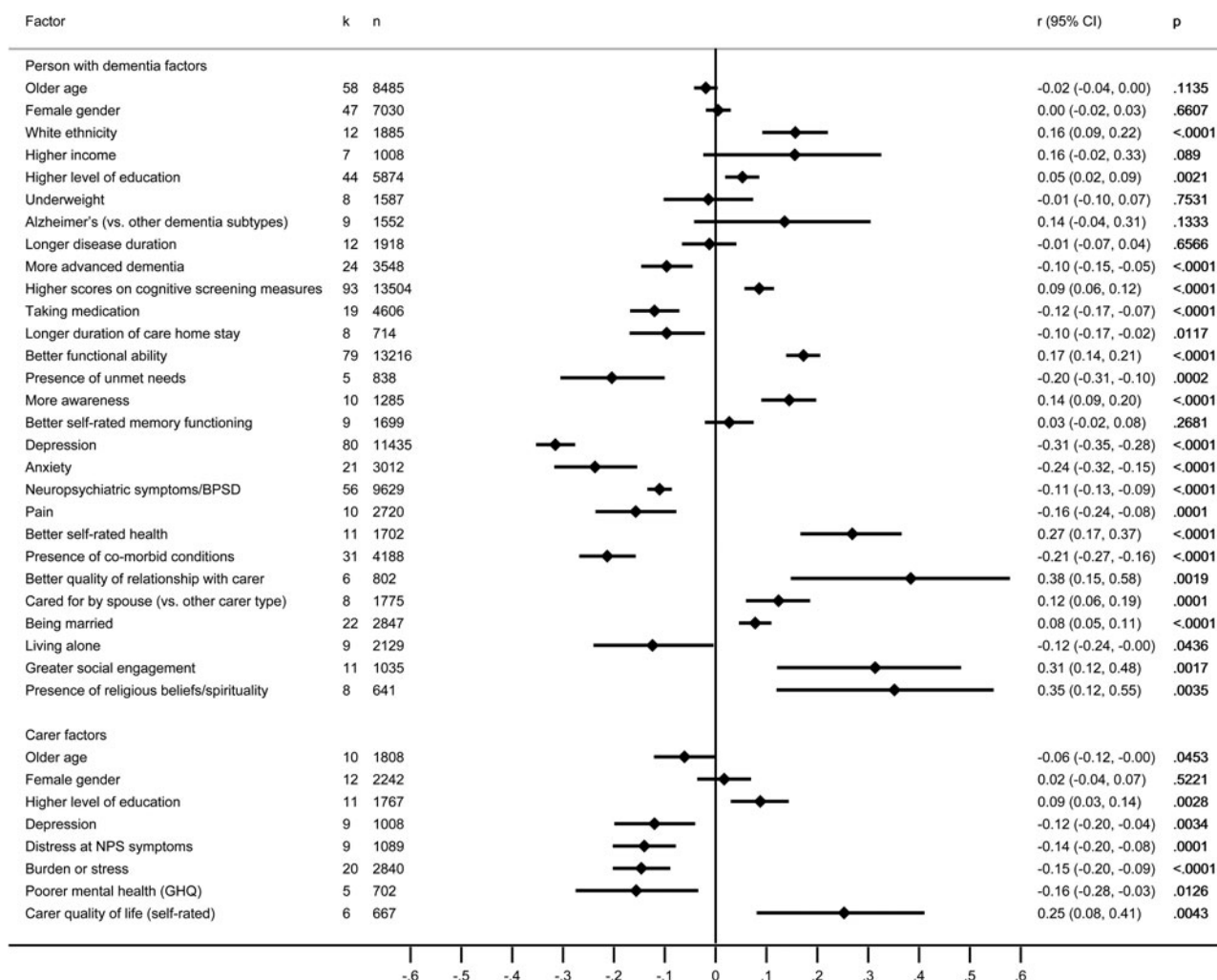
Fig. 2. Forest plot for factors associated with the quality of life self-ratings made by people with dementia. Note: negative scores indicate that factors were related to poorer QoL, and positive scores indicate that factors were related to better QoL.

Factors associated with better QoL

Greater social engagement, better quality of current relationship with the carer and religious beliefs/spirituality were moderately associated with better QoL across rating types. Better functional ability, self-rated health and awareness, white ethnicity, having a spouse carer and living in the community, and for people in residential settings, being cared for in a specialist dementia unit and receiving more person-centred care had small or mainly small associations. Small or negligible associations were found for cognitive test scores, self-rated memory functioning and being married. The only carer factor with small or moderate associations with better QoL in the person with dementia was the carer's self-rated QoL.

Factors associated with poorer QoL

Depression and neuropsychiatric symptoms showed mainly moderate associations with poorer QoL across rating types. Greater severity of dementia, anxiety, pain, presence of unmet needs, presence of co-morbid conditions and living alone showed mainly small associations. Use of medication, more advanced dementia and longer duration of stay in residential care showed small or

negligible associations. Carer burden/stress and distress at symptoms had moderate or small associations with poorer QoL, while small associations were found for carer depression, mental health and time spent caring.

Factors not significantly associated with QoL

Non-significant or negligible associations with QoL were found across rating types for age, gender or educational level of the person with dementia and carer, income of the person with dementia, type of dementia and disease duration.

Factors predicting longitudinal trajectories of QoL

Baseline predictors of QoL outcomes were examined in 20 longitudinal studies reporting associations with 25 factors relating to the person with dementia and two factors relating to the carer, of which only eight factors pertaining to the person with dementia were included in the meta-analysis, based on 19 studies (Fig. 4 and online Supplementary Table S17). Follow-up ranged from 2 months to 5 years (mean 18.2 months). Non-significant or negligible associations were found for gender, age and more advanced
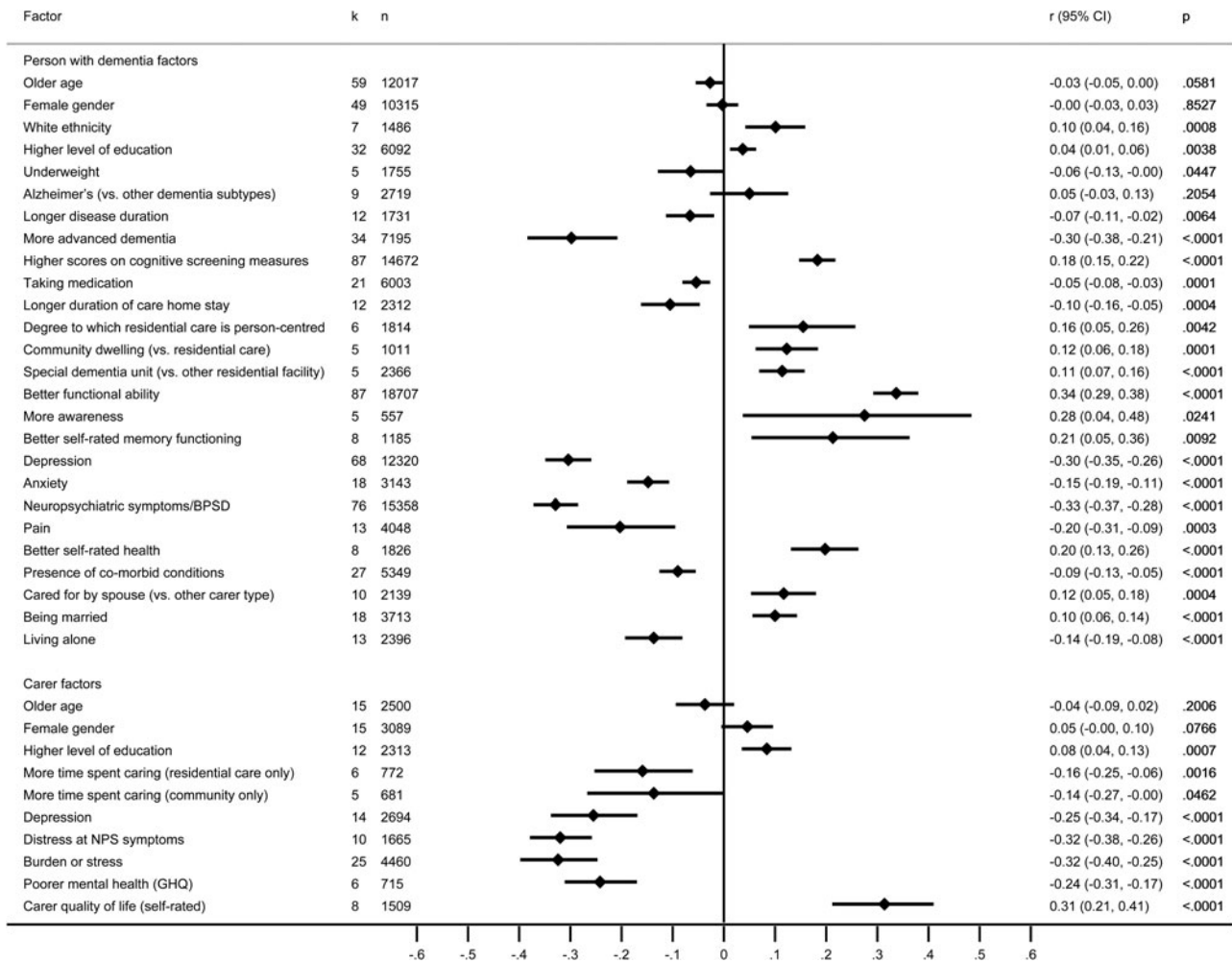
Factor	k	n	r (95% CI)	p
Person with dementia factors				
Older age	59	12017	-0.03 (-0.05, 0.00)	.0581
Female gender	49	10315	-0.00 (-0.03, 0.03)	.8527
White ethnicity	7	1486	0.10 (0.04, 0.16)	.0008
Higher level of education	32	6092	0.04 (0.01, 0.06)	.0038
Underweight	5	1755	-0.06 (-0.13, -0.00)	.0447
Alzheimer's (vs. other dementia subtypes)	9	2719	0.05 (-0.03, 0.13)	.2054
Longer disease duration	12	1731	-0.07 (-0.11, -0.02)	.0064
More advanced dementia	34	7195	-0.30 (-0.38, -0.21)	<.0001
Higher scores on cognitive screening measures	87	14672	0.18 (0.15, 0.22)	<.0001
Taking medication	21	6003	-0.05 (-0.08, -0.03)	.0001
Longer duration of care home stay	12	2312	-0.10 (-0.16, -0.05)	.0004
Degree to which residential care is person-centred	6	1814	0.16 (0.05, 0.26)	.0042
Community dwelling (vs. residential care)	5	1011	0.12 (0.06, 0.18)	.0001
Special dementia unit (vs. other residential facility)	5	2366	0.11 (0.07, 0.16)	<.0001
Better functional ability	87	18707	0.34 (0.29, 0.38)	<.0001
More awareness	5	557	0.28 (0.04, 0.48)	.0241
Better self-rated memory functioning	8	1185	0.21 (0.05, 0.36)	.0092
Depression	68	12320	-0.30 (-0.35, -0.26)	<.0001
Anxiety	18	3143	-0.15 (-0.19, -0.11)	<.0001
Neuropsychiatric symptoms/BPSD	76	15358	-0.33 (-0.37, -0.28)	<.0001
Pain	13	4048	-0.20 (-0.31, -0.09)	.0003
Better self-rated health	8	1826	0.20 (0.13, 0.26)	<.0001
Presence of co-morbid conditions	27	5349	-0.09 (-0.13, -0.05)	<.0001
Cared for by spouse (vs. other carer type)	10	2139	0.12 (0.05, 0.18)	.0004
Being married	18	3713	0.10 (0.06, 0.14)	<.0001
Living alone	13	2396	-0.14 (-0.19, -0.08)	<.0001
Carer factors				
Older age	15	2500	-0.04 (-0.09, 0.02)	.2006
Female gender	15	3089	0.05 (-0.00, 0.10)	.0766
Higher level of education	12	2313	0.08 (0.04, 0.13)	.0007
More time spent caring (residential care only)	6	772	-0.16 (-0.25, -0.06)	.0016
More time spent caring (community only)	5	681	-0.14 (-0.27, -0.00)	.0462
Depression	14	2694	-0.25 (-0.34, -0.17)	<.0001
Distress at NPS symptoms	10	1665	-0.32 (-0.38, -0.26)	<.0001
Burden or stress	25	4460	-0.32 (-0.40, -0.25)	<.0001
Poorer mental health (GHQ)	6	715	-0.24 (-0.31, -0.17)	<.0001
Carer quality of life (self-rated)	8	1509	0.31 (0.21, 0.41)	<.0001

Fig. 3. Forest plot for factors associated with informant ratings of the quality of life of the person with dementia. Note: negative scores indicate that factors were related to poorer QoL, and positive scores indicate that factors were related to better QoL.

dementia. Depression and neuropsychiatric symptoms in the person with dementia had small associations with worse QoL outcomes, while better baseline QoL ratings, better functional ability and higher scores on cognitive screening tests had small associations with better QoL outcomes. Where comparisons could be made the direction of associations was consistent with that found in cross-sectional studies.

Heterogeneity and sub-group analyses

There was a moderate-to-large degree of between-study heterogeneity for the majority of factors. Sub-group analyses investigated the effects of (a) dementia sub-type by separately analysing studies that focused specifically on people diagnosed with Alzheimer's disease and studies that did not focus specifically on people diagnosed with Alzheimer's disease; (b) living situation of the person with dementia (community and residential care settings); (c) type of carer completing the ratings of QoL (family member and health care professionals); and (d) type of QoL measure used (dementia-specific, health-related and generic). Distinguishing sub-groups in this way had little impact on overall effect sizes or degree of heterogeneity (online Supplementary Tables S19a–S23j).

Moderator variables

Meta-regressions for moderate effect sizes found no moderation effects of age or MMSE score (online Supplementary Tables S24a–S25d). Sensitivity analyses suggested that inserting 0 for non-significant p values and removing articles rated poor in quality had limited impact on the results (online Supplementary Tables S26a–S34).

Discussion

To our knowledge, this is the first comprehensive systematic review exploring factors associated with QoL, well-being and life satisfaction in people with dementia, and the first meta-analysis of factors associated with QoL. We found few studies that have investigated well-being or life satisfaction, possibly because the policy focus on these constructs is relatively recent; therefore, meta-analyses could only be conducted for studies assessing QoL. The majority of studies were cross-sectional, with considerable between-study heterogeneity. Although most factors examined were significantly related to QoL, with the direction of association consistent across rating types, no factors were strongly associated, and most associations were small or negligible. Where moderate associations were found, confidence intervals were
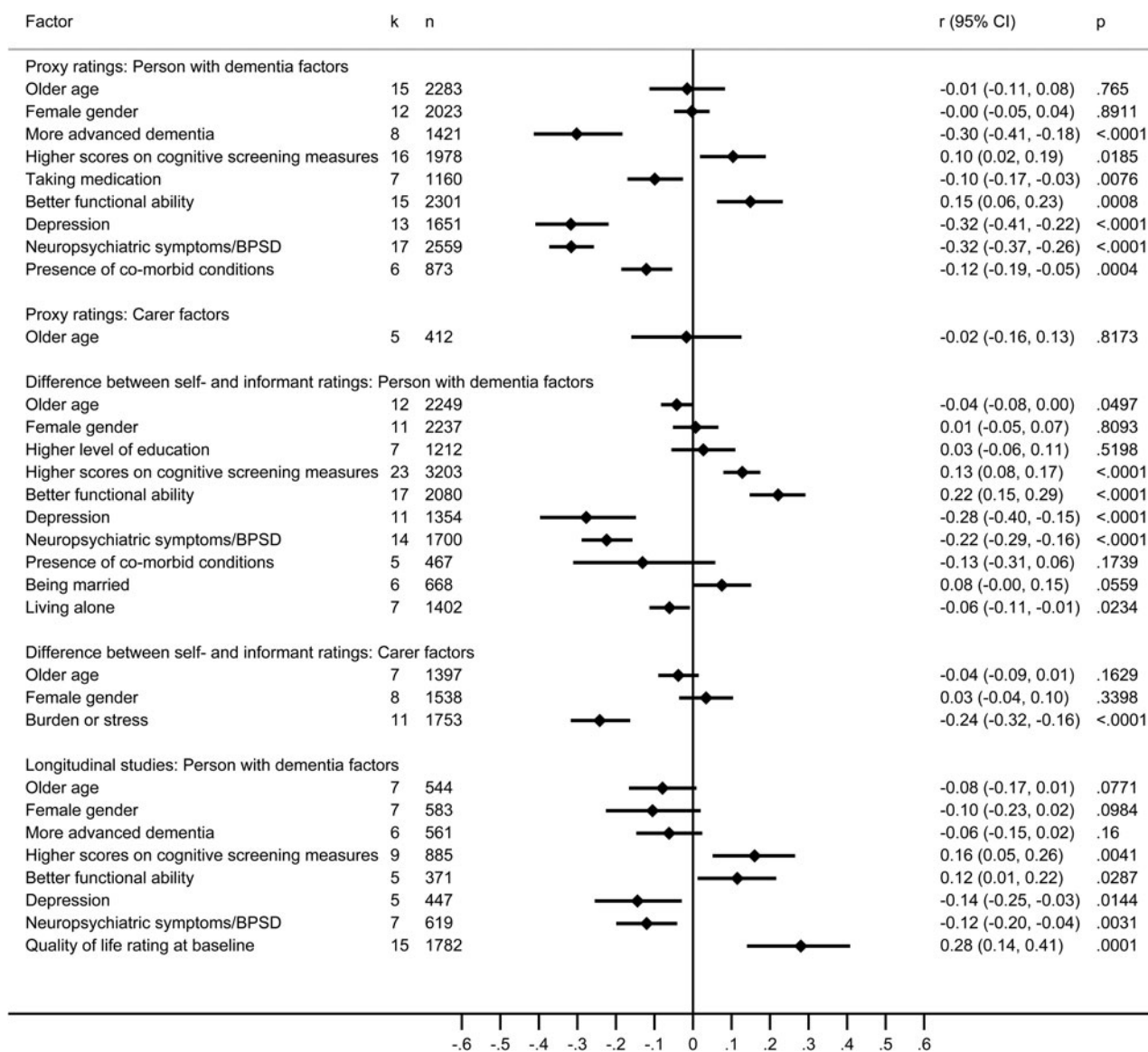
Factor	k	n	r (95% CI)	p
Proxy ratings: Person with dementia factors				
Older age	15	2283	-0.01 (-0.11, 0.08)	.765
Female gender	12	2023	-0.00 (-0.05, 0.04)	.8911
More advanced dementia	8	1421	-0.30 (-0.41, -0.18)	<.0001
Higher scores on cognitive screening measures	16	1978	0.10 (0.02, 0.19)	.0185
Taking medication	7	1160	-0.10 (-0.17, -0.03)	.0076
Better functional ability	15	2301	0.15 (0.06, 0.23)	.0008
Depression	13	1651	-0.32 (-0.41, -0.22)	<.0001
Neuropsychiatric symptoms/BPSD	17	2559	-0.32 (-0.37, -0.26)	<.0001
Presence of co-morbid conditions	6	873	-0.12 (-0.19, -0.05)	.0004
Proxy ratings: Carer factors				
Older age	5	412	-0.02 (-0.16, 0.13)	.8173
Difference between self- and informant ratings: Person with dementia factors				
Older age	12	2249	-0.04 (-0.08, 0.00)	.0497
Female gender	11	2237	0.01 (-0.05, 0.07)	.8093
Higher level of education	7	1212	0.03 (-0.06, 0.11)	.5198
Higher scores on cognitive screening measures	23	3203	0.13 (0.08, 0.17)	<.0001
Better functional ability	17	2080	0.22 (0.15, 0.29)	<.0001
Depression	11	1354	-0.28 (-0.40, -0.15)	<.0001
Neuropsychiatric symptoms/BPSD	14	1700	-0.22 (-0.29, -0.16)	<.0001
Presence of co-morbid conditions	5	467	-0.13 (-0.31, 0.06)	.1739
Being married	6	668	0.08 (-0.00, 0.15)	.0559
Living alone	7	1402	-0.06 (-0.11, -0.01)	.0234
Difference between self- and informant ratings: Carer factors				
Older age	7	1397	-0.04 (-0.09, 0.01)	.1629
Female gender	8	1538	0.03 (-0.04, 0.10)	.3398
Burden or stress	11	1753	-0.24 (-0.32, -0.16)	<.0001
Longitudinal studies: Person with dementia factors				
Older age	7	544	-0.08 (-0.17, 0.01)	.0771
Female gender	7	583	-0.10 (-0.23, 0.02)	.0984
More advanced dementia	6	561	-0.06 (-0.15, 0.02)	.16
Higher scores on cognitive screening measures	9	885	0.16 (0.05, 0.26)	.0041
Better functional ability	5	371	0.12 (0.01, 0.22)	.0287
Depression	5	447	-0.14 (-0.25, -0.03)	.0144
Neuropsychiatric symptoms/BPSD	7	619	-0.12 (-0.20, -0.04)	.0031
Quality of life rating at baseline	15	1782	0.28 (0.14, 0.41)	.0001

Fig. 4. Forest plots for factors associated with proxy ratings of quality of life, the difference between self- and informant ratings of quality of life, and baseline factors associated with longitudinal studies of quality of life. Note: negative scores indicate that factors were related to poorer QoL, and positive scores indicate that factors were related to better QoL. Longitudinal studies included both self- and informant ratings of QoL.

typically wide. Demographic and disease characteristics were largely unrelated to QoL, while social, health- and care-related factors were more likely to show associations. Factors reflecting relationships, social engagement and functional ability were associated with better QoL, along with living in the community and having a spouse carer, or receiving specialised and person-centred care in residential settings. Factors indicative of poorer physical and mental health, such as co-morbid conditions, pain, depression, anxiety, neuropsychiatric symptoms, more advanced dementia and for people in residential settings a longer duration of stay, were associated with poorer QoL, as were carer burden and distress. The moderate associations of carer burden and distress with informant-rated QoL suggests that subjective burden could be contributing to lower scores reported in carer-rated as opposed to self-rated QoL. Due to the small number of factors and heterogeneous follow-up periods, longitudinal evidence about predictors of QoL was limited, with self-rated QoL at baseline the strongest predictor of later QoL outcomes.

Our observation that demographic factors are largely unrelated to QoL is consistent with a previous narrative review of HRQoL (Banerjee et al. 2009). Aside from this, the overall picture is one of a large number of factors showing occasionally moderate but mainly small or negligible, though statistically significant, associations with QoL. A recent narrative review also reported a complex picture of associations across domains (Jing et al. 2016). Thus, QoL appears subject to many influences, some inter-related, which may co-vary in differing combinations to influence individual ratings.

In line with the current meta-analysis, the importance of positive relationships and health for QoL has been emphasised in a recent meta-synthesis of qualitative studies (O'Rourke et al. 2015a). However, that review also highlighted the domains of agency and place (feeling settled or unsettled), as key elements of the experience of people with dementia associated with QoL; these factors have not been reflected in quantitative evaluations to date. This serves as a reminder that potential associations

examined in quantitative studies may not necessarily reflect all those aspects of life that people with dementia find most relevant. The finding here of poorer physical and mental health being related to QoL is consistent with the emphasis on depression, neuropsychiatric symptoms and functional ability in Lawton's dementia-specific model of QoL (Lawton, 1994), and with evidence from qualitative research showing that people with dementia describe mood and functional ability as important for QoL (O'Rourke *et al.* 2015a). However, the relevance of other factors included in Lawton's model, such as cognitive competencies, is less well supported by our findings. Our findings further indicate that, beyond the dimensions identified by Lawton, many other factors are associated with QoL, though to a lesser degree.

Our review found that numerous measures were employed to assess QoL, although the QoL-AD (Logsdon *et al.* 2000) predominated. Several previous reviews have focused on the measurement of QoL (Ready & Ott, 2003; Ettema *et al.* 2005; Bowling *et al.* 2015; Algar *et al.* 2016; Missotten *et al.* 2016). The absence of a clear shared definition and theoretical model of QoL is reflected in the wide variation in focus and content among available measures. Analysis of domains covered in commonly used measures of dementia-specific QoL (Missotten *et al.* 2016), however, indicates that items explore some of the same factors for which associations with QoL are typically examined, particularly affect, but also social interaction, functional ability, neuropsychiatric symptoms, cognition and physical health. This raises concerns about circularity and overlap in measurement. Furthermore, it is unclear whether the quantitative assessment of QoL adequately reflects the perspective of people with dementia (O'Rourke *et al.* 2015b). While items in some measures are based on data from qualitative interviews with people with dementia, many measures have been developed with little or no direct input from people with dementia (Bowling *et al.* 2015) and few large-scale studies have been conducted that enable people with dementia to say what is important for their QoL (Clare *et al.* 2014a).

Because of the breadth of included studies, we decided to statistically analyse only factors for which there was data available from five or more studies. Focusing the review in this way allowed us to summarise current understanding and reduce reporting of associations for which there was limited evidence. However, this precluded quantitative analyses for life satisfaction and well-being, and limited the number of factors in the analysis of longitudinal studies. We necessarily examined factors separately, and could not account for likely inter-correlations. A number of studies did not provide exact data for non-significant findings, so a potential limitation resulted from inserting zero correlations from those studies; however, this had a minimal effect on associations or heterogeneity. Most of the studies that did not focus exclusively on those diagnosed with Alzheimer's disease analysed responses from people with different dementia diagnoses as one group, which precluded separate analysis for different dementia sub-types. Methodologically, the widespread misuse of the term 'proxy' when researchers mean 'informant' created challenges for comparing findings between studies. For example, in DEMQOL-Proxy (Smith *et al.* 2005), instructions allow informants to make either proxy or informant ratings, so ratings from this instrument were difficult to classify correctly. Our review highlights the need for application of clear and consistent terminology and the standardisation of methods (e.g. standard follow-up periods and sample size calculations), and a robust conceptual and methodological framework to guide work in this area.

The findings point to some limitations in how we understand and evaluate living well with dementia. Available measures may not capture what is most meaningful to each individual (Bowling *et al.* 2015) or indeed everything that is relevant to living well. In this respect, broadening the perspective to include subjective well-being and satisfaction with life may be informative; these constructs have rarely been assessed, and as yet evidence is limited (Clare *et al.* 2014a). The pattern we observed of numerous small associations generally supports the idea that QoL is multifaceted, as suggested by Lawton's framework (1994). It might also reflect the operation of individual differences in what is deemed most important for QoL, so there may be value in considering more personalised approaches to assessment, particularly as no QoL measure includes all of the factors that our review suggests may be important to the QoL of people with dementia. However, developing and implementing personalised approaches would present significant challenges.

The findings raise questions about the use of QoL as an outcome measure in psychosocial intervention trials. First, if QoL is subject to many influences, changes in one area of life may have little effect on the overall picture, so it may not be reasonable to expect interventions that are effective in improving some primary outcomes to influence scores on QoL measures. Second, as noted above, potential circularity in measurement may create a distorted picture. Therefore, the relevance of QoL measures for assessing effectiveness of interventions may need re-evaluation.

Conclusion

Our findings suggest that efforts to improve QoL might focus on supporting relationships, social engagement and everyday functioning, addressing poor physical and mental health, and ensuring high-quality care. However, there is a need for longitudinal evidence that can point to ways of maintaining or improving QoL over time and enable identification of people at risk of declining QoL, so that preventive interventions can be targeted to this group.

commenting on and approving text of review. CH, JH, IRJ, RM, SMN, CQ, JR, JT, CRV, YTW: Abstract screening, interpretation of results, commenting on and approving text of review.

Declaration of Interest. None.

References

Albert SM, Jacobs DM, Sano M, Marder K, Bell K, Devanand D et al. (2001) Longitudinal study of quality of life in people with advanced Alzheimer's disease. *The American Journal of Geriatric Psychiatry* **9**, 160–168.

Algar K, Woods RT and Windle G (2016) Measuring the quality of life and well-being of people with dementia: a review of observational measures. *Dementia* **15**, 832–857.

Ballard C, Gauthier S, Corbett A, Brayne C, Aarsland D and Jones E (2011) Alzheimer's disease. *The Lancet* **377**, 1019–1031.

Banerjee S, Samsi K, Petrie CD, Alvir J, Treglia M, Schwam EM et al. (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**, 15–24.

Beer C, Flicker L, Horner B, Bretland N, Scherer S, Lautenschlager NT et al. (2010) Factors associated with self and informant ratings of the quality of life of people with dementia living in care facilities: a cross sectional study. *PLoS ONE* **5**, e15621.

Beerens HC, Zwakhalen SM, Verbeek H, Ruwaard D and Hamers JP (2013) Factors associated with quality of life of people with dementia in long-term care facilities: a systematic review. *International Journal of Nursing Studies* **50**, 1259–1270.

Borenstein M, Hedges LV, Higgins JPT and Rothstein HR (2005) *Comprehensive Meta-Analysis, Version 2.* Englewood: Biostat.

Borenstein M, Hedges LV, Higgins JPT and Rothstein HR (2009) *Introduction to Meta-Analysis.* Chichester: John Wiley & Sons.

Bowling A, Rowe G, Adams S, Sands P, Samsi K, Crane M et al. (2015) Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales. *Aging & Mental Health* **19**, 13–31.

Clare L, Nelis SM, Quinn C, Martyr A, Henderson C, Hindle JV et al. (2014a) Improving the experience of dementia and enhancing active life – living well with dementia: study protocol for the IDEAL study. *Health and Quality of Life Outcomes* **12**, 164.

Clare L, Quinn C, Hoare Z, Whitaker R and Woods RT (2014b) Care staff and family member perspectives on quality of life in people with very severe dementia in long-term care: a cross-sectional study. *Health and Quality of Life Outcomes* **12**, 175.

Cohen J (1988) *Statistical Power Analysis for the Behavioral Sciences.* Hillsdale, NJ: Lawrence Earlbaum Associates.

Cordner Z, Blass DM, Rabins PV and Black BS (2010) Quality of life in nursing home residents with advanced dementia. *Journal of the American Geriatrics Society* **58**, 2394–2400.

Crespo M, Hornillos C and Bernaldo de Quiros M (2013) Factors associated with quality of life in dementia patients in long-term care. *International Psychogeriatrics* **25**, 577–585.

Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy.* London: Department of Health.

DerSimonian R and Laird N (1986) Meta-analysis in clinical trials. *Controlled Clinical Trials* **7**, 177–188.

Diener E and Chan MY (2011) Happy people live longer: subjective well-being contributes to health and longevity. *Applied Psychology: Health and Well-Being* **3**, 1–43.

Downs SH and Black N (1998) The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health* **52**, 377–384.

DuRant RH (1994) Checklist for the evaluation of research articles. *Journal of Adolescent Health* **15**, 4–8.

Edelman P, Fulton BR, Kuhn D and Chang CH (2005) A comparison of three methods of measuring dementia-specific quality of life: perspectives of residents, staff, and observers. *The Gerontologist* **45**, 27–36.

Ettema TP, Dröes RM, de Lange J, Mellenbergh GJ and Ribbe MW (2005) A review of quality of life instruments used in dementia. *Quality of Life Research* **14**, 675–686.

Folstein MF, Folstein SE and McHugh PR (1975) "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research* **12**, 189–198.

Higgins JPT, Thompson SG, Deeks JJ and Altman DG (2003) Measuring inconsistency in meta-analyses. *BMJ* **327**, 557–560.

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

Institute of Medicine (2012) *Living Well with Chronic Illness: A Call for Public Health Action.* Washington: National Academies Press.

Jing W, Willis R and Feng Z (2016) Factors influencing quality of life of elderly people with dementia and care implications: a systematic review. *Archives of Gerontology and Geriatrics* **66**, 23–41.

Kane RA, Kling KC, Bershadsky B, Kane RL, Giles K, Degenholtz HB et al. (2003) Quality of life measures for nursing home residents. *The Journals of Gerontology Series A: Biological Sciences & Medical Sciences* **58**, 240–248.

Kitwood T (1997) The Person Comes First. Buckingham: Open University Press.

Lawrence V, Fossey J, Ballard C, Moniz-Cook ED and Murray J (2012) Improving quality of life for people with dementia in care homes: making psychosocial interventions work. *British Journal of Psychiatry* **201**, 344–351.

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

Li X-J, Suishu C, Hattori S, Liang H-D, Gao H, Feng C-Q et al. (2013) The comparison of dementia patient's quality of life and influencing factors in two cities. *Journal of Clinical Nursing* **22**, 2132–2140.

Logsdon RG, Gibbons LE, McCurry SM and Teri L (2000) Quality of life in Alzheimer's disease: patient and caregiver reports. In Albert SM and Logsdon RG (eds). *Assessing Quality of Life in Dementia.* New York: Springer, pp. 17–30.

Missotten P, Dupuis G and Adam S (2016) Dementia-specific quality of life instruments: a conceptual analysis. *International Psychogeriatrics* **28**, 1245–1262.

Moyle W and O'Dwyer ST (2012) Quality of life in people living with dementia in nursing homes. *Current Opinion in Psychiatry* **25**, 480–484.

Novelli MMPC and Caramelli P (2010) The influence of neuropsychiatric and functional changes on quality of life in Alzheimer's disease. *Dementia & Neuropsychologia* **4**, 47–53.

O'Rourke HM, Duggleby W, Fraser KD and Jerke L (2015a) Factors that affect quality of life from the perspective of people with dementia: a meta-synthesis. *Journal of the American Geriatrics Society* **63**, 24–38.

O'Rourke HM, Fraser KD and Duggleby W (2015b) Does the quality of life construct as illustrated in quantitative measurement tools reflect the perspective of people with dementia? *Journal of Advanced Nursing* **71**, 1812–1824.

Peterson RA and Brown SP (2005) On the use of beta coefficients in meta-analysis. *Journal of Applied Psychology* **90**, 175–181.

Ready RE and Ott BR (2003) Quality of life measures for dementia. *Health and Quality of Life Outcomes* **1**, 11.

Robertson S, Cooper C, Hoe J, Hamilton O, Stringer A and Livingston G (2017) Proxy rated quality of life of care home residents with dementia: a systematic review. *International Psychogeriatrics* **29**, 569–581.

Sanderson S, Tatt ID and Higgins JPT (2007) Tools for assessing quality and susceptibility to bias in observational studies in epidemiology: a systematic review and annotated bibliography. *International Journal of Epidemiology* **36**, 666–676.

Small N (2007) Living well until you die: quality of care and quality of life in palliative and dementia care. *Annals of the New York Academy of Sciences* **1114**, 194–203.

Smith SC, Lamping DL, Banerjee S, Harwood RH, Foley B, Smith P et al. (2005) Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment* **9**, 1–93.

St. John PD and Montgomery PR (2010) Cognitive impairment and life satisfaction in older adults. *International Journal of Geriatric Psychiatry* **25**, 814–821.

Trigg R, Skevington SM and Jones RW (2007) How can we best assess the quality of life of people with dementia? The Bath Assessment of Subjective Quality of life in Dementia (BASQID). *The Gerontologist* **47**, 789–797.

Wilson IB and Cleary PD (1995) Linking clinical variables with health-related quality of life. *JAMA* **273**, 59–65.

Woods RT, Nelis SM, Martyr A, Roberts J, Whitaker CJ, Markova I *et al.* (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**, 94.

World Health Organization (1995) *The World Health Organization Quality of Life Assessment. Field Trial Version for Adults. Administration Manual.* Geneva: World Health Organization.

Zank S and Leipold B (2001) The relationship between severity of dementia and subjective well-being. *Aging & Mental Health* **5**, 191–196.

Zaza S, Wright-De Agüero LK, Briss PA, Truman BI, Hopkins DP, Hennessy MH *et al.* Task Force on Community Preventive Services (2000) Data collection instrument and procedure for systematic reviews in the Guide to Community Preventive Services. *American Journal of Preventive Medicine* **18**, 44–74.