**Supplementary Table 1: Articles excluded at the full-text screening stage**

|  |  |
| --- | --- |
| Article only investigated comparisons between different QoL measures (Number of studies=4) | Crespo *et al.* (2012); Inouye *et al.* (2009); Kolanowski *et al.* (2007); Mador *et al.* (2002) |
| Article was an intervention study (Number of studies=13) | Albert (2004); Birks and Cochrane Neurological Network (2005); Caramelli *et al.* (2014); Charras and Gzil (2013); Gitlin *et al.* (2010); Jo and Song (2015); Kwok *et al.* (2012); Larsson *et al.* (2011); Lee *et al.* (2008); Meguro *et al.* (2008); Mowrey *et al.* (2013); te Boekhorst *et al.* (2013); Yokota *et al.* (2006) |
| People with dementia constituted less than 75% of the sample (Number of studies=54) | Abrahamson *et al.* (2012); Abrahamson *et al.* (2013); Afzal *et al.* (2010); Almomani *et al.* (2014); Baró *et al.* (2006); Berwig *et al.* (2009); Bilotta *et al.* (2012); Bishop *et al.* (2008); Byrne and MacLean (1997); Calero and Navarro (2011); Chaput (2000); Charles *et al.* (2015); Chekani *et al.* (2016); Comijs *et al.* (2005); Custers *et al.* (2013); Degenholtz *et al.* (2008); Ding *et al.* (2009); Fernández-Mayoralas *et al.* (2015); Goodrow *et al.* (1979); Jetten *et al.* (2010); Kane *et al.* (2003); Lalic *et al.* (2016); Lee *et al.* (2015a); Leroi *et al.* (2012); Li *et al.* (2013a); Llácer *et al.* (2002); Lucas-Carrasco and March (2010); Luzny and Ivanova (2009); Martín-García *et al.* (2013); Morgan *et al.* (1987); Moyle *et al.* (2012); Murphy *et al.* (2009); Müther *et al.* (2010); Oliva-Moreno *et al.* (2010); Olsson *et al.* (2013); Oudman and Zwart (2012); Parsaik *et al.* (2012); Patterson *et al.* (2006); Ready *et al.* (2002a); Ready *et al.* (2006); Ready and Ott (2007); Richter *et al.* (2008); Richter *et al.* (2004); Schwartz *et al.* (2011); Scocco *et al.* (2006); Shippee *et al.* (2015a); Shippee *et al.* (2015b); Shippee *et al.* (2016); St. John and Montgomery (2010); Suwalska *et al.* (2002); Terada *et al.* (2015); Tommis *et al.* (2007); Waldemar *et al.* (2004a, 2004b) |
| Review articles (Number of studies=15) | Homma (2003); Kasai and Meguro (2013); Korczyn and Davidson (1999); Logsdon *et al.* (2007); Lund *et al.* (2005); Mills Jr and Glendenning (2014); Russell (1996); Sefton *et al.* (2008); Selai and Trimble (1998); Selai *et al.* (2001b); Teri and Logsdon (1991); Torrington (2006); Whitehouse and Rabins (1992); Whitehouse (1999); Whitehouse *et al.* (2003) |
| The article did not include a measure of QoL (Number of studies=6) | Carvalho-Bos *et al.* (2007); Cicciu *et al.* (2013); Cipher and Clifford (2004); Hickey and Bourgeois (2000); Trudeau *et al.* (2003); Wimo *et al.* (1990) |
| The article did not include any data that could be converted to a correlation (Number of studies=49) | Arons *et al.* (2012); Asakawa *et al.* (2008); Bureau-Chalot *et al.* (2002); DeJong *et al.* (1989); Dello Russo *et al.* (2008); Dichter *et al.* (2015); Elliott *et al.* (2009); Engel *et al.* (2006a, 2006b); Forstmeier *et al.* (2013); Gómez-Gallego *et al.* (2014); González-Vélez *et al.* (2015); Gross *et al.* (2015); Hassani Mehraban *et al.* (2014); Hewitt *et al.* (2013); Holst and Edberg (2011); Hongisto *et al.* (2015); Hurley *et al.* (1992); Inouye *et al.* (2010a); Inouye *et al.* (2010b); Jensen-Dahm *et al.* (2012); Karlawish *et al.* (2004c); Koopmans *et al.* (2009); Kuhn *et al.* (2002); Kurz *et al.* (2003); Lem (2015); Leon *et al.* (2000); Livingston *et al.* (2006); López-Bastida *et al.* (2006); Martin-Cook *et al.* (2005); Matano (2000); Miller *et al.* (2010b); Missotten *et al.* (2009); Naglie *et al.* (2012); Navarro-Gil *et al.* (2014); Neumann *et al.* (1999); Peitsch *et al.* (2015); Roberts (2007); Sano *et al.* (1999); Senanarong *et al.* (2008); Smit *et al.* (2014); University Of Kent Personal Social Services Research Unit (2015a, 2015b); Villar *et al.* (2015); Ward and Ashaye (2008); Wettstein *et al.* (2014); Willemse *et al.* (2015); Yeardley *et al.* (1995); Zbrozek *et al.* (2004) |
| The article included only qualitative analyses (Number of studies=7) | Cahill *et al.* (2004); du Toit and Surr (2011); Fukushima *et al.* (2005); Innes and Surr (2001); Katsuno (2005); Morioka *et al.* (2005); Steultjens and van’t Leven (2008) |
| The sample did not include any participants with dementia (Number of studies=4) | Allerhand *et al.* (2014); Cuijpers *et al.* (1999); Hodgson and Cutler (1997); Papastavrou *et al.* (2012) |
| The article was a commentary on other studies (Number of studies=4) | Ballard (2009); Banerjee (2007); Forbes (2004); Hess (2009) |
| The article was a theoretical paper (Number of studies=3) | Jonker *et al.* (2004); Lawton (1994); Lawton (1997) |

**Supplementary Table 2: Data quality proforma**

The checklist has been designed to act as a traffic light system:

* If you think that the criteria are met fully this will be graded as green and given a score of 3.
* If you think that the criteria are partly met or if you can’t tell from the information provided this will be graded as amber and given a score of 2.
* If you think that the criteria are not met this will be graded as red and given a score of 1.

Checklist items:

1) Is there a clear description of the research question?

Green: The hypotheses/aim(s) or research question(s) of the study were well described and clear.

Amber: The hypotheses/aim(s) or research question(s) of the study were adequately described or slightly unclear clear.

Red: The hypotheses/aim(s) or research question(s) of the study were poorly described, unclear or non-existent.

2) Is there a clear description of the inclusion and exclusion criteria?

Green: The inclusion/exclusion criteria of the study were well described and clear.

Amber: The inclusion/exclusion criteria of the study were adequately described or slightly unclear.

Red: The inclusion/exclusion criteria of the study were poorly described, unclear or non-existent.

3) Is there an appropriate description of the sampling method and source of recruitment?

Green: The sampling method and source of recruitment of the study were well described and clear (e.g. participants were ‘recruited from memory clinics’ or were ‘community-dwelling’).

Amber: The sampling method and source of recruitment of the study were adequately described or slightly unclear clear.

Red: The sampling method and source of recruitment of the study was poorly described, unclear or non-existent (i.e. there was no description of how or where participants were recruited).

4a) Was there an appropriate description of the participants’ age and sex?

Green: The mean age or age stratification was provided and the number of fe/males was provided.

Amber: Either the mean age or age stratification or the number of fe/males was provided.

Red: Neither the mean age or age stratification nor the number of fe/males was provided.

4b) Was there an appropriate description of the participants’ diagnoses?

Green: The diagnosis was provided for all participants. Analysis included only people diagnosed with dementia.

Amber: Diagnostic information was provided but analysis included people without dementia, including those diagnosed with MCI.

Red: There was a vague description of the sample (i.e. "dementia" without specific diagnostic categories).

4c) Was there an appropriate description of the participants’ dementia severity and details of the MMSE score or equivalent?

Green: Both a description of dementia severity (mild, moderate, severe) and MMSE (or equivalent, e.g. CDR score or MoCA, 3MS, DRS etc.) was provided.

Amber: Either a description of dementia severity (mild, moderate, severe) or MMSE (or equivalent, e.g. CDR score or MoCA, 3MS, DRS etc.) was provided.

Red: Neither a description of dementia severity (mild, moderate, severe) nor MMSE (or equivalent, e.g. CDR score or MoCA, 3MS, DRS etc.) was provided.

5) Is the sample size large enough to test the hypothesis objectively? Was an *a priori* power calculation reported in the paper?

Green: There was an a priori power calculation reported irrespective of sample size.

Amber: The sample was larger than 30 but there was no a priori power calculation reported.

Red: The sample was less than 30 and there was no a priori power calculation reported.

6) Did the study use standardised measures (or if new measures were used had they undergone reliability and validity testing)?

Green: The study used standardised measures (or if new measures were used they had undergone reliability and validity testing).

Amber: The study used some standardised measures (or if new measures were used they had not undergone reliability and validity testing).

Red: The study used no standardised measures (or if new measures were used they had not undergone reliability and validity testing).

7) Was appropriate statistical testing employed (i.e. suitable covariates used, repeated measures in longitudinal studies)? (See Table e1 for appropriate statistical tests)

Green: The study used appropriate statistical tests (see extra guidance below for what would be considered appropriate statistical tests for cross-sectional and longitudinal studies).

Amber: The study used some appropriate statistical tests.

Red: The study used inappropriate statistical tests.

**Table e1. Appropriate statistical tests for cross-sectional and longitudinal studies**

|  |  |
| --- | --- |
| **Study questions** | **Statistical analysis** |
| **(1) Cross-sectional study** | |
| (1.1) Compare difference in QoL between 2/3 groups | t test |
| ANOVA |
| Univariable regression |
| Multivariable regression |
| Non-parametric analysis |
| (1.2) Relationship between QoL and other continuous variables | Correlation |
| Univariable regression |
| Multivariable regression |
| Non-parametric analysis |
| (1.3) QoL (Binary measure) and categorical variables | Logistic regression (binary outcome) |
| Chi-square test |
| Non-parametric analysis |
| **(2) Longitudinal study** | |
| (2.1) Change in QoL across different groups | ANCOVA |
| Univariable regression |
| Multivariable regression |
| Non-parametric analysis |
| (2.2) Adjusting for correlation of repeated measures (QoL) | Multilevel modelling |
| Generalised estimating equation |
| Time series analysis |
| (2.3) Mediator/effect Modifier | Structural Equation Modelling (SEM) |

8) If multicentre data were used, did the researchers compare the results from multiple sources (e.g. multiple centres) before pooling the data for final analysis?

Green: The multicentre study had compared the results from different centres and had taken this into consideration in the analysis.

Amber: The multicentre study had compared the results from different centres but had not taken this into consideration in the analysis.

Red: The multicentre study did not report a comparison of the results from different centres.

9) Longitudinal studies only: have the characteristics of participants lost to follow-up been described?

Green: The characteristics of participants lost to follow-up were well described or there were no participants lost to follow-up.

Amber: The characteristics of participants lost to follow-up were adequately described or the number of participants lost to follow-up was so small that the findings would not have been affected by their inclusion.

Red: The characteristics of participants lost to follow-up were poorly described or not mentioned at all.

10) Were any conflicts of interest declared that could have biased the findings of the study?

Green: Conflicts of interest were declared but could not have biased the findings of the study.

Amber: There was no statement concerning conflict(s) of interest in the paper.

Red: Conflicts of interest were declared and could have biased the findings of the study (e.g. authors receive royalties from measures used is the study).

Q8 and Q9 were not included in the data quality scoring as these did not apply to the majority of studies.

**Supplementary Table 3. Studies utilising self-ratings of quality of life by people with dementia**

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Study** | **Country of study** | **n** | **Females** | **Mean age** | **Severity** | **Dementia type** | **Living situation** | **QoL measure** | **Factors included in the meta-analysis** | **Quality rating** |
| Allan *et al.* (2006) | UK | 198 | 84 | 76 (6.2) | CAMCOG 67.8 (13.76) | AD 40, PDD 46, DLB 32, VaD 38, Controls 42 | Not specified | SF-36 | Co-morbidity | Good |
| Andersen *et al.* (2004) | Denmark | 211 | 122 | 78.1 (5.47) | 21.0 (4.75) | Mostly AD | Mostly community | EQ-5D | Age, ADL, Gender, Diagnosis, Living alone, CSM | Good |
| Andrieu *et al.* (2016) | France | 534 | 331 | 79.6 (5.9) | 19.5 (3.9) | AD | Community | QoL-AD | Age, Anxiety, ADL, NPS, Depression, Gender, Education, Co-morbidity, Diet, Relationship, Living alone, CSM, Medication, Duration, Burden, Age C, Gender C | Good |
| Arlt *et al.* (2008) | Germany | 100 | 54 | 70.49 (8.49) | 22.74 (4.37) | AD (58%), Mixed and MCI (11%), bvFTD (9%), VaD (7%), Semantic dementia (1%) | Community 98, Nursing home 2 | WHO-8 | Depression, GDS, CSM | Good |
| Azcurra (2012) | Argentina | 44 | 30 | 85.3 (5.6) | 13.2 (1.2) | AD | Long-term care residents (intervention) | SRQLS | Anxiety, ADL, Depression, Education, Religion, Co-morbidity, Care home stay, CSM, Social engagement, Medication, Burden | Good |
| 44 | 27 | 86.4 (4.9) | 14.1 (1.4) | AD | Long-term care residents (active control) |
| 44 | 29 | 85.8 (5.1) | 14.6 (1.4) | AD | Long-term care residents (passive control) |
| Bakker *et al.* (2014) | Netherlands | 215 | 102 | 61.1 (5.4) | Not specified | AD 117, bvFTD 27, PPA 13, VaD 24, Mixed 8, Other 16 | Community | QoL-AD | Age, NPS, Depression, Gender, Unmet needs, GDS | Good |
| Beer *et al.* (2010) | Australia | 226 | not specified | 85.3 (7.9) | 14 (median) | Dementia | Residential care facilities | QoL-AD | Age, NPS, Gender, Diet, Pain, CSM, Medication, Distress | Satisfactory |
| Beerens *et al.* (2014) | England, Estonia, Finland, France, Germany, Netherlands, Spain, Sweden | 791 | 74% | 84.1 (6.4) | 11.9 (6.3) | Dementia | Long-term care residents | QoL-AD | Depression, Pain, Medication | Satisfactory |
| 1123 | 63% | 82.2 (6.6) | 14.3 (6.6) | Dementia | Home care |
| Giebel *et al.* (2015a) | 122 | 71.30% | 83 (6.5) | 13.37 (2.27) | AD 44, VaD 39, mixed 8, FTD 2, DLB 5 | Community 63, Nursing home 59 | QoL-AD | Age, ADL, NPS, Diagnosis, CSM | Good |
| Giebel *et al.* (2015b) | 126 | 71.30% | 82 (6.8) | 4.9 (3.1) | AD 44, VaD 39, mixed 8, FTD 2, DLB 5 | Community 214, Nursing home 197 | QoL-AD | None | Good |
| Giebel *et al.* (2016b) | 957 | 596 | 82.3 (6.5) | 14.5 (6.6) | AD 514, VaD 153, Mixed 53, Other 227 | Community (home care) | QoL-AD | None | Good |
| 581 | 423 | 84.3 (6.1) | 12.1 (6.2) | AD 248, VaD 127, Mixed 35, Other 171 | Nursing home (long term care) | QoL-AD | None |
| Berwig *et al.* (2011) | Germany | 16 | 8 | 78.5 (4.5) | 20.3 (2.7) | AD | Community | DEMQOL | Depression | Good |
| Bhattacharya *et al.* (2010) | Denmark | 321 | 54.80% | 76.2 (7.1) | 24.0 (2.6) | AD (72.4%), Mixed (24.8%) | Community | EQ-5D  EQ-5D VAS  QoL-AD | ADL, NPS, Depression, CSM | Satisfactory |
| Black *et al.* (2012) | US | 220 | 65% | 83.6 (5.9) | 17.8 (7.6) | Dementia | Community | QoL-AD | Age, ADL, NPS, Depression, Gender, Education, Co-morbidity, Ethnicity, CSM, Medication, Distress | Good |
| Black *et al.* (2013) | 254 | 65% | 83.6 (5.9) | 17.8 (7.6) | 265 AD, 38 MCI | Community | QoL-AD | Unmet needs | Good |
| Bosboom *et al.* (2012a) | Australia | 226 | 169 | 85.9 (7.7) | 15.9 (5.9) | Dementia | Residential aged care facilities | QoL-AD | Medication | Satisfactory |
| Bosboom *et al.* (2012b) | Australia | 80 | 67.50% | 78.3 (7.9) | Not specified | AD | Community | QoL-AD | Age, Anxiety, Awareness, ADL, NPS, Depression, Gender, Education, Living alone, Medication, Being married, Memory rating, Distress, Age C, Gender C | Good |
| Bosboom and Almeida (2014) | 47 | 72.30% | 78.7 (8.2) | 15.1 (5.6) | AD | Community | QoL-AD | CSM | Good |
| Bosboom *et al.* (2013) | 47 | 72.30% | 78.7 (8.2) | 15.1 (5.6) | AD | Community | QoL-AD | None | Satisfactory |
| Bosboom and Almeida (2016) | 80 | 67.50% | 78.3 (7.9) | Not specified | AD | Community | QoL-AD | None | Good |
| Brod *et al.* (1999) | US | 95 | 59% | 78.7 (7.43) | Mild 45, Moderate 50 | Dementia | Community 89, Health care facility 6 | DQoL | Depression, CSM | Good |
| Bruvik *et al.* (2012) | Norway | 230 | 123 | 78.4 (7.5) | 21.3 (3.6) | Dementia | Community | QoL-AD | Age, ADL, NPS, Depression, Gender, Education, CSM, Duration, Being married | Good |
| Buckley *et al.* (2012) | US | 71 | 151 | 85.60 (5.77) | 19.78 (7.25) | AD 181, remainder not specified | Not specified | Single global QoL question (rated self as excellent) | ADL, NPS, Health, Gender, Education, GDS, CSM, Duration | Good |
| 123 | Single global QoL question (rated self as good) |
| Buffum *et al.* (2001) | US | 33 | 1 | 78.5 (7.2) | 14 (9.6; n = 19) | Dementia | Nursing home | Discomfort Scale | NPS, GDS, Pain, CSM | Good |
| Burgener *et al.* (2015) | US | 31 | 26 | 78.3 (8.3) | 20.4 (6.1) | Dementia | Community | SF-36 | Education, CSM, Social engagement | Satisfactory |
| Caddell and Clare (2012) | Wales | 50 | 26 | 77.8 (7.4) | 23.7 (2.7) | AD 38, VaD 9, Mixed 3 | Community | QoL-AD | Memory rating, Social engagement | Good |
| Camic *et al.* (2013) | England | 10 | 5 | 75 (6.7) | 19 (7.9) | AD 6, VaD 2, Mixed 1, MCI 1 | Community | DEMQOL | NPS | Satisfactory |
| Campbell *et al.* (2008) | US | 149 | 93 | 78.7 (8.5) | 19.8 (6.2) | AD 101, VaD 15, FTD 1, Mixed 7, Other 22, 10 Unreported | Not specified | Single question - How would you rate your general health? | Awareness, Ethnicity | Good |
| Castro-Monteiro *et al.* (2016) | Spain | 208 | 82.67% | 85.57 (6.73) | 13.24 (8.07) | Non-specific dementia (49.7%), AD (36.4%), VaD (6.5%), Mixed (4.4%), Alcohol-related dementia (1.1%), DLB (1.1%), PDD (.8%) | 14 Residential care facilities | QoL-AD | Age, ADL, Depression, Gender, Co-morbidity, GDS, CSM, Social engagement | Good |
| Chan *et al.* (2011) | Hong Kong | 111 | 80 | 77.7 (7.4) | 15.8 (4.7) | AD | Community | QoL-AD | Age, Depression, Gender, Education, Co-morbidity, Income, Living alone, CSM, Being married | Good |
| Chiu *et al.* (2008) | Taiwan | 71 | 61.20% | 75.23 (8.03) | 17.61 (3.78) | AD | Not specified | DQoL | Age, ADL, NPS, Depression, Education, CSM, Depression C | Satisfactory |
| Cines *et al.* (2015) | US | 104 | 68 | 77.55 (8.03) | 24.19 (2.64) | AD | Not specified | QoL-AD | Age, Awareness, Gender, Education, Ethnicity | Good |
| Conde-Sala *et al.* (2009) | Spain | 236 | 157 | 77.8 (6.9) | Mild 76, Moderate 154, Severe 6 | Dementia | Community | QoL-AD | Anxiety, ADL, NPS, Education, Living alone, CSM, Being married, QoL C, Burden | Good |
| Conde-Sala *et al.* (2010) | 251 | 166 | 77.4 | 18.05 | Dementia | Community | QoL-AD | Age, Depression, Gender, Relationship, Education C, Gender C | Satisfactory |
| Conde-Sala *et al.* (2014b) | 119 | 76 | 77.0 (6.7) | 18.9 (3.6) | Dementia | Community | QoL-AD | Depression, Awareness | Good |
| Conde-Sala *et al.* (2013a) | Spain | 164 | 98 | 77.6 (7.2) | 17.9 (5.8) | AD | Not specified | QoL-AD | ADL, CSM | Good |
| Conde-Sala *et al.* (2014a) | 141 | 83 | 77.6 (7.2) | 17.6 (5.9) | AD | Not specified | QoL-AD | Depression, Burden, Gender C | Good |
| Conde-Sala *et al.* (2016) | 221 | 140 | 77.8 (0.4) | 18.3 (0.3) | AD | Not specified | QoL-AD | Awareness, NPS, GDS | Good |
| Crespo *et al.* (2013) | Spain | 102 | 79.40% | 86.07 (6.46) | 13.3 (5.88) | Dementia | Nursing home | QoL-AD | Age, ADL, NPS, Depression, Gender, Diet, GDS, CSM, Medication, Care home stay | Good |
| Dawson *et al.* (2013) | US | 131 | 55.70% | 77.15 (9.45) | 22.48 (5.84) | AD 50%, Mixed .8%, MCI 5.9%, VaD 5.1%, Other 24.6%, other memory diagnosis 13.6% | Community | QoL-AD | Anxiety, ADL, NPS, Depression, Gender, Education, Ethnicity, Relationship, CSM | Satisfactory |
| Dourado *et al.* (2014) | Brazil | 201 | 130 | 75.6 (7.3) | 20.3 (3.8) | AD | Not specified | QoL-AD | Awareness | Good |
| Dourado *et al.* (2016) | 69 | 72% | 76.8 (7.3) | 21.4 (3.5) | AD | Not specified | QoL-AD | Age, ADL, NPS, Depression, Gender, Education, CSM, Duration, Burden, Education C, Age C, Gender C | Good |
| Nogueira *et al.* (2015) | 54 | 18 | 73.1 (6.3) | 20.4 (4.15) | AD | Community | QoL-AD | QoL C | Good |
| de Sousa *et al.* (2013) | 41 | 28 | 77.3 (7.8) | 21.0 (3.93) | AD | Community | QoL-AD | None | Good |
| de Sousa *et al.* (2015) | 69 | 72 | 76.8 (7.3) | 21.4 (3.5) | AD | Not specified | QoL-AD | None | Satisfactory |
| Duhig *et al.* (2012) | France, Italy, Spain, UK, US | 379 | Not specified | Not specified | Not specified | AD | Not specified | EQ-5D | Age, ADL, NPS, Memory rating | Poor |
| Edelman *et al.* (2004a) | US | 36 | 58.30% | 80.5 (5.8) | 16.7 (4.5) | Dementia | Adult day centres | DQoL  QoL-AD | None | Satisfactory |
| Edelman *et al.* (2005) | 27 | 80.00% | 85.3 (5.4) | 16.5 (3.5) | Dementia | Assisted living facility | QoL-AD  DQoL | ADL, Depression, Co-morbidity, CSM | Satisfactory |
| 38 | 85.50% | 86.0 (6.8) | 15.1 (4.0) | Dementia | Special care facilities | QoL-AD  DQoL |
| Ettema *et al.* (2007b) | Netherlands | 67 | 49 | 84.59 (6.04) | GDS 5.28 (.79) | Dementia | Nursing home | COOP/WONCA | ADL, NPS, Depression, Co-morbidity, Social engagement | Good |
| Fleming *et al.* (2016) | Australia | 275 | 211 | 84.33 (8.66) | GDS2 10, GDS3 45, GDS4 55, GDS5 67, GDS6 98 | Controls 51, Dementia 75, AD 1, DLB 1, FTD 1, Huntingtons 11, Korsakoffs 5, PDD 29, VaD 13, Mixed 86, unspecified 2 | Nursing home | DEMQOL | Age, ADL, Gender, Co-morbidity, Diagnosis, Ethnicity, GDS, Care home stay, Medication, Being married, Memory rating | Satisfactory |
| Fonseca *et al.* (2015) | Brazil | 28 | 19 | 77.1 (5.6) | 15.8 (3.9) | AD | Community | QoL-AD | Age, ADL, NPS, Depression, Education, CSM | Satisfactory |
| Fuh and Wang (2006) | Taiwan | 81 | 49 | 77.2 (6.8) | 20.1 (4.5) | AD | Not specified | QoL-AD | Age, ADL, NPS, Depression, Education, Co-morbidity, CSM, Distress | Satisfactory |
| Gallrach (2010) | New Zealand | 53 | 22 | 77.7 | CDR.5 19, CDR1 25, CDR2 8, CDR3 1 | AD 31, VaD 14, Mixed 8 | Community | QoL-AD | ADL, NPS, Depression, Co-morbidity, Diagnosis, GDS, CSM, QoL C, Burden, Distress | Good |
| Gerritsen *et al.* (2005) | Netherlands | 92 | 79% | 79.4 | 18.4 (6.6) | Dementia | Nursing home | Single question - Overall, how would you rate the quality of your life at the moment? | NPS, CSM | Satisfactory |
| Gerritsen *et al.* (2007) | 43 | 78% | 80.5 (9.26) | 11.8 (9.26) | Dementia | Nursing home (low cognition group only) | Single question - Overall, how would you rate the quality of your life at the moment? | Depression | Satisfactory |
| Geschke *et al.* (2013) | Germany | 60 | 38 | 78.7 (6.4) | 20.2 (6.0) | AD 46, VaD 6, Unspecified dementia 8 | Community | QoL-AD  SF-36 | Depression, Co-morbidity, CSM | Poor |
| Gitlin *et al.* (2014) | US | 88 | 46 | 81.7 (8) | 17.7 (4.6) | Dementia | Community | QoL-AD | NPS, Co-morbidity, Unmet needs, Pain, CSM, Depression C | Satisfactory |
| Gómez-Gallego *et al.* (2012a) | Spain | 102 | 70 | 78.09 (7.02) | Mild 38, Moderate 56, Severe 8 | AD | Community | QoL-AD | Anxiety, ADL, NPS, Depression, CSM, Medication, Burden, Distress | Good |
| Gómez-Gallego *et al.* (2012b) | 102 | 70 | 78.09 (7.02) | 18.51 (5.99) | AD | Community | QoL-AD | Gender, Education, Relationship, Being married, Gender C | Good |
| Gómez-Gallego *et al.* (2017) | 192 | 118 | 75.8 (6.14) | 20.41 (3.7) | AD | Community | QoL-AD | ADL | Good |
| Gómez-Gallego *et al.* (2015) | Spain | 81 | 68.60% | 72.09 (6.39) | 18.51 (4.29) | AD | Community | DEMQOL | Depression, Co-morbidity, Pain, CSM | Good |
| Gräske *et al.* (2012) | Germany | 49 | 76 | 79 (9.5) | 11.5 (9.6) | Dementia (83.7%) | Community living in shared housing | QoL-AD | Age, ADL, NPS, Gender, Care home stay, CSM | Satisfactory |
| Harvey *et al.* (2005) | US | 183 | 51.90% | 78.8 | Not specified | AD 171, DLB 5, VaD 7 | Community | QoL-AD | ADL, GDS | Good |
| Heggie *et al.* (2012) | Canada | 102 | 75 | 74.4 (9.5) | 3MS 70.6 (18.7) | Dementia | Community (rural and remote settings) | QoL-AD | Age, ADL, NPS, Depression, Education, GDS, CSM, Burden | Good |
| Hoe *et al.* (2005) | England | 37 | 58 | 80.0 (8.8) | 7.0 (3.2) | AD | Nursing home | QoL-AD | Age, Education | Good |
| Hoe *et al.* (2007) | 191 | 160 | 81 | 14.7 (8.3) | AD | Lived alone 51, Lived with others 91, Lived in care home 82 | QoL-AD | Anxiety, ADL, NPS, Depression, CSM, Medication | Satisfactory |
| Livingston *et al.* (2008) | 195 | 160 | 81.1 (7.5) | 16.7 (6.9) | AD | Not specified | QoL-AD life as whole item | Health, GDS | Good |
| Hoe *et al.* (2006) | England, Wales | 119 | 192 | 86.5 (7.4) | 8.7 (7.8) | Dementia | Nursing home | QoL-AD | Anxiety, ADL, NPS, Depression, Unmet needs, GDS, CSM | Satisfactory |
| Huang *et al.* (2009) | Taiwan | 120 | 58 | 78.40 (9.13) | 18.64 (6.23) | AD | Community | QoL-AD | NPS, Relationship quality, Co-morbidity, GDS, CSM, QoL C | Satisfactory |
| Huang *et al.* (2015) | Taiwan | 106 | 64 | 80.29 (7.86) | 15.39 (5.22) | Dementia | Community 58, Nursing home 48 | QoL-AD | Age, Depression, Gender, Education, Relationship quality, Relationship, GDS, CSM, Being married, Depression C, Education C, Age C, Gender C | Good |
| Hurt *et al.* (2008) | France, England, Greece | 46 | Not specified | 78 | 20.80 (5.4) | Dementia | Community | QoL-AD | Age, Anxiety, NPS, Depression, CSM, Duration | Good |
| Hurt *et al.* (2010) | England, Finland, France, Greece, Italy, Poland | 174 | 107 | 77.2 (6.5) | 20.6 (4.9) | AD | Not specified | DEMQOL | Age, Awareness, ADL, NPS, Depression, Education, CSM, Duration, Being married | Good |
| James *et al.* (2005) | US | 181 | 113 | 76.7 (8.3) | 17.0 (7.1) | AD | Community | Single question - How would you rate your overall quality of life at present? | Age, Depression, Gender, Education, Ethnicity, GDS, CSM, Being married | Satisfactory |
| Karlawish *et al.* (2001a) | 91 | Not specified | Not specified | Not specified | Not specified | Community | Single question - How would you rate the overall quality of your relative’s life at present? | None | Satisfactory |
| Johnson *et al.* (2014) | US | 104 | 70.20% | 77.8 (9.8) | 23.4 (4.24) | Dementia or MMSE <26 | Not specified | QoL-AD | CSM | Satisfactory |
| Jones *et al.* (2015) | England | 150 | 53.80% | 79.7 (8.5) | 14.6 (6.8) | AD | Community 86%, Residential home 14% | EQ-5D  DEMQOL  BASQID | ADL, NPS, CSM | Good |
| Trigg *et al.* (2012a, 2012b) | 166 | 53.80% | 79.7 (8.5) | 14.6 (6.8) | AD | Community 86%, Residential home 14% | BASQID  EQ-5D  DEMQOL | ADL | Good |
| Trigg *et al.* (2015) | 70 | 39 | 78.19 (8.48) | 19.40 (4.67) | AD | Community | EQ-5D  DEMQOL | None | Good |
| Jönsson *et al.* (2006) | Sweden, Denmark, Finland, Norway | 208 | 62.30% | 75.9 | 19.2 | AD | Community | QoL-AD  EQ-5D VAS  EQ-5D | CSM | Good |
| Kamchatnov *et al.* (2002) | Russia | 56 | Not specified | 50-59 | Mild | VaD | Not specified | SF-36 | Anxiety, Depression, CSM | Poor |
| Karim *et al.* (2008) | England | 36 | 18 | 78 | Mild 6, Moderate 30 | Dementia | Not specified | DQoL | Health, CSM | Satisfactory |
| Karlawish *et al.* (2004b) | US | 68 | Not specified | Not specified | 20.3 (4.5) | AD | Not specified | EQ-5D  DDI  HUI2  SF-12 | Awareness, ADL, Depression, CSM | Poor |
| Karlawish *et al.* (2008a) | 93 | 51 | 76.8 (2.7) | 21.3 (4.3) | AD | Community | EQ-5D  HUI2 | Awareness, ADL, Depression, Ethnicity, CSM | Good |
| Zbrozek *et al.* (2006) | 110 | Not specified | Not specified | Not specified | AD | Community | HUI2 | ADL, Depression, CSM | Satisfactory |
| Karttunen *et al.* (2011) | Finland | 228 | 51.30% | 75.1 (6.6) | 21.5 (3.4) | AD | Community | QoL-AD  15D | Age, ADL, NPS, Gender, Education, Income, CSM, Medication, Being married, Depression C | Good |
| Kasper *et al.* (2009) | US | 146 | ≥80% | 60% ≥80 | 75.9% >18 | AD | Community | ADRQL | ADL, Co-morbidity, Relationship, Living alone, CSM, Duration, QoL C, Education C, Age C, Gender C | Satisfactory |
| Katsuno (2003) | Japan | 22 | 18 | 79.0 (6.2) | 20.8 (2.8) | AD 18, VaD 3, unspecified 1 | Community 20, Assisted living 2 | QLI | Religion | Satisfactory |
| Kaufman *et al.* (2007) | Canada | 70 | 69% | 78.43 (8.64) | 23.66 (3.86) | AD | Not specified | QoL-AD  EQ-5D VAS | Age, Gender, Education, Religion, CSM | Good |
| Knorr *et al.* (2007) | Germany | 179 | 61% | 79 | Not specified | Dementia | Not specified | DEMQOL | Age, Depression, Duration, Memory rating | Poor |
| Kosteniuk *et al.* (2014) | Canada | 148 | 99 | 74.5 (8.8) | 3MS 75.2 (14.7) | AD 110, Other 55 | Community | QoL-AD | Depression | Satisfactory |
| Kunz (2010) | Germany | 335 | 67.50% | 80.2 (6.7) | 18.6 (3.8) | Dementia | Community | EQ-5D | ADL, CSM | Satisfactory |
| Lacey *et al.* (2015) | Austria, Canada, Germany, US | 2204 | 1188 | 72.4 (8.94) | 21.0 (3.22) | AD | Community | QoL-AD | ADL, NPS, CSM | Good |
| Lai *et al.* (2015) | Hong Kong | 125 | 71 | 81.34 (7.81) | 15.75 (6.62) | "Cognitively impaired" 99 | Nursing home | WHOQOL-100 | Age, Gender, Diet, Pain, Memory rating | Satisfactory |
| Lapid *et al.* (2011) | US | 34 | 27 | 94.1 (2.7) | 19.1 (4.5) | Dementia with stroke and Parkinsonism | Community | LASA | Depression, CSM | Good |
|  | 41 | 37 | 94.2 (2.8) | 17.7 (5.7) | Dementia | Community |
| León-Salas *et al.* (2011a) | Spain | 40 | 88.10% | 83.2 (6.3) | 12.0 (4.5) | AD 86.8%, Mixed 13.2% | Nursing home | QoL-AD | ADL, NPS, Depression, GDS, Care home stay, CSM, Duration | Good |
| Li *et al.* (2013b) | China | 200 | 112 | 77.62 (7.79) | Not specified | Dementia | Community 180, Hospital 20 | DQoL | NPS, Co-morbidity, Being married | Satisfactory |
| Japan | 205 | 168 | 85.49 (6.89) | Not specified | Dementia | Nursing home 27, Care home 34, Group home 26, Day service 48, Other 70 | NPS, Depression, Education, Diet |
| Logsdon *et al.* (2000) | US | 77 | 47% | 78.3 (6.1) | 17.1 (5.6) | AD | Community | QoL-AD | Depression, Education, Depression C | Satisfactory |
| Logsdon *et al.* (2002) | 155 | 44% | 77.2 (6.8) | 18.1 (5.9) | AD | Community | QoL-AD | ADL, Depression, CSM, Burden, Depression C | Good |
| Logsdon *et al.* (2005) | 95 | 66% | 79.9 (7.7) | 14.0 (7.0) | AD | Community | QoL-AD | Age, Anxiety, Gender, Duration | Satisfactory |
| Lucas-Carrasco *et al.* (2010) | Spain | 102 | 67 | 79.2 (7.0) | 19.49 (4.45) | MCI 19, AD 47, VaD 14, Mixed 10, Other 6, Unknown 6 | Community | DEMQOL | Age, ADL, Depression, Health, Gender, Education, Diagnosis, CSM, Being married | Good |
| Lucas-Carrasco *et al.* (2011a) | 101 | 68 | 79.3 (7) | 19.5 (4.2) | AD 47, VaD 13, Mixed 10, Unspecified 14, Other 17 | Community | DQoL | Age, ADL, Depression, Gender, Education, CSM, Being married | Good |
| Lucas-Carrasco *et al.* (2011b) | 104 | 62.50% | 78.6 (7.2) | 18.3 (4.3) | AD 47, VaD 13, Mixed 10, Unspecified 14, Other 17 | Community | WHOQOL-BREF | Age, ADL, Depression, Health, Gender, Education, Co-morbidity, CSM, Being married | Good |
| Mate *et al.* (2012) | Australia | 167 | 90 | 83.5 (4.8) | CAMCOG-R 71.1 (10.7) | Dementia | Community | WHOQOL-BREF | Age, ADL, Depression, Gender, Diagnosis, CSM, Being married | Good |
| Matsui *et al.* (2006) | Japan | 140 | 84 | 72.4 (7.3) | 20.3 (4.2) | AD | Community | QoL-AD | Age, ADL, NPS, Gender, Education, CSM, Memory rating | Good |
| Menne *et al.* (2009) | US | 211 | 51% | 76.07 (8.95) | 22.01 (4.67) | Dementia | Community | QoL-AD | Age, Depression, Gender, Education, Relationship quality, Co-morbidity, Diagnosis, Ethnicity, Relationship, CSM | Satisfactory |
| Menne *et al.* (2012) | 210 | 49.50% | 75.8 (9.23) | 22 (4.64) | Dementia | Community | QoL-AD | ADL, Health, Religion, Diet, Income, Duration, Social engagement | Good |
| Miranda-Castillo *et al.* (2010a) | England | 152 | 78 | 79.2 (6.8) | 19.13 (7.2) | Dementia | Community | QoL-AD | Unmet needs | Good |
| Miranda-Castillo *et al.* (2010b) | 129 | 78 | 79.85 (6.4) | 19.1 (7.2) | Dementia | Community | QoL-AD | Living alone | Good |
| Mo *et al.* (2004) | Canada | 319 | Not specified | Not specified | Not specified | Dementia | Not specified | HUI3 | Diagnosis | Poor |
| Mulhern *et al.* (2013) | England | 325 | 220 | 79.4 (8.5) | 18.1 (6.6) | AD | Community 305, Nursing home 50 | DEMQOL-short  DEMQOL  EQ-5D | ADL, NPS, Depression, CSM | Good |
| Naglie *et al.* (2006) | Canada | 60 | 37 | 78.6 | 18.9 (4.5) | AD | Own home 49, Senior’s apartment 4, Retirement home 6, Nursing home 1 | EQ-5D  EQ-5D VAS  QWB  QoL-AD | Age, ADL, Depression, Health, Co-morbidity, CSM | Good |
| Naglie *et al.* (2011a) | Canada | 369 | 179 | 80.7 (7.8) | 22.3 (4.3) | AD | Community | EQ-5D  EQ-5D VAS  QWB  QoL-AD | Age, ADL, NPS, Depression, Gender, Education, Co-morbidity, CSM, Being married | Good |
| Naglie *et al.* (2011c) | 272 | 50.2% | 82.2 | 20.2 | AD | Community | EQ-5D  EQ-5D VAS  QWB  QoL-AD | None | Satisfactory |
| Nagpal *et al.* (2015) | US | 111 | 59 | 76.80 (8.90) | 20.7 (3.80) | Dementia | Community | QoL-AD | Education, Religion, Ethnicity, CSM, Being married, Burden, Education C | Satisfactory |
| Nakanishi *et al.* (2011) | Japan | 116 | Not specified | 86.2 (6.0) | 15.1 (4.2) | Dementia | Nursing home | QoL-AD | Age, Anxiety, ADL, NPS, Depression, Gender, Care home stay, GDS, CSM | Satisfactory |
| Nikmat *et al.* (2015a) | Malaysia | 219 | 108 | 72.61 (4.74) | short MMSE 5.52 (2.47) | Cognitive impairment | Home care 109, Nursing home 110 | WHO-8 | Age, ADL, Depression, Health, Gender, Education, Relationship quality, Co-morbidity, Ethnicity, Income, Living alone, CSM, Being married, Social engagement | Good |
| Nikmat *et al.* (2015b) | 49 | 27 | 70.11 | 5.915 | Dementia | Nursing home 30, Community 19 | WHO-8  AQoL-8 | Depression | Good |
| Novella *et al.* (2001a) | Belgium, France, Luxembourg, Switzerland | 108 | 120 | 81.8 (7.0) | 12.75 | AD 107, VaD 18, Alcohol 6, other 17 | Not specified | DHP | Co-morbidity | Satisfactory |
| Novella *et al.* (2001b) | 125 | 76 | 82.7 | 13 | AD 68.42%, VaD 16.54%, Mixed 8.27%, Metabolic/alcohol 2.26%, DLB 1.5%, Other 3% | Community 22.5%, Hospital 36.8%, Institution 40.7% | SF-36 | Co-morbidity | Good |
| Ankri *et al.* (2003) | 130 | 113 | 82.9 (8.32) | 12.8 (5.6) | AD (70.4%) | Community 22.5%, Hospital 36.8%, Institution 40.7% | EQ-5D  EQ-5D VAS | Age, ADL, CSM | Good |
| Novelli and Caramelli (2010) | Brazil | 30 | 73.30% | 75.5 (6.7) | 20.2 (2.6) | AD | Not specified | QoL-AD | None | Good |
| 30 | 66.70% | 76.2 (6.2) | 14.0 (2.8) | AD | Not specified | QoL-AD | None |
| Novelli *et al.* (2010) | 60 | 42 | 75.85 | 17.1 | AD | Not specified | QoL-AD | Age, ADL, NPS, Depression, Education, CSM, QoL C, Depression C, Age C | Good |
| Oremus *et al.* (2012) | Canada | 216 | 106 | 80 | Not specified | AD | Not specified | EQ-5D | Education C | Good |
| Orgeta *et al.* (2015a) | England, Wales | 478 | 238 | 75.5 (7.3) | CDR Mild 74.6%, CDR Moderate 25.4% | Dementia | Community | EQ-5D  EQ-5D VAS | Anxiety, ADL, Depression, Relationship, GDS, Being married, Burden | Satisfactory |
| Orgeta *et al.* (2015b) | 463 | 238 | 77.6 | CDR Mild 74.6%, CDR Moderate 25.4% | Dementia | Community | QoL-AD | Age, Anxiety, ADL, Depression, Health, Gender, Education, Living alone, GDS, Being married, GHQ, Burden, Education C, Age C, Gender C | Good |
| Woods *et al.* (2012) | 479 | 242 | 77.53 (7.3) | CDR Mild 74.6%, CDR Moderate 25.4% | AD 106, VaD 23, DLB 1, Mixed 17, Unknown 36 | Community | QoL-AD  EQ-5D  EQ-5D VAS | Memory rating | Good |
| Perales *et al.* (2014) | England | 110 | 63.60% | 86.6 (3.6) | 21.3 (4.8) | AD 76, VaD 4, Mixed 25, Other dementia 2, AD 2, 1 VaD with delirium 1 | House/flat 78, Sheltered/warden 18, Nursing home 13, Hospital 1 | DEMQOL | Age, ADL, Health, Gender, Education, CSM, Being married | Good |
| Rummel (2012) | US | 27 | 35 | 83.89 (6.78) | 7.94 (7.49) | Dementia | Memory care unit 52%, Skilled nursing facility 35%, Adult day program 13% | QoL-AD | Anxiety, ADL, NPS, Depression, CSM, Burden | Good |
| Sanchez-Arenas *et al.* (2014) | Mexico | 109 | 70 | 78.52 (7.09) | Not specified | 53 AD, 29 VaD, 13 Mixed, 1 Temporal lobe, 1 FTD, 2 Semantic Dementia, 1 CBD, 2 PDD, 4 other | Not specified | EQ-5D  EQ-5D VAS | ADL, Co-morbidity, CSM | Good |
| Schölzel-Dorenbos *et al.* (2011) | Netherlands | 168 | 106 | 78 (6) | 22.7 (3.9) | AD 105, VaD 15, Mixed or other 55 | Community | EQ-5D VAS | Age, ADL, NPS, Depression, Gender, Co-morbidity, GDS, CSM, Distress, Depression C, Education C, Age C, Gender C | Good |
| Schulz *et al.* (2010) | US | 105 | 63 | 77.3 (8.2) | ≤15 26, 16-23 37, ≥24 42 | AD | Community | QoL-AD  DEMQOL  SF-12 | None | Satisfactory |
| Schulz *et al.* (2013) | 79 | 27 | 76.0 (8.5) | 23.1 (3.6) | AD | Community | SF-12 | Age, Gender, Education, Ethnicity, Income, CSM, Being married, Burden, Depression C, Education C, Age C, Gender C | Good |
| Selai *et al.* (2001a) | England | 22 | 10 | 65 (8) | ≥10 | Mostly AD | Community | QOLAS | Age, ADL, Depression, Gender, CSM, Social engagement, GHQ | Satisfactory |
| Shata *et al.* (2015) | Egypt | 100 | 56 | 67.61 (6.41) | 11.86 (1.97) | Dementia | Community | QoL-AD | ADL, Depression | Good |
| Sheehan *et al.* (2012) | England | 48 | 83 | 85 | CDR 0.5 = 2, CDR 1 = 14, CDR 2 = 64, CDR 3 = 29. | Dementia | General hospital inpatients | QoL-AD  EQ-5D | Age, ADL, Depression, Gender, GDS, GHQ | Satisfactory |
| Shin *et al.* (2005) | US | 62 | 36 | 75.53 (7.87) | 19.36 (5.22) | AD | Community | QoL-AD | Anxiety, NPS, Depression | Good |
| Siedlecki *et al.* (2009) | France, US | 277 | 56.70% | 75.79 (7.82) | mMMSE 41.60 (6.23) | AD | Community | AAIQoL | Age, ADL, Depression, CSM | Good |
| Sloane *et al.* (2005) | US | 78 | 79% | 85 | Mild 12%, Moderate 25%, Severe 27%, Very severe 37% | AD 54%, VaD 4%, Mixed 5%, Other 37% | Nursing home | AAIQoL  DQoL  QoL-AD | ADL, NPS, Depression, Pain, CSM | Good |
| Smith *et al.* (2005) | England | 69 | 59 | 78.65 (8.30) | 16.01 (8.53) | Dementia | Community | DEMQOL  DQoL  QoL-AD  SF-12 | Age, ADL, Depression, Gender, CSM | Good |
| Smith *et al.* (2007) | 64 | 43 | 78.49 (8.32) | 19.93 (4.84) | Dementia | Community | DEMQOL  DQoL  QoL-AD | None | Satisfactory |
| Snow *et al.* (2005) | US | 89 | 0 | 74.0 (9.37) | DRS scores <46 9, 47-102 39, 102-139 45 | Dementia | Community | QoL-AD | ADL, NPS, Depression, Pain, CSM, Depression C | Satisfactory |
| de Sousa and do Amaral (2014) | Portugal | 73 | 42 | 77.9 (7.7) | Not specified | AD | Not specified | QoL-AD | Diet | Satisfactory |
| Spector and Orrell (2006) | England | 76 | 67 | 85.2 (7.4) | 13 (4.8) | Dementia | Nursing home | QoL-AD | None | Good |
| Spector *et al.* (2016) | England | 50 | 20 | 78.40 (6.97) | 20.92 (5.20) | Dementia | Community | QoL-AD | Relationship quality | Good |
| Stewart-Archer (2012) | US | 136 | 98 | 85 (7.15) | 16.87 (4.08) | Dementia | Nursing home 89, Community 35, Supportive housing 12 | QoL-AD | Age, Depression, Gender, Education, Income, CSM, Being married | Good |
| Struttmann *et al.* (1999) | France | 27 | 26 | 73.2 (8.0) | Not specified | Dementia | Neurology hospital ward | WHOQOL-100 | Age | Poor |
| Sura *et al.* (2015) | US | 112 | 64 | 65-79 59, ≤80 53 | Not specified | Dementia | Not specified | SF-12 | Age, ADL, Health, Gender, Education, Ethnicity, Income, Medication, Being married | Satisfactory |
| Trigg *et al.* (2007) | England | 47(sample 1) | 32 | <65 7, 65-74 24, 75-84 19, ≤85 10 | 18.44 (4.07) | AD 49, VaD 8, FTD 3 | Living alone 8, Living with spouse 45, Living with relative/other 5, Residential 2 | BASQID | Depression | Good |
| England | 143(sample 2) | 88 | <65 8, 65-74 29, 75-84 85, ≤85 28 | 18.06 (4.63) | AD 123, VaD 19, FTD 8 | Living alone 25, Living with spouse 93, Living with relative/other 21, Residential 11 | BASQID | Age, CSM |
| Trigg *et al.* (2011) | England | 69 | 30 | <65 3, 65-74 10, 75-84 49, ≤85 7 | 22.43 (2.44) | AD 54, VaD 7, FTD 5, DLB 3 | Living alone 14, Living with spouse 49, Living with relative/other 6 | BASQID | Age, Awareness, ADL, Gender, CSM | Good |
| Trigg *et al.* (2012c) | 53 | 30 | 78.77 (6.53) | 21.96 (2.89) | AD 45, VaD 9, FTD 3, DLB 3 | Living alone 14, Living with spouse 49, Living with relative/other 6 | BASQID | None | Good |
| Vogel *et al.* (2006) | Denmark | 48 | Not specified | 77.0 (5.8) | 24.9 (2.3) | AD | Community | QoL-AD  EQ-5D VAS | Age, NPS, Depression, Gender, CSM | Good |
| Voigt-Radloff *et al.* (2012) | Germany, Netherlands | 285 | 163 | 77.3 (7.2) | 20.8 (3.5) | AD or VaD | Community | DQoL | ADL, Depression, CSM | Good |
| Whitlatch *et al.* (2005) | US | 97 | 60 | 77 (9) | 20.7 (3.8) | AD 42%, Non-specific dementia 25%, stroke 11%, Other dementia 11%, PD 8%, Other 3% | Community | QoL-AD | Social engagement | Satisfactory |
| Winter *et al.* (2011) | Russia | 98 | 64 | 77.5 (8.8) | ≤14 83 | AD or VaD | Not specified | EQ-5D VAS  EQ-5D | Age, Gender | Satisfactory |
| Wlodarczyk *et al.* (2004) | Australia | 69 | 60 | 71.7 (8.5) | 21.09 | AD | Australian elderly care centres | AQoL | ADL, CSM | Good |
| Wolak *et al.* (2009) | France, Switzerland | 120 | 77 | 82.2 (6.0) | 20.8 (4.5) | AD | Living alone 28, Living with spouse 70, Institution/sheltered 18, Other 3 | QoL-AD | ADL, NPS, Co-morbidity, CSM, Burden, Distress | Satisfactory |
| Wolak *et al.* (2010) | 155 | 98 | 81.8 (6.0) | 20.8 (4.4) | AD 122, Other 33 | Living alone 28, Living with spouse 70, Institution/sheltered 18, Other 3 | DQoL | Burden | Good |
| Wolak *et al.* (2011) | 150 | 98 | 81.8 (6.0) | 20.8 (4.4) | AD 122, Other 33 | Mix community and institution | DQoL | ADL, NPS, Depression, GDS, CSM | Good |
| Wolak-Thierry *et al.* (2015) | 123 | 63.40% | 82.0 (6.0) | MMSE ranged between 11-29 | AD | Not specified | QoL-AD  DQoL | NPS, Depression, GDS | Good |
| Barbe *et al.* (2017) | 121 | 78 | 82.0 (6.2) | 20.7 (4.5) | AD | Community 103 | DQoL | Age, Anxiety, ADL, Education, Diet, Medication | Good |
| Woods *et al.* (2006) | England | 201 | 158 | 85.3 (7.0) | 14.4 (3.8) | Dementia | Residential 172 | QoL-AD | Anxiety, NPS, Depression, GDS, CSM | Good |
| Thorgrimsen *et al.* (2003) | 201 | 158 | 85.3 (7.0) | 14.4 (3.8) | Dementia | Residential 172 | QoL-AD | None | Good |
| Selwood *et al.* (2005) | 24 | 42 | 81.5 (6.0) | 9.8 (7.4) | Dementia | Inpatient, Day hospital, Nursing home, Residential home | DQOL | None | Good |
| Woods *et al.* (2014) | Wales | 98 | 54 | 78.7 (7.7) | 24.2 (2.8) | AD 51, VaD 30, Mixed 20 | Community | QoL-AD | Age, Anxiety, Awareness, ADL, NPS, Depression, Education, Relationship quality, CSM, GHQ, Distress, Age C, Religion\*, Co-morbidity\*, Diagnosis\*, Being married\*, Education C\*, Gender C\* | Good |
| Nelis *et al.* (2012) | 97 | 46 | 77.98 (7.68) | 24.43 (2.64) | AD 59, VaD 25, Mixed 13 | Community | QoL-AD | Gender | Good |
| Clare *et al.* (2013) | 95 | 49 | 78.56 (7.91) | 24.13 (2.87) | AD 49, VaD 29, Mixed 17 | Community | QoL-AD | None | Good |
| Clare *et al.* (2014b) | 51 | 25 | 76.75 (7.88) | 24.5 (2.80) | AD 31, VaD 11, Mixed 9 | Community | QoL-AD | Medication | Good |
| Yap *et al.* (2008) | Singapore | 67 | 45 | 78.4 (7.5) | 16.1 (5.4) | AD 58.6%, mixed 32.8%, VaD 6.9%, PDD 1.7% | Live with spouse 81.7% | QoL-AD | ADL, Depression, GHQ | Satisfactory |
| Yeager and Hyer (2008) | US | 25 | 60% | 77 | Not specified | AD or Dementia | Community | 5 items from GDS-15 | NPS | Satisfactory |
| Yeaman *et al.* (2013) | US | 10 | 0 | 82.5 (4.99) | 17.8 (6.07) | AD | Community | QoL-AD | ADL | Satisfactory |
| Yu *et al.* (2013) | China | 195 | 48% | 73.6 (7.7) | MoCA 7.26 (5.51) | AD | Community | QoL-AD | Anxiety, ADL, Depression | Good |
| Zimmerman *et al.* (2005) | US | 71 | Not specified | Not specified | 7.5 | Dementia | Residential care or Assisted living | DQoL  AAIQoL  QoL-AD | Medication | Good |
| Zucchella *et al.* (2015) | Italy | 135 | 93 | 78.2 (5.9) | 15.3 (7.5) | AD | Live with carer 56.3% | QoL-AD | ADL, Depression | Satisfactory |

Note: articles were judged to be of poor quality if scored ≤20 or below, satisfactory scored between >20 and <26, good scored ≥26. Shading indicates articles using the same study data. “Severity” refers to Mini-Mental State Examination score unless otherwise specified. \* indicates data not reported in articles

Quality of life measure abbreviations: 12-Item Short Form Health Survey (SF-12), 15-dimensional (15D), 36-Item Short Form Health Survey (SF-36), Activity and Affect Indicators of QOL (AAIQoL), Alzheimer's Disease Related Quality of Life (ADRQL), Assessment of Quality of Life (AQoL), Bath Assessment of Subjective Quality of Life in Dementia (BASQID), Dartmouth COOP Functional Health Assessment charts/WONCA (COOP/WONCA), Dementia Quality of Life Questionnaire (DEMQOL), Dementia Quality of Life Instrument (DQoL), Disability and Distress Index (DDI), Duke Health Profile (DHP), EuroQol five dimensions questionnaire (EQ-5D), Geriatric Depression Scale-15 (GDS-15), Health Utility Index (HUI), Linear Analogue Self Assessment (LASA), Quality of Life Assessment Schedule (QOLAS), Quality of Life Index (QLI), Quality of Life in Alzheimer's Disease (QoL-AD), Quality of Well-Being scale (QWB), Self-Reported Quality of Life Scale (SRQLS), Visual Analogue Scale, (VAS), World Health Organization (WHO), World Health Organization Quality of Life (WHOQOL)

Severity abbreviations: Cambridge Cognition Examination (CAMCOG), Clinical Dementia Rating (CDR), Dementia Rating Scale (DRS), Global Deterioration Scale (GDS), Mini-Mental State Examination (MMSE), Modified Mini-Mental State Examination (3MS), Modified Mini-Mental State Examination (mMMSE), Montreal Cognitive Assessment (MoCA)

Dementia type abbreviations: Alzheimer's disease (AD), Behavioural-variant frontotemporal dementia (bvFTD), Corticobasal degeneration (CBD), Dementia with Lewy bodies (DLB), Frontotemporal Dementia (FTD), mild cognitive impairment (MCI), Parkinson's Disease Dementia (PDD), Primary Progressive Aphasia (PPA), Vascular dementia (VaD)

Factors included in the meta-analysis abbreviations: Alzheimer’s (vs. other dementia subtypes) (Diagnosis), Better functional ability (ADL), Better quality of relationship with carer (Relationship quality), Better self-rated health (Health), Better self-rated memory functioning (Memory rating), Burden or stress (Burden), Cared for by spouse (vs. other carer type) (Relationship), Carer Depression (Depression C), Carer quality of life (self-rated) (QoL C), Distress at NPS symptoms (Distress), Female gender (Gender), Female gender carer (Gender C), Greater social engagement (Social engagement), Higher income (Income), Higher level of education (Education), Higher level of carer education (Education C), Higher scores on cognitive screening measures (CSM), Longer duration of care home stay (Care home stay), Longer disease duration (Duration), More advanced dementia (GDS), More awareness (Awareness), Neuropsychiatric symptoms/BPSD (NPS), Older age (Age), Older age carer (Age C), Poorer mental health (General Health Questionnaire (GHQ)) (GHQ), Presence of co-morbid conditions (Co-morbidity), Presence of religious beliefs/spirituality (Religion), Presence of unmet needs (Unmet needs), Taking medication (Medication), Underweight (Diet), White ethnicity (Ethnicity)

**Supplementary Table 4. Studies utilising informant ratings of quality of life in people with dementia**

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Study** | **Country of study** | **Relationship of informant to person with dementia** | **n** | **Females** | **Mean age** | **Severity** | **Dementia type** | **Living situation** | **QoL measure** | **Factors included in the meta-analysis** | **Quality rating** |
| Albert *et al.* (2000) | US | Mix | 145 | Not specified | 76 (8.7) | Not specified | AD | Mostly community | AAIQoL | ADL, GDS, CSM | Satisfactory |
| US | Mix | 196 | Not specified | 83.5 (7.5) | Not specified | AD | Mostly community | AAIQoL | ADL, GDS |
| Albert *et al.* (1996) | US | Mix | 130 | 60.50% | 72.4 (8.1) | 37.8 (5.9) | AD | Mostly community | AAIQoL | None | Satisfactory |
| Albert *et al.* (2001) | Mix | 150 | Not specified | 74.18 (8.05) | Not specified | AD | Mostly community | AAIQoL | NPS | Good |
| Andrieu *et al.* (2016) | France | Family | 526 | 331 | 79.6 (5.9) | 19.5 (3.9) | AD | Community | QoL-AD | Age, Anxiety, ADL, NPS, Depression, Gender, Education, Co-morbidity, Diet, Relationship, Living alone, CSM, Medication, Duration, Burden, Age C, Gender C | Good |
| Arismendi Arismendi *et al.* (2013) | Spain | Family | 58 | 37 | 81.2 (6.3) | Not specified | AD | Not specified | EQ-5D VAS | Age, Gender, Co-morbidity, Relationship, Medication, Duration | Satisfactory |
| Arlt *et al.* (2008) | Germany | Family | 97 | 54 | 70.49 (8.49) | 22.74 (4.37) | AD 58%, Mixed and MCI 11%, bvFTD 9%, VaD 7%, Semantic dementia 1% | Community 95, Nursing home | WHO-8  SF-12 | Depression, GDS, CSM | Good |
| Arons *et al.* (2013) | Netherlands | Family | 175 | 106 | 78.6 (5.7) | Not specified | AD 105, VaD 15, Mixed 49, Other 6 | Not specified | EQ-5D VAS  EQ-5D | Age, Gender | Good |
| Barca *et al.* (2011) | Norway | Family | 156 | 103 | 82.9 (7.7) | 11.1 (8.2) | AD 107, VaD 18, Other 31 | Nursing homes 82, Geriatric psychiatry departments 74 | QUALID | Age, ADL, Depression, Gender, Co-morbidity, Living alone, GDS, CSM, Being married | Satisfactory |
| Beer *et al.* (2010) | Australia | Health care professional | 324 | Not specified | 85.3 (7.9) | 14 (median) | Dementia | Residential care facilities | QoL-AD  ADRQL | Age, NPS, Gender, Diet, Pain, CSM, Medication, Distress | Satisfactory |
| Family | 292 |
| Beerens *et al.* (2014) | England, Estonia, Finland, France, Germany, Netherlands, Spain, Sweden | Health care professional | 791 | 74% | 84.1 (6.4) | 11.9 (6.3) | Dementia | Long-term care residents | QoL-AD | Depression, Pain, Medication | Good |
| Family | 1123 | 63% | 82.2 (6.6) | 14.3 (6.6) | Dementia | Home care |
| Giebel *et al.* (2014) | Mix | 263 | 154 | 82.6 (5.6) | 21.8 (1.4) | AD 139, VaD 41, Mixed 14, FTD 2, DLB 9, Other 58 | Care home or community but at risk of care home within 6 months | QoL-AD | Age, ADL, NPS, Diagnosis | Good |
| Mix | 521 | 365 | 82.7 (6.6) | 15 (2.9) | AD 282, VaD 81, Mixed 35, FTD 2, DLB 8, Other 105 |
| Mix | 242 | 156 | 81.2 (6.9) | 4.8 (3.5) | AD 122, VaD 52, Mixed 12, DLB 5, Other 50 |
| Giebel *et al.* (2015a) | Mix | 122 | 71.30% | 83 (6.5) | 13.37 (2.27) | AD 44, VaD 39, Mixed 8, FTD 2, DLB 5 | Community 63, Care home 59 | QoL-AD | Living alone, CSM, Age C | Good |
| Giebel *et al.* (2015b) | Mix | 414 | 71.30% | 82 (6.8) | 4.9 (3.1) | dementia | Community 214, Care home 197 | QoL-AD | None | Good |
| Giebel *et al.* (2016b) | Family | 957 | 596 | 82.3 (6.5) | 14.5 (6.6) | AD 514, VaD 153, Mixed 53, Other 227 | Community (home care) | QoL-AD | None | Good |
| Family | 581 | 423 | 84.3 (6.1) | 12.1 (6.2) | AD 248, VaD 127, Mixed 35, Other 171 | Nursing home (Long term care) | QoL-AD |
| Benhabib *et al.* (2013) | Canada | Health care professional | 31 | 2 | 85.8 (3.7) | 8.7 (6.7) | AD | Long-term care residents | QUALID | Anxiety, NPS, Depression, GDS | Satisfactory |
|  |  |  |  |  |  |  |  |  |  |  |  |
| Bhattacharya *et al.* (2010) | Denmark | Family | 321 | 54.80% | 76.2 (7.1) | 24.0 (2.6) | AD 72.4%, Mixed 24.8% | Community | EQ-5D  EQ-5D VAS  QoL-AD | ADL, NPS, Depression, CSM | Satisfactory |
| Vogel *et al.* (2012) | Family | 102 | 76 (7.1)  Baseline | 76 (7.1) Baseline | 22.7 (0.41) 12 months; 18.0 (0.75) 18 months | AD | Community (91% at 12-month, 86.3% at 36-month) | QoL-AD  EQ-5D VAS | None | Good |
| Black *et al.* (2012) | US | Family | 254 | 65% | 83.6 | 17.8 | Dementia | Community | QoL-AD  ADRQL | Age, ADL, NPS, Depression, Health, Gender, Education, Co-morbidity, Ethnicity, Relationship, CSM Medication, QoL C, Burden, Distress, Depression C, Education C, Age C, Gender C, Time caring (community) | Good |
| Black *et al.* (2013) | Family | 254 | 65% | 83.6 (5.9) | 17.8 (7.6) | 265 AD, 38 MCI | Community | QoL-AD  ADRQL | None | Good |
| Bosboom *et al.* (2012b) | Australia | Family | 80 | 67.50% | 78.3 (7.9) | Not specified | AD | Community | QoL-AD | Age, Anxiety, Awareness, ADL, NPS, Depression, Gender, Education, Living alone, Medication, Being married, Memory rating, Distress, Age C, Gender C | Good |
| Bosboom and Almeida (2014) | Family | 47 | 72.30% | 78.7 (8.2) | 15.1 (5.6) | AD | Community | QoL-AD | CSM | Good |
| Bosboom *et al.* (2013) | Family | 47 | 72.30% | 78.7 (8.2) | 15.1 (5.6) | AD | Community | QoL-AD | None | Satisfactory |
| Bosboom and Almeida (2016) | Family | 80 | 67.50% | 78.3 (7.9) | Not specified | AD | Community | QoL-AD | None | Good |
| Boyer *et al.* (2004) | Belgium, France, Luxembourg, Switzerland | Family  Health care professional | 95 | 76 | 81.8 (8.2) | 15.7 (4.1) | AD 68, VaD 16, Mixed 8, Other 8 | Community 20%, Hospital 40%, Institution 40% | NHP | Age, ADL, Gender, Living alone, CSM, Duration | Good |
| Bruvik *et al.* (2012) | Norway | Family | 230 | 123 | 78.4 (7.5) | 21.3 (3.6) | Dementia | Community | QoL-AD | Age, ADL, NPS, Depression, Gender, Education, CSM, Duration, Being married | Satisfactory |
| Bryan *et al.* (2005) | England | Family  Health care professional | 64 | 36 | 76 (53-91) | 18 (5.8) (3-26) | AD or VaD | Community | EQ-5D | Anxiety, ADL, NPS, Depression | Good |
| Buckley *et al.* (2012) | US | Family | 81 | 151 | 85.60 (5.77) | 19.78 (7.25) | AD 181, remainder not specified | Not specified | Single global QoL question (rated self as excellent) | ADL, NPS, Health, Gender, Education, GDS, CSM, Duration | Good |
| 144 | Single global QoL question (rated self as good) |
| Castro-Monteiro *et al.* (2016) | Spain | Mix | 525 | 434 | 85.57 (6.73) | 13.24 (8.07) | Non-specific dementia (49.7%), AD (36.4%), VaD (6.5%), Mixed (4.4%), Alcohol-related dementia (1.1%), DLB (1.1%), PDD (.8%) | Residential care facilities | QoL-AD  QUALID | Age, ADL, Depression, Gender, Co-morbidity, GDS, CSM | Satisfactory |
| Castro-Monteiro *et al.* (2014) | Health care professional | 274 | 224 | 84.70 (6.51) | 12.96 (8.51) | Dementia | Residential care | EQ-5D  QoL-AD | None | Satisfactory |
| Díaz-Redondo *et al.* (2014) | Mix | 525 | 434 | 85.57 (6.73) | 13.24 (8.07) | Mostly AD | Nursing home | EQ-5D  EQ-5D VAS | Age, Depression, Gender, Education, Co-morbidity, GDS, CSM | Good |
| Chan *et al.* (2011) | Hong Kong | Family | 111 | 80 | 77.7 (7.4) | 15.8 (4.7) | AD | Community | QoL-AD | Age, Depression, Gender, Education, Co-morbidity, Living alone, CSM, Being married, Time caring (community) | Good |
| Chiu *et al.* (2008) | Taiwan | Family | 51 | 61.20% | 75.23 (8.03) | 17.61 (3.78) | AD | Not specified | DQoL | Age, ADL, NPS, Depression, Education, CSM, Depression C | Satisfactory |
| Clare *et al.* (2014a) | Wales | Family  Health care professional | 105 | 72 | 81.47 (8.63) | FAST 6 25, FAST 7 80 | Dementia 40, AD 26, VaD 19, Mixed 6, FTD/Picks 3, CADASIL 1, Not stated 10 | Nursing home | QUALID | Age, ADL, NPS, Gender, Relationship, Care home stay, Medication, Memory rating, PCC | Good |
| Cohen-Mansfield *et al.* (2015) | US | Health care professional | 179 | 72.10% | 86.08 (8.62) | 8.79 (6.44) | Dementia | Nursing home | SDS | ADL, Pain, CSM, Memory rating | Good |
| Conde-Sala *et al.* (2009) | Spain | Family | 236 | 157 | 77.8 (6.9) | Mild 76, Moderate 154, Severe 6 | Dementia | Community | QoL-AD | Age, Anxiety, NPS, Depression, Gender, Education, Living alone, CSM, Being married, QoL C, Burden | Good |
| Conde-Sala *et al.* (2010) | Family | 251 | 166 | 77.4 | 18.05 | Dementia | Community | QoL-AD | ADL, Relationship, Education C, Gender C | Satisfactory |
| Conde-Sala *et al.* (2014b) | Family | 119 | 76 | 77.0 (6.7) | 18.9 (3.6) | Dementia | Community | QoL-AD | None | Good |
| Conde-Sala *et al.* (2013b) | Spain | Family | 221 | 140 | 78.6 (74.4-82.5) | 19.0 (15.0-22.5) | AD | Not specified | QoL-AD | Depression, Gender, Education, GDS, CSM, Being married, QoL C, Burden | Good |
| Conde-Sala *et al.* (2013a) | Family | 164 | 98 | 77.6 (7.2) | 17.9 (5.8) | AD | Not specified | QoL-AD | Awareness, ADL | Good |
| Conde-Sala *et al.* (2014a) | Family | 141 | 83 | 77.6 (7.2) | 17.6 (5.9) | AD | Not specified | QoL-AD | Gender C | Good |
| Conde-Sala *et al.* (2016) | Family | 221 | 140 | 77.8 (0.4) | 18.3 (0.3) | AD | Not specified | QoL-AD | Awareness, NPS | Good |
| Cordner *et al.* (2010) | US | Family  Health care professional | 119 | 65 | 81.6 (6.8) | SIRS 10.3 (6.7) | Dementia | Nursing home | Single question - How would you rate [resident’s] overall quality of life in the past two weeks?  ADRQL | Age, NPS, Gender, Education, Co-morbidity, Ethnicity, GDS, Care home stay, Duration | Satisfactory |
| Crespo *et al.* (2013) | Spain | Family  Health care professional | 197 | 79.40% | 86.07 (6.46) | 13.3 (5.88) | Dementia | Nursing home | QoL-AD | Age, ADL, NPS, Depression, Gender, Diet, GDS, Relationship, Care home stay, CSM, Medication, Dementia unit, Burden, Depression C, Age C, Gender C | Good |
| Dooley and Hinojosa (2004) | US | Family | 40 | 24 | 77.08 (8.86) | Not specified | AD | Community | AAIQoL | Burden | Satisfactory |
| Dourado *et al.* (2016) | Brazil | Family | 69 | 72% | 76.8 (7.3) | 21.4 (3.5) | AD | Not specified | QoL-AD | Age, Awareness, ADL, NPS, Depression, Gender, Education, CSM, Duration, Burden, Education C, Age C, Gender C | Good |
| de Sousa *et al.* (2013) | Family | 41 | 28 | 77.3 (7.8) | 21.0 (3.93) | AD | Community | QoL-AD | None | Good |
| de Sousa *et al.* (2015) | Family | 69 | 72 | 76.8 (7.3) | 21.4 (3.5) | AD | Not specified | QoL-AD | None | Satisfactory |
| Edelman *et al.* (2005) | US | Health care professional | 55 | 80.00% | 85.3 (5.4) | 11.1 (6.8) | Dementia | Assisted living facility | QoL-AD  ADRQL | ADL, Depression, Co-morbidity, CSM, Dementia unit | Satisfactory |
| Health care professional | 117 | 85.50% | 86.0 (6.8) | 7.9 (6.8) | Dementia | Special care facilities | QoL-AD  ADRQL | ADL, Depression, Co-morbidity, CSM | Satisfactory |
| Edelman *et al.* (2004a) | Health care professional | 54 | 58.30% | 80.5 (5.8) | 16.7 (4.5) | Dementia | Adult day centres | QoL-AD  ADRQL | None | Satisfactory |
| Falk *et al.* (2007) | Sweden | Health care professional | 169 | 148 | 86 (6) | 10 (7) | AD, DLB and VaD 39,  Multi-infarct dementia, Cerebrovascular infarcts, Postsubarachnoidal  bleeding 39, Mixed 8, Non-specified dementia 83. | Dementia special care units | QUALID | NPS, Depression, CSM, Medication | Good |
| Fuh and Wang (2006) | Taiwan | Family | 81 | 49 | 77.2 (6.8) | 20.1 (4.5) | AD | Not specified | QoL-AD | Age, ADL, NPS, Depression, Education, Co-morbidity, CSM, Distress | Satisfactory |
| Gallrach (2010) | New Zealand | Family | 53 | 22 | 77.7 | CDR.5 19, CDR1 25, CDR2 8, CDR3 1 | AD 31, VaD 14, Mixed 8 | Community | QoL-AD | ADL, NPS, Depression, Co-morbidity, Diagnosis, GDS, CSM, QoL C, Burden, Distress, Time caring (community) | Good |
| Garre-Olmo *et al.* (2010) | Spain | Health care professional | 160 | 123 | 82.6 (11.6) | 4.1 (6.3) | Dementia | Long-term care | QUALID | NPS, Pain, CSM | Good |
| Garre-Olmo *et al.* (2012) | Health care professional | 160 | 123 | 82.6 (11.6) | 4.1 (6.3) | Dementia | Long-term care | QUALID | ADL, Pain | Good |
| Geschke *et al.* (2013) | Germany | Family | 60 | 38 | 78.7 (6.4) | 20.2 (6.0) | Dementia | Community | QoL-AD  SF-36 | Depression, Co-morbidity, CSM | Good |
| Giebel *et al.* (2016a) | England | Family | 20 | 8 | 77 (8.3) | 23.6 (2.26) | AD 40%, Not specified 60% | Community | QoL-AD | ADL, GHQ | Good |
| Gitlin *et al.* (2014) | US | Family | 88 | 46 | 81.7 (8) | 17.7 (4.6) | Dementia | Community | QoL-AD | NPS, Co-morbidity, Pain, CSM, Depression C | Satisfactory |
| Goldfeld *et al.* (2012) | US | Health care professional | 319 | 86.20% | 85.4 | Not specified | Dementia | Nursing home | HUI2 | Co-morbidity | Satisfactory |
| Gómez-Gallego *et al.* (2012a) | Spain | Family  Health Care Professional | 102 | 70 | 78.09 (7.02) | 38 mild >20, 56 moderate 11-20, 8 severe <11 | AD | Community | QoL-AD | Anxiety, ADL, NPS, Depression Relationship, CSM, Being married, Burden, Distress | Satisfactory |
| Gómez-Gallego *et al.* (2012b) | Family  Health Care Professional | 102 | 70 | 78.09 (7.02) | 18.51 (5.99) | AD | Community | QoL-AD | Age, Gender, Education, Medication, Being married, Gender C | Satisfactory |
| González-Salvador *et al.* (2000) | US | Health care professional | 120 | 96 | 81.6 (7.9) | 5.8 (6.9) | AD 78, VaD 26, Other 16 | Long term care | ADRQL | Age, NPS, Depression, GDS, Care home stay, CSM, Medication, Age C, Time caring (care home) | Satisfactory |
| Gräske *et al.* (2012) | Germany | Health care professional | 104 | 76 | 79 (9.5) | 11.5 (9.6) | Dementia (83.7%) | Community in shared housing | QoL-AD | ADL, NPS, | Satisfactory |
| Gräske *et al.* (2014b) | Family | 104 | 73% | 79.0 (9.5) | GDS | Dementia (83.6%) | Not specified | ADRQL  QoL-AD  QUALIDEM | Age, Gender, GDS, CSM | Good |
| Gräske *et al.* (2014a) | Germany | Health care professional | 133 | 105 | 85.4 (7.2) | GDS4 2, GDS5 4, GDS6 29, GDS7 98 | Dementia | Care home | ADRQL  QUALIDEM | NPS, Gender, GDS, Burden, Time caring (care home) | Good |
| Harvey *et al.* (2005) | US | Family | 183 | 51.90% | 78.8 | Not specified | AD 171, DLB 5, VaD 7 | Community | QoL-AD | ADL, GDS | Good |
| Heggie *et al.* (2012) | Canada | Family | 114 | 75 | 74.4 (9.5) | 3MS 70.6 (18.7) | Dementia | Community (rural and remote settings) | QoL-AD | Age, ADL, NPS, Depression, Education GDS, CSM, Burden | Good |
| Hendriks *et al.* (2014) | Netherlands | Health care professional | 330 | 67% | 85.2 (7.4) | Not specified | AD 43%, VaD 24%, Mixed 19%, DLB/PDD 6%, Other 9% | Nursing home | QUALID | NPS, Pain | Good |
| Hoe *et al.* (2006) | England, Wales | Health care professional | 224 | 192 | 86.5 (7.4) | 8.7 (7.8) | Dementia | Residential care homes | QoL-AD | Anxiety, ADL, NPS, Depression, GDS, CSM | Satisfactory |
| Hoe *et al.* (2007) | England | Mix  Family 167  Health Care Professional 24 | 191 | 160 | 81 | 14.7 (8.3) | AD | Lived alone 51, Lived with others 91, Lived in care home 82 | QoL-AD | Anxiety, ADL, NPS, Depression, CSM, Medication, Depression C, Time caring (care home) | Satisfactory |
| Huang *et al.* (2009) | Taiwan | Family | 120 | 58 | 78.40 (9.13) | 18.64 (6.23) | AD | Community | QoL-AD | NPS, GDS, CSM | Satisfactory |
| Huang *et al.* (2015) | Taiwan | Family | 106 | 64 | 80.29 (7.86) | 15.39 (5.22) | Dementia | Nursing home 48, Community 58 | QoL-AD | Age, Depression, Gender, Education, Co-morbidity, Relationship, GDS, CSM, Being married, Community vs residential, QoL C, Depression C, Education C, Age C, Gender C, Time caring (care home) | Good |
| Hurt *et al.* (2008) | France, England, Greece | Family | 116 | 104 | 74.80 (8.36) | 16.5 (6.79) | Dementia | Community | QoL-AD | Age, Anxiety, NPS, Depression, CSM, Duration, Distress, Time caring (community) | Good |
| James *et al.* (2005) | US | Family | 173 | 113 | 76.7 (8.3) | 17.0 (7.1) | AD | Community | Single question - How would you rate the overall quality of your relative’s life at present? | Age, Depression, Gender, Education, Ethnicity, GDS, CSM, Being married | Satisfactory |
| Karlawish *et al.* (2001b) | Family | 40 | 27 | 74.9 (8.0) | 16.3 (7.8) | AD | Community | Single question - How would you rate the overall quality of your relative’s life at present? | NPS, Health, Burden, Depression C, Age C, Gender C | Satisfactory |
| Jönsson *et al.* (2006) | US | Family | 208 | 62.30% | 75.9 | 19.2 | AD | Community | QoL-AD  EQ-5D VAS  EQ-5D | Age, NPS, Gender, Education, Living alone, CSM, Medication, Community vs residential | Good |
| Bostrom *et al.* (2007) | Family | 34 | 15 | 77.4 | 17.3 | DLB | Community | EQ-5D | ADL, Living alone | Good |
| Karlawish *et al.* (2004a) | US | Family | 68 | Not specified | Not specified | 20.3 (4.5) | AD | Not specified | EQ-5D  DDI  HUI2  SF-12 | ADL, CSM, Burden, Depression C | Poor |
| Karlawish *et al.* (2008b) | Family | 100 | Not specified | 76.8 (2.7) | 20.83 (4.44) | AD | Community | EQ-5D  HUI2 | ADL, CSM, Burden | Good |
| Zbrozek *et al.* (2006) | Family | 110 | Not specified | Not specified | Not specified | AD | Community | HUI2 | ADL, CSM, Depression C | Satisfactory |
| Karttunen *et al.* (2011) | Finland | Family | 240 | 51.30% | 75.1 (6.6) | 21.5 (3.4) | AD | Community 70% with spouse, 30% alone | VAS  QoL-AD | Age, ADL, GDS, Medication, Depression C | Good |
| Kavirajan *et al.* (2009) | US | Family | 408 | 224 | 80 (7) | Not specified | AD 304, VaD 31, Other 63 | Community 387 | HUI2  HUI3 | NPS, Depression, Co-morbidity, GDS | Good |
| Kazui *et al.* (2008) | Japan | Health care professional | 91 | 73.60% | 84.1 (6.9) | Not specified | AD 28, VaD 31, Other 2, Unknown 30 | Care home | QLQD | Age, Gender, GDS, Care home stay | Poor |
| Kerner *et al.* (1998) | US | Family | 159 | 35.70% | 73.7 (7.1) | Not specified | AD | Community | QWB | CSM, NPS | Satisfactory |
| Khoo *et al.* (2013) | Singapore | Family | 627 | 459 | 78 (8) | CDR.5 53, CDR1 256, CDR2 302, CDR3 56 | AD 320, AD with CVD 241, VaD 84, Other 22 | Not specified | QoL-AD | Anxiety, NPS, Depression | Good |
| Kolanowski *et al.* (2009) | US | Researcher | 87 | 77% | 85.7 (6.3) | 14.2 (4.5) | Dementia | Nursing home | Activity engagement | CSM | Good |
| Kolanowski *et al.* (2014) | Researcher | 128 | 77% | 86.11 (6.0) | 14.2 (4.5) | Dementia | Nursing home | Activity engagement | None | Satisfactory |
| Kolanowski *et al.* (2002) | US | Researcher | 1 | 0 | 79 | 4 | AD | Dementia care unit | OERS | None | Good |
| Kunz (2010) | Germany | Family | 351 | 67.50% | 80.2 (6.7) | 18.6 (3.8) | Dementia | Community | EQ-5D | ADL, CSM | Satisfactory |
| Kuo *et al.* (2010) | Taiwan | Family | 140 | 69 | 79.7 | Mild 33, Mild-moderate 42, Moderate 30, Severe 35 | Dementia | Community 89, Care home 51 | EQ-5D | ADL, CSM, Community vs residential, Time caring (care home) | Satisfactory |
| Lacey *et al.* (2015) | Austria, Canada, Germany, US | Family | 2204 | 1188 | 72.4 (8.94) | 21.0 (3.22) | AD | Community | QoL-AD  HUI3 | ADL, NPS, CSM | Good |
| McLaughlin *et al.* (2010) | Family | 166 | 93 | 75.9 (6.8) | 20.3 (4.6) | AD | Community | QoL-AD  HUI3 | GDS | Good |
| Lapid *et al.* (2011) | US | Family | 41 | 37 | 94.2 (2.8) | 17.7 (5.7) | Dementia | Community | LASA | Depression, CSM | Good |
| Family | 34 | 27 | 94.1 (2.7) | 19.1 (4.5) | Dementia with stroke and Parkinsonism | Community |
| Lawton *et al.* (1996) | US | Researcher | 237 | Not specified | 87.82 (5.83) | Not specified | Dementia | Nursing home | OERS | NPS, Depression, CSM | Satisfactory |
| Lee *et al.* (2015b) | US | Researcher | 171 | 135 | 83.64 (6.39) | 7.35 (7.20) | Dementia | Nursing home 110, Assisted living 67 | ODAS | Co-morbidity, Pain | Satisfactory |
| León-Salas *et al.* (2011a) | Spain | Family | 101 | 88.10% | 83.2 (6.3) | 7.2 (6.1) | AD 81.2%, Mixed 18.8% | Nursing home | QoL-AD | ADL, NPS, Depression, GDS, Care home stay, CSM, Duration | Good |
| León-Salas *et al.* (2011b) | Family | 92 | 54 | 73.8 (6.7) | 14.1 (6.6) | AD | Community | ADRQL | Age, ADL, NPS, Depression, Education, Co-morbidity, GDS, Living alone, CSM, Medication, Duration, Being married, Burden, Education C, Age C | Good |
| León-Salas *et al.* (2013) | Health care professional | 108 | 87% | 83.9 (6.2) | 7.0 (6.2) | AD | Nursing home | ADRQL | Age, ADL, NPS, Depression, Education, GDS, CSM, Duration, Community vs residential | Good |
| León-Salas *et al.* (2015) | Spain | Health care professional | 475 | 396 | 85.8 (6.8) | Not specified | Dementia | Nursing home | EQ-5D | Age, ADL, Gender, Education, Co-morbidity, Being married, Memory rating | Satisfactory |
| Logsdon *et al.* (2000) | US | Family | 77 | 47% | 78.3 (6.1) | 17.1 (5.6) | AD | Community | QoL-AD | Depression, Depression C | Satisfactory |
| Logsdon *et al.* (2002) | Family | 155 | Not specified | 77.2 (6.8) | 18.1 (5.9) | AD | Community | QoL-AD | ADL, NPS, Depression, CSM, Memory rating, Burden, Depression C | Good |
| Logsdon *et al.* (2005) | Family | 95 | 66% | 79.9 (7.7) | 14.0 (7.0) | AD | Community | QoL-AD | Age, Anxiety, Gender, Education, Duration | Satisfactory |
| Logsdon and Teri (1997) | US | Family | 42 | 21 | 74.0 (8.0) | 18.4 (6) | AD | Community | PES-AD | CSM | Good |
| Lucas-Carrasco *et al.* (2013) | Spain | Family | 100 | 66 | 79.18 (7.09) | 17.68 (4.19) | AD 61, VaD 17, Mixed 14, Unspecified 8 | Community | CBSQLD | Age | Good |
| Makai *et al.* (2012) | Netherlands | Family  Health Care Professional | 96 | 68.00% | 82 (9.1) | Not specified | dementia | Nursing home | ICECAP-O  EQ-5D  EQ-5D VAS | Age, ADL, Gender, Education C | Satisfactory |
| Makai *et al.* (2014) | Germany | Health care professional | 95 | 56.80% | 76.7 (8.5) | Mild 5.3%, Moderate 34.7%, Severe 60% | AD 60%, Other 40% (ICD-10, F01; VaD; F02 other specified dementias) | Nursing home | ICECAP-O | Age, ADL, Gender, Diagnosis, Care home stay, CSM, Being married, Time caring (care home) | Satisfactory |
| Marventano *et al.* (2015) | Spain | Health care professional | 429 | 352 | 85.8 (6.7) | CDR mild 64, CDR moderate 110, CDR severe 255 | Dementia | Nursing home | QoL-AD | Age, ADL, Depression, Gender, Education, Care home stay, GDS | Good |
| Matsui *et al.* (2006) | Japan | Family | 140 | 84 | 72.4 (7.3) | 20.3 (4.2) | AD | Community | QoL-AD | Age, ADL, NPS, Gender, Education, CSM, Memory rating | Good |
| Miller *et al.* (2008) | US | Family | 407 | 55.80% | 77.860 (7.462) | 15.002 (5.801) | AD | Community | HUI3 | Age, ADL, NPS, Gender, Education, Ethnicity, CSM, Being married, Distress | Good |
| Miller *et al.* (2009) | Family | 421 | 55.80% | 77.9 (7.5) | 15.00 (5.80) | AD | Community | ADRQL | ADL, NPS | Good |
| Miller *et al.* (2010a) | Family | 413 | 56% | 77.9 (7.5) | 15.00 (5.80) | AD | Community and Assisted living | ADRQL  HUI3 | None | Good |
| Miller *et al.* (2012) | Family | 409 | 56.00% | 77.9 (7.5) | 15 (5.8) | AD | Community | HUI3 | Burden, Depression C | Satisfactory |
| Miranda-Castillo *et al.* (2010a) | England | Family | 128 | 78 | 79.2 (6.8) | 19.13 (7.2) | Dementia | Community | QoL-AD | None | Good |
| Miranda-Castillo *et al.* (2010b) | Family | 119 | 78 | 79.85 (6.4) | 19.1 (7.2) | Dementia | Community | QoL-AD | Living alone | Good |
| Missotten *et al.* (2008b) | Belgium | Family | 357 | 303 | 84.19 (7.14) | 8.56 (6.81) | Dementia | Long-term care 83% | ADRQL | Age, ADL, NPS, Gender, GDS, CSM, Community vs residential | Good |
| Missotten *et al.* (2007) | Family | 127 | 109 | 82.42 (7.01) | 8.46 (7.21) | Dementia | Institution 114 | ADRQL | None | Good |
| Missotten *et al.* (2008a) | Family | 42 | 100 | 84.57 (6.31) | (MMSE 0-3) | Dementia | Nursing home or Home care | ADRQL | None | Good |
| 23 | 47 | 84.23 (7.18) | (MMSE 4-8) |
| 45 | 69 | 84.83 (7.73) | (MMSE 9-13) |
| 42 | 59 | 83.51 (7.19) | (MMSE 14-18) |
| 18 | 21 | 84.76 (6.8) | (MMSE 19-23) |
| Mjørud *et al.* (2014b) | Norway | Health care professional | 661 | 472 | 85.34 (8.63) | Not specified | AD 353, VaD 26, Mixed 12, DLB 22, other/unspecified 221, FTD 27 | Nursing home | QUALID | Age, ADL, NPS, Health, Gender, Care home stay, GDS, Medication, Dementia unit | Good |
| Mjørud *et al.* (2014c) | Health care professional | 198 | 156 | 87 (7.7) | CDR1 49, CDR2 73, CDR3 76 | AD 94, Other 104 | Nursing home | QUALID | NPS, Medication | Satisfactory |
| Mjørud *et al.* (2014a) | Health care professional | 661 | 472 | 85.34 (8.63) | CDR1 149, CDR2 222, CDR3 290 | AD 353, VaD 26, mixed 12, DLB 22, FTD 27, unspecified 221 | Nursing home | QUALID | None | Good |
| Mougias *et al.* (2011) | Greece | Family | 161 | 109 | 76.87 (7.03) | 11.5 (7.08) | AD 101, VaD 32, DLB 13, FTD 13, PDD 2 | Community | ADRQL | Age, ADL, NPS, Depression, Gender, Education, Co-morbidity, Diagnosis, GDS, Relationship, Living alone, CSM, Medication, Being married, Burden, Depression C, Education C, Age C, Gender C, Time caring (community) | Good |
| Mulhern *et al.* (2013) | England | Family | 325 | 220 | 79.4 (8.5) | 18.1 (6.6) | AD | Community 275, Nursing home 50 | EQ-5D | ADL, NPS, Depression, CSM | Good |
| Murman *et al.* (2002), Murman *et al.* (2009) | US | Family | 149 | 54% | 76.75 (8.62) | 14.94 (8.35) | AD 89.26%, DLB 10.74% | Not specified | QWB  EQ-5D  HUI2 | Age\*, ADL\*, NPS\*, Education\*, Co-morbidity\*, GDS\*, CSM\*, Burden\*, Distress\*, Age C\* | Satisfactory |
| Naglie *et al.* (2006) | US | Family | 60 | 37 | 78.6 | 18.9 (4.5) | AD | Own home 49, Senior’s apartment 4, Retirement home 6, Nursing home 1 | QWB  HUI3  EQ-5D  EQ-5D VAS  QoL-AD  SF-36 | ADL, Depression, Health, Co-morbidity, CSM | Good |
| Naglie *et al.* (2011b) | US | Family | 410 | 208 | 80.7 (7.9) | 20.8 (6.2) | AD | Community | QWB  HUI3  EQ-5D  EQ-5D VAS  QoL-AD  SF-36 | Age, ADL, NPS, Depression, Gender, Co-morbidity, CSM, Being married, Burden, Depression C | Good |
| Naglie *et al.* (2011c) | Family | 272 | 50.2% | 82.2 | 20.2 | AD | Community | EQ-5D  EQ-5D VAS  QWB  QoL-AD  HUI3  SF-36 | None | Satisfactory |
| Nagpal *et al.* (2015) | US | Family | 111 | 59 | 76.80 (8.90) | 20.7 (3.80) | Dementia | Community | QoL-AD | Education, Ethnicity, CSM, Being married, Burden, Education C | Satisfactory |
| Nakanishi *et al.* (2011) | Japan | Health care professional | 116 | Not specified | 86.2 (6.0) | 15.1 (4.2) | Dementia | Nursing home | QoL-AD | Age, Anxiety, ADL, NPS, Depression, Gender, Care home stay, GDS, CSM | Satisfactory |
| Nakanishi *et al.* (2012) | Japan | Health care professional | 1366 | 83.20% | 85.56 (7.43) | 4.15 (.87) out of 6, higher is worse | Dementia | Nursing home | ADRQL | ADL | Satisfactory |
| Neumann *et al.* (2000) | US | Family | 679 | 67% | 81 (9) | CDR.5 7%, CDR1 29%, CDR2 34%, CDR3 21%, CDR4 7%, CDR5 2% | AD | Community 52%, assisted living 24%, Nursing home 24% | HUI2  HUI3 | GDS | Poor |
| Novelli *et al.* (2010) | Brazil | Family | 60 | 42 | 75.85 | 17.1 | AD | Not specified | QoL-AD | ADL, NPS, Depression, CSM, QoL C, Depression C, Education C, Gender C | Good |
| Novelli and Caramelli (2010) | Family | 30 | 73.30% | 75.5 (6.7) | 20.2 (2.6) | AD | Not specified | QoL-AD | None | Good |
| Family | 30 | 66.70% | 76.2 (6.2) | 14.0 (2.8) | AD | Not specified | QoL-AD | None |
| Orgeta *et al.* (2015a) | England, Wales | Family | 488 | 238 | 75.5 (7.3) | CDR mild 74.6%, CDR moderate 25.4% | Dementia | Community | EQ-5D  EQ-5D VAS | Age, Anxiety, Depression, Relationship, GDS, GHQ, Burden, Age C | Satisfactory |
| Orgeta *et al.* (2015b) | Family | 488 | 238 | 77.6 | CDR mild 74.6%, CDR moderate 25.4% | Dementia | Community | QoL-AD | Age, Anxiety, Depression, Health, Gender, Education, Relationship, Living alone, GDS, Being married, GHQ, Burden, Education C, Age C, Gender C | Good |
| Woods *et al.* (2012) | Family | 488 | 242 | 77.53 (7.3) | CDR mild 74.6%, CDR moderate 25.4% | AD 106, VaD 23, DLB 1, Mixed 17, Unknown 36 | Community | QoL-AD  EQ-5D  EQ-5D VAS | ADL, QoL C, Depression C | Good |
| Pelletier and Landreville (2007) | Canada | Health care professional | 49 | 89.80% | 82.7 (7.8) | FAST 3 4.1%, FAST 4 2%, FAST 5 16.3%, FAST 6 53.1%, FAST 7 24.5% | AD | Not specified | Discomfort Scale | NPS | Good |
| Porzsolt *et al.* (2004) | Austria | Health care professional | 217 | 173 | 84 (61-105) | GDS 5.7 (1.1) | AD 34.5%, VaD 61.5%, other 4% | Nursing home | The Vienna List | ADL, GDS | Satisfactory |
| Rabins (2000) | US | Family | 61 | Not specified | Not specified | Not specified | Dementia | Not specified | ADRQL | Depression, GDS, CSM | Poor |
| Røen *et al.* (2015) | Norway | Mix | 169 | 117 | 84.9 (6.7) | 14.0 (6.0) | Dementia | Nursing home | QUALID | Age, ADL, NPS, Depression, Gender, GDS | Satisfactory |
| Rummel (2012) | US | Family  Health care professional | 48 | 35 | 83.89 (6.78) | 7.94 (7.49) | Dementia | Memory care unit 52%, Skilled nursing facility 35%, Adult day program 13% | QoL-AD | Anxiety, ADL, NPS, Depression, CSM, PCC, Burden | Good |
| Salek *et al.* (1996), Salek *et al.* (1999) | Wales | Family | 70 | 34 | 75.3 (52-90) | Not specified | AD 45, Mixed 25 | Community | CDQLP | CSM | Satisfactory |
| Samus *et al.* (2005) | US | Health care professional | 134 | 108 | 86.1 (6.7) | 14.64 (7.67) | AD 78, VaD 17, DLB 1, Mixed/Not specified 38 | Nursing home | ADRQL | Age, Anxiety, NPS, Depression, Health, Gender, Education, Co-morbidity, Ethnicity, Care home stay, CSM, Being married | Satisfactory |
| Samus *et al.* (2006) | Health care professional | 198 | 156 | 86.1 (6.7) | 13.6 (3.1) | AD 78, VaD 17, DLB 1, Mixed/Not specified 38, no dementia 64 | Nursing home | ADRQL | None | Good |
| Bicket *et al.* (2010) | Health care professional | 194 | 77.80% | 85.4 (8.8) | Not specified | Dementia | Assisted living | ADRQL | None | Satisfactory |
| Schulz *et al.* (2010) | US | Family | 105 | 63 | 77.3 (8.2) | ≤15 26, 16-23 37, ≥24 42 | AD | Community | QoL-AD | None | Satisfactory |
| Family | 121 | Not specified | Not specified | ≤15 82, 16-23 25, ≥24 10 | AD | Community | QoL-AD | None |
| Selai *et al.* (2001a) | England | Family | 22 | 10 | 65 (8) | ≥10 | Mostly AD | Community | QOLAS | ADL, NPS, Gender | Satisfactory |
| Shata *et al.* (2015) | Egypt | Family | 100 | 56 | 67.61 (6.41) | 11.86 (1.97) | Dementia | Community | QoL-AD | ADL, Depression | Good |
| Sheehan *et al.* (2012) | England | Family | 109 | 83 | 85 | CDR.5 2, CDR1 14, CDR2 64, CDR3 29 | Dementia | General hospital inpatients | QoL-AD  EQ-5D | Age, ADL, Depression, Gender, GDS, GHQ | Good |
| Shin *et al.* (2005) | US | Family | 62 | 36 | 75.53 (7.87) | 19.36 (5.22) | AD | Community | QoL-AD | Anxiety, NPS, Depression | Good |
| Siedlecki *et al.* (2009) | France, US | Family | 277 | 56.70% | 75.79 (7.82) | mMMSE 41.60 (6.23) | AD | Community | AAIQoL | Age, ADL, NPS, Depression, CSM | Good |
| Sixsmith *et al.* (2008) | Estonia, Finland, Germany, Sweden, UK | Health care professional | 394 | 292 | 83.86 (8.37) | 5.4 | Dementia | Residential care 320, Community 74 | QUALID | ADL, Gender, Co-morbidity, Diet, Pain, Medication | Poor |
| Sjögren *et al.* (2013) | Sweden | Health care professional | 1245 | 870 | 85.0 (7.5) | Not specified, but mostly severe | Dementia | Nursing home | QUALID | PCC | Satisfactory |
| Edvardsson *et al.* (2014) | Health care professional | 1257 | 872 | 86 (7.5) | GRS 11.30 | Dementia | Nursing home | QUALID | None | Satisfactory |
| Sloane *et al.* (2005) | US | Health care professional | 246 | 79% | 85 | Mild 12%, Moderate 25%, Severe 27%, Very severe 37% | Dementia | Nursing home | AAIQoL  ADRQL  QoL-AD | ADL, NPS, Depression, Pain, CSM | Good |
| Dobbs *et al.* (2005) | Health care professional | 329 | Not specified | 84.7 | Not specified | Dementia | Residential care or Assisted living | AAIQoL | ADL, NPS, Depression, Diet, Pain, CSM | Satisfactory |
| Winzelberg *et al.* (2005) | Health care professional | 335 | 268 | 85.25 | 7.5 | Dementia | Residential care or Assisted living | QoL-AD | Age, ADL, NPS, Depression, Gender, Ethnicity, Pain, CSM, PCC | Satisfactory |
| Zimmerman *et al.* (2005) | Health care professional | 241 | 333 | 203 under 85, 206 85 and over | 7.5 | Dementia | Residential care or Assisted living | ADRQL | Medication, PCC | Good |
| Smith *et al.* (2005) | England | Family | 48 | 59 | 78.65 (8.30) | 16.01 (8.53) | Dementia | Not specified | QoL-AD  SF-12 | Age, ADL, Depression, Gender, CSM, GHQ, Age C, Gender C | Good |
| Smith *et al.* (2007) | Family | 77 | 43 | 78.49 (8.32) | 19.93 (4.84) | Dementia | Community | QoL-AD | GHQ | Satisfactory |
| Family | 21 | 16 | 79.23 (8.42) | 2.9 (3.6) | Dementia | Community | QoL-AD | None |
| Snow *et al.* (2005) | US | Family | 89 | 0 | 74.0 (9.37) | DRS scores <46 9, 47-102 39, 102-139 45 | Dementia | Community | QoL-AD | ADL, NPS, Depression, Pain, CSM, Depression C | Satisfactory |
| Snow *et al.* (2009) | Family | 171 | 52 | 75.81 (6.19) | Not specified | Dementia | Community | PES-AD | Pain | Good |
| Ball *et al.* (2010) | Family | 171 | 3% | 76 (6.04) | Not specified | Dementia | Community | PES-AD | None | Satisfactory |
| Spector *et al.* (2016) | England | Family | 50 | 20 | 78.40 (6.97) | 20.92 (5.20) | Dementia | Community | QoL-AD | None | Good |
| Telenius *et al.* (2013) | Norway | Health care professional | 166 | 125 | 86.9 (7.36) | 15.6 (4.9) | Dementia | Nursing home | QUALID | Age, ADL, Gender, Co-morbidity, Care home stay, CSM, Medication | Good |
| Terada *et al.* (2002) | Japan | Mix  (Health care professional 90%) | 264 | 180 | 81.5 (7.9) | Moderate to Severe dementia | AD 119, VaD 79, Mixed 37, Other 27 | Geriatric health services 112, Hospital 104, Nursing home 11%, home 7%, Group home 1% | QLQD | ADL, CSM | Good |
| Terada *et al.* (2013) | Health care professional | 112 | 80 | 80.9 | Not specified | AD 70, VaD 35, Other 7 | Geriatric health services facilities | QLQD | PCC | Satisfactory |
| Health care professional | 104 | 59 | 80.9 | Not specified | AD 56, VaD 29, Other 19 | Hospital | None |
| Thomas *et al.* (2006) | France | Health care professional | 100 | 64 | 80.2 (6.8) | 12.8 (5.8) | AD 84, Mixed 9, DLB 7 | Community | ADRQL | Age, ADL, NPS, Depression, Diagnosis, CSM, Duration, QoL C, Age C | Satisfactory |
| Trigg *et al.* (2011) | England | Family | 68 | 30 | <65 3, 65-74 10, 75-84 49, ≤85 7 | 22.43 (2.44) | AD 54, VaD 7, FTD 5, DLB 3 | Living alone 14, Living with spouse 49, Living with relative/other 6 | ADRQL | Awareness, ADL, CSM | Good |
| Trigg *et al.* (2015) | England | Family | 145 | 88 | 77.78 (9.24) | 12.64 (8.57) | AD | Community | EQ-5D  DEMQOL | ADL, NPS, CSM | Good |
| Vogel *et al.* (2006) | Denmark | Family | 48 | Not specified | 77.0 (5.8) | 24.9 (2.3) | AD | Community | QoL-AD  EQ-5D VAS | Age, NPS, Depression, Gender, CSM | Good |
| Volicer *et al.* (1999) | US | Researcher | 57 | 77.20% | 82.7 (7.5) | 5.2 (4.8) | AD | Nursing home | OERS | NPS, Depression | Satisfactory |
| Warden *et al.* (2003) | US | Health care professional | 19 | Not specified | 78.1 (5) | 2.8 (4.5) | Dementia | Nursing home | Discomfort Scale | Pain | Satisfactory |
| Weiner *et al.* (2000) | US | Health care professional | 41 | 28 | 80.6 | 11.53 (6.23) | AD | Nursing home | QUALID | Anxiety, ADL, NPS, Depression, CSM | Satisfactory |
| Weyerer *et al.* (2010) | Germany | Health care professional | 725 | 600 | 83.15 | dementia score 9.9 (1 no impairment - 16 severe) | Dementia | Nursing home | AAIQoL | Dementia unit | Satisfactory |
| Whitlatch *et al.* (2005) | US | Family | 111 | 60 | 77 (9) | 20.7 (3.8) | AD 42%, non-specific dementia 25%, stroke 11%, Other dementia 11%, PD 8%, Other 3% | Community | QoL-AD | None | Satisfactory |
| Wlodarczyk *et al.* (2004) | Australia | Family | 78 | 60 | 71.7 (8.5) | 20.2 (5.6) | AD | Australian elderly care centres | AQoL | ADL, CSM | Good |
| Wolak *et al.* (2009) | France, Switzerland | Family | 120 | 77 | 82.2 (6.0) | 20.8 (4.5) | AD | Living alone 28, Living with spouse 70, Institution/sheltered 18, other 3 | QoL-AD | ADL, NPS, Co-morbidity, Burden, Distress | Satisfactory |
| Wolak-Thierry *et al.* (2015) | Family | 123 | 63.40% | 82.0 (6.0) | MMSE between 11-29 | AD | Not specified | QoL-AD | Depression, GDS, CSM | Good |
| Wolfs *et al.* (2007) | Netherlands | Family | 196 | 150 | 77.8 (6.7) | 20.21 (5.78) | AD 97, VaD 26, Mixed 21, Other 20 | Community | EQ-5D  EQ-5D VAS | CSM | Satisfactory |
| Yamamoto-Mitani *et al.* (2004) | Japan | Health care professional | 623 | 477 | 81.7 (7.9) | Early 92, Moderate 209, Severe 186, Very severe 136 | AD 184, VaD 281, Mixed 43, Other 115 | Nursing home 185, Hospital 81, Geriatric health services facilities 114, Day care 243 | ADRQL | Age, ADL, Gender, Diagnosis, GDS, Dementia unit, Education C, Gender C | Satisfactory |
| Yap *et al.* (2008) | Singapore | Family | 67 | 45 | 78.4 (7.5) | 16.1 (5.4) | AD 58.6%, Mixed 32.8%, VaD 6.9%, PDD 1.7% | Live with spouse 81.7% | QoL-AD | ADL, NPS, Depression, Memory rating, GHQ, Burden | Satisfactory |
| Young (2001) | US | Health care professional | 104 | 82 | 86.3 | 8.55 (7.78) | Dementia | Nursing home | Discomfort Scale | ADL, NPS, Depression, Pain, CSM | Good |
| Yu *et al.* (2013) | China | Family | 87 | 48% | 73.6 (7.7) | MoCA 7.26 (5.51) | AD | Community | QoL-AD | Anxiety, ADL, Depression, Burden | Good |
| Zucchella *et al.* (2015) | Italy | Family | 135 | 93 | 78.2 (5.9) | 15.3 (7.5) | AD | Live with carer 56.3% | QoL-AD | NPS, Depression | Satisfactory |

Note: articles were judged to be of poor quality if scored ≤20 or below, satisfactory scored between >20 and <26, good scored ≥26. Shading indicates articles using the same study data. “Severity” refers to Mini-Mental State Examination score unless otherwise specified. \* indicates data not reported in articles

Quality of life measure abbreviations: 12-Item Short Form Health Survey (SF-12), 36-Item Short Form Health Survey (SF-36), Activity and Affect Indicators of QOL (AAIQoL), Alzheimer's Disease Related Quality of Life (ADRQL), Assessment of Quality of Life (AQoL), Community Dementia Quality of Life Profile (CDQLP), Cornell-Brown Scale for Quality of Life in Dementia (CBSQLD), Dementia Quality of Life Questionnaire (DEMQOL), Dementia Quality of Life Instrument (DQoL), Disability and Distress Index (DDI), EuroQol five dimensions questionnaire (EQ-5D), Health Utility Index (HUI), Investigating Choice Experiments for the Preferences of Older People CAPability for Older people (ICECAP-O), Linear Analogue Self Assessment (LASA), Nottingham Health Profile (NHP), Observable Displays of Affect Scale (ODAS), Observed Emotion Rating Scale (OERS), Pleasant Events Schedule-Alzheimer's disease (PES-AD), Quality of Life Assessment Schedule (QOLAS), Quality of Life in Alzheimer's Disease (QoL-AD), QUAlity of LIfe in DEMentia (QUALIDEM), Quality of Life in Late Stage Dementia Scale (QUALID), Quality of Life Questionnaire for Dementia (QLQD), Quality of Well-Being scale (QWB), Source of Discomfort Scale (SDS), Visual Analogue Scale, (VAS), World Health Organization (WHO)

Severity abbreviations: Clinical Dementia Rating (CDR), Dementia Rating Scale (DRS), Functional Assessment Staging Test (FAST), Geriatric Rating Scale (GRS), Global Deterioration Scale (GDS), Mini-Mental State Examination (MMSE), Modified Mini-Mental State Examination (3MS), Modified Mini-Mental State Examination (mMMSE), Montreal Cognitive Assessment (MoCA), Severe Impairment Rating Scale (SIRS)

Dementia type abbreviations: Alzheimer's disease (AD), Behavioural-variant frontotemporal dementia (bvFTD), Cerebral Autosomal-Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy (CADASIL), Cerebrovascular disease (CVD), Dementia with Lewy bodies (DLB), Frontotemporal Dementia (FTD), mild cognitive impairment (MCI), Parkinson's Disease Dementia (PDD), Vascular dementia (VaD)

Factors included in the meta-analysis abbreviations: Alzheimer’s (vs. other dementia subtypes) (Diagnosis), Better functional ability (ADL), Better self-rated health (Health), Better self-rated memory functioning (Memory rating), Burden or stress (Burden), Cared for by spouse (vs. other carer type) (Relationship), Carer Depression (Depression C), Carer quality of life (self-rated) (QoL C), Community vs residential (Community dwelling (vs. residential care)), Degree to which residential care is person-centred (PCC), Dementia unit (Special dementia unit (vs. other residential facility)), Distress at NPS symptoms (Distress), Higher level of education (Education), Higher level of carer education (Education C), Higher scores on cognitive screening measures (CSM), Female gender (Gender), Female gender carer (Gender C), Longer duration of care home stay (Care home stay), Longer disease duration (Duration), More awareness (Awareness), More advanced dementia (GDS), More time spent caring (community only) (Time caring (community)), More time spent caring (residential care only) (Time caring (care home)), Neuropsychiatric symptoms/BPSD (NPS), Older age (Age), Older age carer (Age C), Poorer mental health (General Health Questionnaire (GHQ)) (GHQ), Presence of co-morbid conditions (Co-morbidity), Taking medication (Medication), Underweight (Diet), White ethnicity (Ethnicity)

**Supplementary Table 5. Studies utilising proxy ratings of quality of life in people with dementia**

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Study** | **Country of study** | **Relationship of informant to person with dementia** | **n** | **Females** | **Mean age** | **Severity** | **Dementia type** | **Living situation** | **QoL measure** | **Factors included in the meta-analysis** | **Quality rating** |
| Ballard *et al.* (2001) | England | Health care professional | 112 | 79.50% | 85.5 (6.8) | 8.4 (7.2) | Dementia | Residential/ Nursing home | DCM | NPS, Medication | Satisfactory |
| Bosboom *et al.* (2012b) | Australia | Family | 80 | 67.50% | 78.3 (7.9) | Not specified | AD | Community | QoL-AD | Age, ADL, NPS, Depression, Medication, Gender, Age C | Good |
| Chung (2004) | Hong Kong | Researcher | 43 | 29 | 81.2 (7.01) | CDR1 6, CDR2 15 CDR3 22 | AD 28, VaD 10, Mixed 5 | Nursing home | DCM | GDS | Good |
| de Rooij *et al.* (2012) | Netherlands | Health care professional | 102 | 75 | 84.25 (5.49) | 6.29 (5.93) | Dementia | Dutch traditional sized Nursing home 51, Dutch small scale Nursing home 51 | QUALIDEM | None | Good |
| Belgium | Health care professional | 77 | 67 | 86.81 (6.36) | 7.09 (6.82) | Dementia | Belgian traditional sized Nursing home 30, Belgium small scale Nursing home 47 | QUALIDEM | Depression |
| Edelman *et al.* (2004b) | US | Researcher | 166 | 75% | 83.5 (6.1) | 10.6 (7.1) | Dementia | Special care facilities 62, Assisted living facilities 49, Adult day centres 55 | DCM | Age, ADL, Depression, Co-morbidity, CSM, Gender | Satisfactory |
| Edelman *et al.* (2007) | Health care professional | 30 | 77% | 85.0 (7.8) | 80% MMSE of 0 | Dementia | Nursing home | OQOLDA | Age, ADL, Depression, CSM | Satisfactory |
| Edelman *et al.* (2004a) | Researcher | 54 | 61.80% | 80.8 (6.5) | 12.5 (7.3) | Dementia | Nursing home | DCM | None | Satisfactory |
| Edelman *et al.* (2005) | Researcher | 117 | 85.50% | 86.0 (6.8) | 7.9 (6.8) | Dementia | special care facilities | DCM | None | Satisfactory |
| Researcher | 55 | 80.00% | 85.3 (5.4) | 11.1 (6.8) | Dementia | assisted living facility | DCM | None |
| Kuhn *et al.* (2005) | Researcher | 111 | 75% | 83.5 | 10.6 | Dementia | Special care facilities 62, Assisted living facilities 49, Adult day centres 55 | DCM | None | Satisfactory |
| Ettema *et al.* (2007a) | Netherlands | Health care professional | 202 | 182 | 84.69 (6.85) | GDS2 2, GDS3 5, GDS4 21, GDS5 64, GDS6 110, GDS7 36 | AD 117, VaD 29, Mixed 22, other 21, unknown 49 | Nursing home | QUALIDEM | ADL, NPS, Depression, GDS | Satisfactory |
| Fleming *et al.* (2016) | Australia | Health care professional | 275 | 211 | 84.33 (8.66) | GDS2 = 10, GDS3 = 45, GDS4 = 55, GDS5 = 67, GDS6 = 98 | Controls 51, Dementia 75, AD 1, DLB 1, FTD 1, Huntingtons 11, Korsakoffs 5, PDD 29, VaD 13, Mixed 86, unspecified 2 | Nursing home | DEMQOL | Age, ADL, GDS, Co-morbidity, Medication, Gender | Satisfactory |
| Funaki *et al.* (2005) | Japan | Researcher | 25 | 18 | 81.2 (6.38) | HDS-R 10.6 (5.9) | AD 14, VaD 2, other 9 | Group home | QLQD | ADL, NPS, | Satisfactory |
| Gómez-Gallego *et al.* (2015) | Spain | Family | 81 | 68.60% | 72.09 (6.39) | 18.51 (4.29) | AD | Community | DEMQOL | NPS, Depression, Co-morbidity, CSM | Good |
| Gräske *et al.* (2015) | Germany | Health care professional | 396 | 275 | 78.4 (11.1) | GDS0-5 63, GDS6 167, GDS7 152 | Dementia | Nursing home | QUALIDEM | Age, NPS, GDS, Gender | Satisfactory |
| Hodgson *et al.* (2014) | US | Family | 88 | 46 | 81.67 (8.02) | 17.7 (4.57) | Dementia | Community | DEMQOL | Age, Co-morbidity, CSM | Good |
| Hurt *et al.* (2010) | England, Finland, France, Greece, Italy, Poland | Family | 155 | 107 | 77.2 (6.5) | 20.6 (4.9) | AD | Not specified | DEMQOL | Age, ADL, NPS, | Good |
| Jones *et al.* (2015) | England | Family | 221 | 53.80% | 79.7 (8.5) | 14.6 (6.8) | AD | Community 86%, Residential home 14% | EQ-5D  DEMQOL | ADL, NPS, CSM | Good |
| Trigg *et al.* (2012a, 2012b) | Family | 249 | 53.80% | 79.7 (8.5) | 14.6 (6.8) | AD | Community 86%, Residential home 14% | EQ-5D  DEMQOL | ADL | Satisfactory |
| Karlawish *et al.* (2001b) | US | Family | 40 | 27 | 74.9 (8.0) | 16.3 (7.8) | AD | Community | Single question - How would your relative rate his or her overall quality of your relative’s life at present? | Age, NPS, GDS, CSM, Gender, Age C | Satisfactory |
| Lucas-Carrasco *et al.* (2010) | Spain | Family | 95 | 67 | 79.2 (7.0) | 19.49 (4.45) | MCI 19, AD 47, VaD 14, Mixed 10, Other 6, unknown 6 | Community | DEMQOL | Age, ADL, Depression, CSM, Gender | Good |
| Mulhern *et al.* (2013) | England | Family | 317 | 220 | 79.4 (8.5) | 18.1 (6.6) | AD | Community 267, Nursing home 50 | DEMQOL | ADL, NPS, Depression, CSM | Good |
| Ní Mhaoláin *et al.* (2012) | Ireland | Family | 115 | 71 | 74.13 (9.14) | 20.5 (6.5) | AD | Community | DEMQOL | Age, ADL, NPS, GDS, CSM, Gender | Good |
| Schiffczyk *et al.* (2011) | Germany | Family | 194 | 57 | 73.0 (7.1) | 17.3 (6.8) | AD or Mixed | Community | QoL-AD | Age, ADL, NPS, Depression, Medication, CSM, Age C | Satisfactory |
| Schiffczyk *et al.* (2010) | Family | 137 | 30.70% | 73.0 (6.7) | 16.9 (6.4) | AD or Mixed | Community | EQ-5D | None | Good |
| Schulz *et al.* (2010) | US | Family | 105 | 63 | 77.3 (8.2) | 26=0-16, 37=16-23, 42=24+ | AD | Community | DEMQOL | None | Satisfactory |
| Sloane *et al.* (2005) | US | Researcher | 222 | 79% | 85 (65-101) | Mild 12%, Moderate 25%, Severe 27%, Very severe 37% | AD 54%, VaD 4%, Mixed 5%, Other 37% | Nursing home | DCM  RSOC-QOL,  OERS | Age, ADL, NPS, Depression, Co-morbidity, Gender | Good |
| Zimmerman *et al.* (2005) | Health care professional | 211 | 333 | <85 203, ≥85 206 | 7.5 | Dementia | Residential care or Assisted living | OERS  DCM | Medication | Good |
| Sloane *et al.* (2007) | UK | Researcher | 133 | Not specified | Not specified | Not specified | Dementia | Nursing home (UK descriptive studies) | DCM | GDS, CSM | Poor |
| Smit *et al.* (2016) | Netherlands | Health care professional | 1144 | 75.20% | 84.22 (7.57) | CPS 3.99 (1.50) | Dementia | Nursing home | QUALIDEM | None | Good |
| Smith *et al.* (2005) | England | Family | 99 | 59 | 78.65 (8.30) | 16.01 (8.53) | Dementia | Community 79%, 21% Residential, Nursing, Sheltered or Dual registered | DEMQOL | ADL, Depression, Gender, Age C | Good |
| Banerjee *et al.* (2006) | Family | 99 | 59 | 78.7 (8.3) | 16.0 (8.5) | Dementia | Community 79%, 21% Residential, Nursing, Sheltered or Dual registered | DEMQOL | Age, NPS, Depression, CSM | Satisfactory |
| Smith *et al.* (2007) | Family | 77 | 43 | 78.49 (8.32) | 19.93 (4.84) | Dementia | Community | DEMQOL | None | Satisfactory |
| Family | 21 | 16 | 79.23 (8.42) | 2.9 (3.6) | Dementia | Community | DEMQOL | None |
| Thornton *et al.* (2004) | UK | Researcher | 64 | 27 | 74.46 (9.58) | CAPE -CAS 10 (7.92) | Dementia | Hospital ward 22, Day hospital 42 | DCM | None | Satisfactory |
| Wetzels *et al.* (2010) | Netherlands | Health care professional | 207 | 72.50% | 83.4 (6.8) | 9.5 (6.0) (GDS 4-6) | AD 36.2%, VaD 11.6%, Mixed 7.2%, Other 44.9% | Nursing home | QUALIDEM | Age, ADL, NPS, Depression, GDS, Medication, Gender | Good |
| Health care professional | 81 | 86.40% | 84.6 (8.0) | 0.7 (1.6) (GDS 7) | AD 45.7%, VaD 7.4%, Mixed 3.7%, Other 43.2% | Nursing home | QUALIDEM | Age, ADL, NPS, Depression, Medication, Gender |
| Ven-Vakhteeva *et al.* (2013) | Health care professional | 207 | 150 | 83.7 | 9.4 (6.1) | Dementia | Nursing home | QUALIDEM | None | Good |
| Wolf-Ostermann *et al.* (2012) | Germany | Health care professional | 56 | 43 | 82.3 (9.25) | GDS4 6, GDS5 5, GDS6 38, GDS7 7 | Dementia | Shared-housing 34, Special care units 22 | QUALIDEM | Gender | Good |

Note: articles were judged to be of poor quality if scored ≤20 or below, satisfactory scored between >20 and <26, good scored ≥26. Shading indicates articles using the same study data. “Severity” refers to Mini-Mental State Examination score unless otherwise specified.

Quality of life measure abbreviations: Dementia Care Mapping (DCM), Dementia Quality of Life Questionnaire (DEMQOL), EuroQol five dimensions questionnaire (EQ-5D), Health Utility Index (HUI), Observed Emotion Rating Scale (OERS), Observing QOL for Dementia Advanced (OQOLDA), Resident and Staff Observation Checklist-Quality of Life Measure (RSOC-QOL), Quality of Life in Alzheimer's Disease (QoL-AD), QUAlity of LIfe in DEMentia (QUALIDEM), Quality of Life Questionnaire for Dementia (QLQD)

Severity abbreviations: Clifton Assessment Procedure for the Elderly-Cognitive Assessment Scale (CAPE-CAS), Clinical Dementia Rating (CDR), Cognitive Performance Scale (CPS), Global Deterioration Scale (GDS), Hasegawa Dementia Scale-Revised (HDS-R), Mini-Mental State Examination (MMSE)

Dementia type abbreviations: Alzheimer's disease (AD), Dementia with Lewy bodies (DLB), Frontotemporal Dementia (FTD), mild cognitive impairment (MCI), Parkinson's Disease Dementia (PDD), Vascular dementia (VaD)

Factors included in the meta-analysis abbreviations: Better functional ability (ADL), Female gender (Gender), Higher scores on cognitive screening measures (CSM), More advanced dementia (GDS), Neuropsychiatric symptoms/BPSD (NPS), Older age (Age), Older age carer (Age C), Presence of co-morbid conditions (Co-morbidity), Taking medication (Medication)

**Supplementary Table 6. Studies utilising difference scores for ratings of quality of life in people with dementia**

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Study** | **Country of study** | **Difference** | **n** | **Females** | **Mean age** | **Severity** | **Dementia type** | **Living situation** | **QoL measure** | **Factors included in the meta-analysis** | **Quality rating** |
| Andrieu *et al.* (2016) | France | Self vs. Family | 501 | 331 | 79.6 (5.9) | 19.5 (3.9) | AD | Community | QoL-AD | Age, ADL, NPS, CSM, Gender, Age C, Living alone, Education, Burden, Gender C | Good |
| Buckley *et al.* (2012) | US | Self vs. Family | 144 | 151 | 85.60 (5.77) | 19.78 (7.25) | Dementia | Not specified | Single global QoL question | NPS, Co-morbidity, CSM, Gender, Education | Good |
| Conde-Sala *et al.* (2014b) | Spain | Self vs. Family | 119 | 76 | 77.0 (6.7) | 18.9 (3.6) | Dementia | Community | QoL-AD | ADL, NPS, Burden | Good |
| Conde-Sala *et al.* (2014a) | Spain | Self vs. Family | 141 | 83 | 77.6 (7.2) | 17.6 (5.9) | AD | Not specified | QoL-AD | ADL, NPS, CSM, Burden, Gender C | Good |
| Conde-Sala *et al.* (2016) | Self vs. Family | 221 | 140 | 77.8 (0.4) | 18.3 (0.3) | AD | Not specified | QoL-AD | None | Good |
| Devine *et al.* (2014) | England | Self vs. Health care professional proxy | 565 | 430 | 86.2 (7.4) | 19.0 (6.5) | Dementia | Nursing home | EQ-5D | Age, Depression, CSM, Gender | Good |
| Edelman *et al.* (2005) | US | Self vs. Health care professional | 65 | 81.5 | 85.6 (5.8) | 15.6 (3.8) | Dementia | Nursing home | QoL-AD | CSM | Satisfactory |
| Fuh and Wang (2006) | Taiwan | Self vs. Family | 81 | 49 | 77.2 (6.8) | 20.1 (4.5) | AD | Not specified | QoL-AD | Age, ADL, NPS, CSM, Education | Satisfactory |
| Gómez-Gallego *et al.* (2015) | Spain | Self vs. Family proxy | 81 | 68.60% | 72.09 (6.39) | 18.51 (4.29) | AD | Community | DEMQOL | NPS, Depression, Co-morbidity, CSM, Burden | Good |
| Huang *et al.* (2009) | Taiwan | Self vs. Family | 120 | 58 | 78.40 (9.13) | 18.64 (6.23) | AD | Community | QoL-AD | Age, NPS, Co-morbidity, CSM, Gender, Age C, Being married, Education, Gender C | Satisfactory |
| Kunz (2010) | Germany | Self vs. Family | 319 | 67.50% | 80.2 (6.7) | 18.6 (3.8) | Dementia | Community | EQ-5D | Age, ADL, CSM, Gender, Age C, Living alone, Burden, Gender C | Satisfactory |
| Novella *et al.* (2001c) | Belgium, France, Luxembourg, Switzerland | Self vs. Family  Self vs. Health care professional | 66 | 63 | 82 (7.9) | 15.6 (3.95) | AD | Community 26.3%, Hospital 46.1%, Institution 27.6% | DHP | Age, ADL, Gender, Living alone | Good |
| Novella *et al.* (2006) | Self vs. Family  Self vs. Health care professional | 63 | 54 | 82 (7.9) | 15.7 (4.2) | AD | Community 26.3%, Hospital 46.1%, Institution 27.6% | SF-36 | Age, ADL, Gender | Good |
| Novelli and Caramelli (2010) | Brazil | Self vs. Family | 30 | 73.30% | 75.5 (6.7) | 20.2 (2.6) | AD | Not specified | QoL-AD | ADL, NPS, Depression, CSM | Good |
| Self vs. Family | 30 | 66.70% | 76.2 (6.2) | 14.0 (2.8) | AD | Not specified | QoL-AD |
| Rummel (2012) | US | Self vs. Family  Self vs. Health care professional  Family vs. Health care professional | 26 | 35 | 83.89 (6.78) | 7.94 (7.49) | Dementia | Memory care unit 52%, Skilled nursing facility 35%, Adult day program 13% | QoL-AD | ADL, NPS, Depression, CSM | Good |
| Sands *et al.* (2004) | US | Self vs. Family | 91 | 63.00% | 78.7 (7.6) | 19.7 (4.5) | AD, DLB, FTD, PDD, VaD | Community | DQoL | Age, ADL, Depression, CSM, Gender, Age C, Being married, Living alone, Burden, Gender C | Satisfactory |
| Schiffczyk *et al.* (2010) | Germany | Self vs. Family | 137 | 30.70% | 73.0 (6.7) | 16.9 (6.4) | AD or Mixed | Community | EQ-5D | CSM | Good |
| Schulz *et al.* (2013) | US | Self vs. Family | 79 | 27 | 76.0 (8.5) | 23.1 (3.6) | AD | Community | QoL-AD  DEMQOL | Age, CSM, Gender, Age C, Being married, Education, Burden, Gender C | Good |
| Spector and Orrell (2006) | England | Self vs. Health care professional | 76 | 67 | 85.2 (7.4) | 13 (4.8) | Dementia | Nursing home | QoL-AD | Age, CSM | Good |
| Tay *et al.* (2014) | Singapore | Self vs. Family | 165 | 91 | 76.8 (6.9) | 18.4 (4.2) | Dementia | Community | QoL-AD | Age, ADL, NPS, Depression, CSM, Gender, Age C, Being married, Living alone, Education, Burden, Gender C | Good |
| Vogel *et al.* (2006) | Denmark | Self vs. Family | 17 | Not specified | 77.0 (5.8) | 24.9 (2.3) | AD | Community | QoL-AD  EQ-5D  EQ-5D VAS | None | Good |
| Zbrozek *et al.* (2006) | US | Self vs. Family | 110 | Not specified | Not specified | Not specified | AD | Community | HUI2 | ADL, Depression, CSM, | Satisfactory |
| Zhao *et al.* (2012) | France, Switzerland | Self vs. Family | 122 | 78 | 82 (6) | 21 (5) | AD | Community or Institutional | QoL-AD | Age, ADL, NPS, Depression, Co-morbidity, CSM, Gender, Age C, Being married, Living alone, Education, Burden, Gender C | Good |
| Zucchella *et al.* (2015) | Italy | Self vs. Family | 135 | 93 | 78.2 (5.9) | 15.3 (7.5) | AD | Live with carer 56.3% | QoL-AD | ADL, NPS, Depression, CSM, Living alone, Burden | Satisfactory |

Note: articles were judged to be of poor quality if scored ≤20 or below, satisfactory scored between >20 and <26, good scored ≥26. Shading indicates articles using the same study data. “Severity” refers to Mini-Mental State Examination score unless otherwise specified.

Quality of life measure abbreviations: 36-Item Short Form Health Survey (SF-36), Dementia Quality of Life Questionnaire (DEMQOL), Dementia Quality of Life Instrument (DQoL), Duke Health Profile (DHP), EuroQol five dimensions questionnaire (EQ-5D), Health Utility Index (HUI), Quality of Life in Alzheimer's Disease (QoL-AD), Visual Analogue Scale, (VAS)

Dementia type abbreviations: Alzheimer's disease (AD), Dementia with Lewy bodies (DLB), Frontotemporal Dementia (FTD), Parkinson's Disease Dementia (PDD), Vascular dementia (VaD)

Factors included in the meta-analysis abbreviations: Better functional ability (ADL), Burden or stress (Burden), Higher level of education (Education), Higher scores on cognitive screening measures (CSM), Female gender (Gender), Female gender carer (Gender C), Neuropsychiatric symptoms/BPSD (NPS), Older age (Age), Older age carer (Age C), Presence of co-morbid conditions (Co-morbidity)

**Supplementary Table 7. Longitudinal studies of quality of life in people with dementia**

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Study** | **Country of study** | **Time period** | **n** | **Females** | **Mean age** | **Severity** | **Dementia type** | **Living situation** | **QoL measure** | **Factors included in the meta-analysis** | **Quality rating** |
| Albert *et al.* (2001) | US | 24 months median | 122 | Not specified | 74.175 (8.05) | Not specified | AD | Mostly community | AAIQoL | CSM | Good |
| Beerens *et al.* (2015) | England, Estonia, Finland, France, Germany, Netherlands, Spain, Sweden | 3 months | 343 | 256 | 84.3 (6.0) | 14.1 (5.2) | Dementia | Not specified | QoL-AD | Baseline QoL | Satisfactory |
| Castro-Monteiro *et al.* (2014) | Spain | 20 months | 274 | 224 | 84.70 (6.51) | 12.96 (8.51) | Dementia | Residential care | EQ-5D  QoL-AD | Baseline QoL | Satisfactory |
| Clare *et al.* (2014b) | Wales | 20 months | 51 | 25 | 76.75 (7.88) | 24.5 (2.80) | AD 31, VaD 11, Mixed 9 | Community | QoL-AD | Age\*, Depression, Baseline QoL, ADL\*, NPS\*, CSM\*, Gender\*, Baseline QoL\* | Good |
| Funaki *et al.* (2005) | Japan | 3 months | 25 | 18 | 81.2 (6.38) | HDS-R 10.6 (5.9) | AD 14, VaD 2, Other 9 | Group home | QLQD | Baseline QoL, | Satisfactory |
| Heggie *et al.* (2012) | Canada | 12 months | 32 | 15 | 72.5 (9.4) | 3MS 75.8 (18.7) | Dementia | Community (rural and remote settings) | QoL-AD | Depression, Baseline QoL | Good |
| Hoe *et al.* (2009) | England, Wales | 5 months | 182 | 152 | 85.8 (7.6) | 7.4 (8.0) | Dementia | Nursing home | QoL-AD | Age, ADL, NPS, Depression, CSM, Gender, GDS, Baseline QoL | Good |
| Livingston *et al.* (2008) | England | 18 months | 122 | Not specified | 80.4 (7.3) | 16.7 (6.9) | AD | Not specified | QoL-AD life as whole item | Age, ADL, NPS, GDS, CSM, Baseline QoL | Good |
| Lyketsos *et al.* (2003) | US | 24 months | 47 | 45 | 80.4 (7.3) | 8.4 (7.2) | Dementia | Long term care | ADRQL | Age, NPS, Depression, CSM, Gender, Baseline QoL | Good |
| Mjørud *et al.* (2014c) | Norway | 10 months | 143 | 116 | 87.2 7.9) | CDR1 23, CDR2 57, CDR3 63 | AD 94, Other 104 | Nursing home | QUALID | Baseline QoL | Satisfactory |
| Nakanishi *et al.* (2016) | Japan | 35.9 (5.4) months | 32 | 27 | 84.3 (5.5) | 15.9 (3.7) | Dementia | Nursing home | QoL-AD | Age, ADL, NPS, CSM, Gender, GDS, Baseline QoL | Poor |
| Sheehan *et al.* (2013) | England | 6 months | 66 | 51 | 86.0 (76.5) | CDR1 4, CDR2 31, CDR3 31. | Dementia | General hospital inpatients | QoL-AD | Age, Gender, GDS, Baseline QoL | Good |
| 12 months | 59 | 37 | 86.5 (6.2) | CDR1 4, CDR2 24, CDR3 31 | Dementia | General hospital inpatients | QoL-AD | Age, Baseline QoL |
| de Sousa *et al.* (2015) | Brazil | 12 months | 55 | 72 | 76.8 (7.3) | 21.4 (3.5) | AD | Not specified | QoL-AD | None | Satisfactory |
| Sura *et al.* (2015) | US | 60 months | 112 | 64 | 65-79 59; ≥80 53 | Not specified | Dementia | Not specified | SF-12 | Baseline QoL | Satisfactory |
| Tatsumi *et al.* (2009) | Japan | 24 months | 96 | 62.50% | 71.8 (8.0) | 17.86 (3.3) | AD | Community | QoL-AD | Age, ADL, NPS, CSM | Good |
| Trigg *et al.* (2015) | England | 18 months | 69 | 39 | 78.19 (8.48) | 19.40 (4.67) | AD | Community | EQ-5D  DEMQOL | Baseline QoL | Good |
| Uhlmann *et al.* (1987) | US | 12 months | 115 | 64.90% | 73.8 | 16.1 (10.0) | AD 75.7% | Lived at home 74%, Lived with adult children 13%, Long term care 13% | Single global HRQoL rating | CSM | Satisfactory |
| Vogel *et al.* (2012) | Denmark | 12 months | 102 | Not specified | 76 (7.1) Baseline | 22.7 | AD | Community 91% | QoL-AD  EQ-5D VAS | Baseline QoL | Good |
| 36 months | 102 | Not specified | 76 (7.1) Baseline | 18.0 | AD | Community 86.3% | QoL-AD  EQ-5D VAS | Baseline QoL |
| Wolf-Ostermann *et al.* (2012) | Germany | 12 months | 56 | 43 | 82.3 (9.25) | GDS4 6, GDS5 5, GDS6 38, GDS7 7 | Dementia | Shared-housing 34, Special care units 22 | QUALIDEM | Gender | Good |
| Woods *et al.* (2006) | England | 2 months | 201 | 158 | 85.3 (7.0) | 14.4 (3.8) | Dementia | Mostly residential 172 | QoL-AD | NPS, Depression, CSM, Gender, GDS, Baseline QoL | Good |

Note: articles were judged to be of poor quality if scored ≤20 or below, satisfactory scored between >20 and <26, good scored ≥26. Shading indicates articles using the same study data. “Severity” refers to Mini-Mental State Examination score unless otherwise specified. \* indicates data not reported in articles

Quality of life measure abbreviations: 12-Item Short Form Health Survey (SF-12), Activity and Affect Indicators of QOL (AAIQoL), Alzheimer's Disease Related Quality of Life (ADRQL), Dementia Quality of Life Questionnaire (DEMQOL), EuroQol five dimensions questionnaire (EQ-5D), Quality of Life in Alzheimer's Disease (QoL-AD), Quality of Life in Late Stage Dementia Scale (QUALID), Quality of Life Questionnaire for Dementia (QLQD), Visual Analogue Scale, (VAS)

Severity abbreviations: Clinical Dementia Rating (CDR), Hasegawa Dementia Scale-Revised (HDS-R), Modified Mini-Mental State Examination (3MS)

Dementia type abbreviations: Alzheimer's disease (AD), Vascular dementia (VaD)

Factors included in the meta-analysis abbreviations: Better functional ability (ADL), Female gender (Gender), Higher scores on cognitive screening measures (CSM), More advanced dementia (GDS), Neuropsychiatric symptoms/BPSD (NPS), Older age (Age), Quality of life rating at baseline (Baseline QoL)

**Supplementary Table 8. Studies assessing well-being in people with dementia**

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Study** | **Country of study** | **n** | **Females** | **Mean age** | **Severity** | **Dementia type** | **Living situation** | **Well-being measure** | **Rating type** | **Data quality** |
| Burgener and Dickerson-Putman (1999) | US | 84 | 51 | 76.5 | 20.5 | AD or VaD | Not specified | PWB-CIP | Informant Longitudinal | Satisfactory |
| Burgener and Twigg (2002) | US | 70 | 55 | 77.3 | 21.52 (4.7) | Dementia | Community | PWB-CIP | Informant Longitudinal | Good |
| Burgener *et al.* (2005) | US | 96 | 55 | 77.3 (7.8) | 21.52 (4.7) | AD, VaD, Mixed, DLB | Assisted living 12, Community 84 | PWB-CIP | Informant | Satisfactory |
| Gerritsen *et al.* (2007) | Netherlands | 34 | 78% | 80.5 (9.26) | 5-13 | Dementia | Nursing home | Positive Affect Scales  Negative Affect Scales | Self | Satisfactory |
| Gilbart and Hirdes (2000) | Canada | 385 |  | 75.6 (15.6) | CPS 3.2 (2.2) | Dementia | Nursing home | SHARP  MIDAS  Mood state | Informant | Poor |
| Muurinen *et al.* (2015) | Finland | 2379 | 78% | 85 | Mild 11%, Moderate 53% Severe 36% | Dementia | Nursing home | Psychological wellbeing was assessed by 6 questions | Self | Satisfactory |

Note: articles were judged to be of poor quality if scored ≤20 or below, satisfactory scored between >20 and <26, good scored ≥26. Shading indicates articles using the same study data. “Severity” refers to Mini-Mental State Examination score unless otherwise specified.

Quality of life measure abbreviations: Measure of Intensity and Duration of Affective States (MIDAS), Psychological Well-being in Cognitively Impaired Persons (PWB-CIP), Short Happiness and Affect Research Protocol (SHARP)

Severity abbreviations: Cognitive Performance Scale (CPS)

Dementia type abbreviations: Alzheimer's disease (AD), Dementia with Lewy bodies (DLB), Vascular dementia (VaD)

**Supplementary Table 9. Studies assessing life satisfaction in people with dementia**

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Study** | **Country of study** | **n** | **Females** | **Mean age** | **Severity** | **Dementia type** | **Living situation** | **Well-being measure** | **Rating type** | **Data quality** |
| Eshkoor *et al.* (2014) | Malaysia | 1210 | 770 | Not specified | Not specified | Dementia | Not specified | Single question - Are you satisfied with your current life? | Self | Poor |
| Makai *et al.* (2012) | Netherlands | 96 | 68.00% | 82 (9.1) | Not specified | Dementia | Nursing home | Cantril’s ladder  Overall life satisfaction | Informant | Satisfactory |
| Zank and Leipold (2001) | Germany | 63 | 76% | 79.2 (8.6) | 17.7 (4.3) | Dementia | Community | Life Satisfaction Questionnaire | Self | Satisfactory |

Note: articles were judged to be of poor quality if scored ≤20 or below, satisfactory scored between >20 and <26, good scored ≥26. Shading indicates articles using the same study data. “Severity” refers to Mini-Mental State Examination score unless otherwise specified.

**Supplementary Table 10: Measures of quality of life used in the included studies, with frequency of use overall and by type of rating**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **QoL measure** | **Number of studies** | | | | | |
|  | **Total** | **Self-ratings** | **Informant ratings** | **Proxy ratings** | **Difference scores** | **Longitudinal measurement** |
| **Dementia specific QoL/HRQoL measures** | | | | | |  |
| Activity and Affect Indicators of QoL (Albert *et al.*, 1996) | 8 | 3 | 7 |  |  | 1 |
| Pleasant Events Schedule-AD (Logsdon and Teri, 1997, Teri and Logsdon, 1991) | 2 |  | 2 |  |  |  |
| Observed Emotion Rating Scale (Lawton *et al.*, 1996) | 4 |  | 3 | 1 |  |  |
| Activity Engagement (Nolan *et al.*, 1995) | 1 |  | 1 |  |  |  |
| Alzheimer's Disease Related Quality of Life (ADRQL) (Rabins *et al.*, 1999) | 13 | 1 | 18 |  |  | 1 |
| Bath Assessment of Subjective Quality of Life in Dementia (BASQID) (Trigg *et al.*, 2007) | 3 | 4 |  |  |  |  |
| Community Dementia Quality of Life Profile (Salek *et al.*, 1996, Salek *et al.*, 1999) | 1 |  | 1 |  |  |  |
| Cornell-Brown Scale for Quality of Life in Dementia (Ready *et al.*, 2002b) | 1 |  | 1 |  |  |  |
| Dementia Care Mapping (Kitwood and Bredin, 1992) | 7 |  |  | 6 |  |  |
| Dementia Quality of Life Questionnaire (DEMQOL) (Smith *et al.*, 2005) | 16 | 11 | 1 | 10 | 2 | 1 |
| Discomfort Scale-Dementia Alzheimer Type (Hurley *et al.*, 1992) | 4 | 1 | 3 |  |  |  |
| Dementia Quality of Life instrument (Brod *et al.*, 1999) | 14 | 13 | 1 |  | 1 |  |
| Observable Displays of Affect Scale (Vogelpohl and Beck, 1997) | 1 |  | 1 |  |  |  |
| Observing QOL for Dementia Advanced (Edelman *et al.*, 2007) | 1 |  |  | 1 |  |  |
| Quality of Life in Alzheimer’s Disease (Logsdon *et al.*, 2000) | 82 | 73 | 60 | 2 | 15 | 12 |
| Quality of Life in Late Stage Dementia Scale (QUALID) (Weiner *et al.*, 2000) | 12 |  | 11 |  |  | 1 |
| QUALIDEM (Ettema *et al.*, 2007a) | 9 |  | 4 | 8 |  |  |
| Quality of Life Questionnaire for Dementia (Terada *et al.*, 2002) | 4 |  | 2 | 1 |  | 1 |
| Resident and Staff Observation Checklist-Quality of Life Measure (Sloane *et al.*, 1991) | 1 |  |  | 1 |  |  |
| Self-Reported Quality of Life Scale (Kane *et al.*, 2003) | 3 | 3 |  |  |  |  |
| Source of Discomfort Scale (Cohen-Mansfield *et al.*, 2015) | 1 |  | 1 |  |  |  |
| The Vienna List (Porzsolt *et al.*, 2004) | 1 |  | 1 |  |  |  |
| **Generic QoL measures** | | | | | | |
| 5 items from Geriatric Depression Scale-15 (Sheikh and Yesavage, 1986) | 1 | 1 |  |  |  |  |
| COOP/WONCA (Nelson *et al.*, 1987) | 1 | 1 |  |  |  |  |
| Investigating Choice Experiments for the Preferences of Older People CAPability measure-Older people (Grewal *et al.*, 2006) | 2 |  | 2 |  |  |  |
| Linear Analogue Self Assessment (Grunberg *et al.*, 1996) | 2 | 2 | 2 |  |  |  |
| Quality of Life Assessment Schedule (Selai *et al.*, 2001a) | 1 | 1 | 1 |  |  |  |
| Quality of Life Index (Ferrans and Powers, 1985) | 1 | 1 |  |  |  |  |
| Single item global QoL question (Buckley *et al.*, 2012, Campbell *et al.*, 2008, Cordner *et al.*, 2010, Gerritsen *et al.*, 2005, James *et al.*, 2005) | 5 | 4 | 5 | 1 | 1 |  |
| World Health Organization-8 (Power, 2003) | 2 | 2 | 1 |  |  |  |
| World Health Organization Quality of Life-100 (Power *et al.*, 1999) | 2 | 2 |  |  |  |  |
| World Health Organization Quality of Life-BREF (World Health Organization, 1996) | 2 | 2 |  |  |  |  |
| **Generic HRQoL or health status measures** | | | | | | |
| 15-dimensional (15D) (Sintonen, 1995) | 1 | 1 |  |  |  |  |
| Assessment of Quality of Life (Hawthorne *et al.*, 1999) | 2 | 2 | 1 |  |  |  |
| Disability and Distress Index (Rosser and Kind, 1978) | 1 | 1 | 1 |  |  |  |
| Duke Health Profile (Parkerson *et al.*, 1990) | 1 | 1 |  |  | 1 |  |
| EQ-5D (The EuroQol Group, 1990) | 25 | 16 | 19 | 2 | 4 | 2 |
| EQ-5D VAS (The EuroQol Group, 1990) | 14 | 11 | 11 |  | 1 | 1 |
| Health Utility Index II (Torrance *et al.*, 1996) | 5 | 1 | 5 |  | 1 |  |
| Health Utility Index III (Furlong *et al.*, 1998) | 7 | 1 | 7 |  |  |  |
| Nottingham Health Profile (Hunt *et al.*, 1981) | 1 |  | 1 |  |  |  |
| Quality of Well-being scale (Kaplan *et al.*, 1976) | 4 | 2 | 4 |  |  |  |
| Single item global HRQoL question (Uhlmann *et al.*, 1987) | 1 | 1 |  |  |  | 1 |
| 12-Item Short Form Health Survey (SF-12) (Ware *et al.*, 1995) | 4 | 4 | 3 |  |  | 1 |
| 36-Item Short Form Health Survey (SF-36) (Ware *et al.*, 1993) | 7 | 5 | 3 |  | 1 |  |

Note: the Activity and Affect Indicators of QoL was split into two sections, in the analysis the first (Activity) was combined with Pleasant Events Schedule-AD and the second (Affect)) was combined with Observed Emotion Rating Scale in the analysis. Health Utility Index II and Health Utility Index II, and SF-12 and SF-36 were combined in the analysis.

**Supplementary Table 11: Mean scores for self-ratings of quality of life**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **QoL measure** | **Range of possible scores** | **Number of studies** | **Mean** | **Range of means reported in the studies** | **Range of scores reported in the studies** | **Direction of scoring** |
| Dementia Quality of Life Questionnaire (DEMQOL) | 28-112 | 7 | 87.5 | 81.2-91.2 | 33–112 | Higher is better |
| Dementia Quality of Life Instrument-Aesthetics | 1-5 | 6 | 3.3 | 2.81-3.7 | 1-5 | Higher is better |
| Dementia Quality of Life Instrument-Feelings of Belonging | 1-5 | 6 | 3.6 | 3.3-3.9 | 1-5 | Higher is better |
| Dementia Quality of Life Instrument-Negative Affect | 1-5 | 8 | 2.4 | 1.9-3.8 | 1-5 | Lower is better |
| Dementia Quality of Life Instrument-Positive Affect | 1-5 | 6 | 3.5 | 3.2-3.6 | 1.5-5 | Higher is better |
| Dementia Quality of Life Instrument-Self-Esteem | 1-5 | 6 | 3.3 | 3.2-3.5 | 1.5-5 | Higher is better |
| EQ-5D | -.59-1 | 9 | 0.7 | .4-.9 | -.1-1 | Higher is better |
| EQ-5D Visual Analogue Scale | 0-100 | 4 | 67.9 | 34.0-79.1 | 20-100 | Higher is better |
| Quality of Life in Alzheimer's Disease | 13-56 | 85 | 35.2 | 26.7-42.8 | 2-52a | Higher is better |
| Quality of Life in Alzheimer's Disease (different scoring) | 1-4 | 6 | 2.9 | 2.51-3.1 | 1.3–4.0 | Higher is better |

a One paper provided data for all participants even where the QoL-AD was only partially completed; hence the lowest score reported (2) is below the minimum score for the full scale (13).

**Supplementary Table 12a: Mean scores for informant ratings of quality of life made by family carers**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **QoL measure** | **Range of possible scores** | **Number of studies** | **Mean** | **Range of means reported in the studies** | **Range of scores reported in the studies** | **Direction of score** |
| Alzheimer's Disease Related Quality of Life | 0-100 | 11 | 71.3 | 55.5-83.1 | 18-100 | Higher is better |
| EQ-5D | -.59-1 | 13 | .6 | .2-.8 | -.4-1 | Higher is better |
| EQ-5D Visual Analogue Scale | 0-100 | 8 | 61.1 | 48.6-.70.8 | 10-100 | Higher is better |
| Health Utility Index 2 | -.03-1 | 5 | .61 | .5-.7 | .2-.1 | Higher is better |
| Health Utility Index 3 | -.36-1 | 8 | .27 | .2-.5 | -.3-1 | Higher is better |
| Quality of Life in Alzheimer's Disease | 13-56 | 57 | 30.7 | 24.5-38.0 | 13-52 | Higher is better |

**Supplementary Table 12b: Mean scores for informant ratings of quality of life made by health care professionals**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **QoL measure** | **Range of possible scores** | **Number of studies** | **Mean** | **Range of means reported in the studies** | **Range of scores reported in the studies** | **Direction of score** |
| Alzheimer's Disease Related Quality of Life | 0-100 | 8 | 70.4 | 59.2-79.9 | 15-100 | Higher is better |
| Quality of Life in Alzheimer's Disease | 13-56 | 12 | 31.2 | 27.0-37.7 | Ranges not provided | Higher is better |
| Quality of Life in Late Stage Dementia Scale | 11-55 | 14 | 22.4 | 18.1-28.8 | 11-45 | Lower is better |

**Supplementary Table 12c: Mean scores for informant ratings of quality of life made by mixed groups of informants including family carers and health care professionals**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **QoL measure** | **Range of possible scores** | **Number of studies** | **Mean** | **Range of means reported in the studies** | **Range of scores reported in the studies** | **Direction of score** |
| Quality of Life in Alzheimer's Disease | 13-56 | 5 | 31.1 | 27.26-36.6 | Ranges not provided | Higher is better |

**Supplementary Table 13a: Factors associated with self-ratings of quality of life by people living with dementia – factors pertaining to the person with dementia factors**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 58 | 8485 | -.019 | -.042-.004 | .1135 | 63.302 | .264 | 9.956 |
| Female gender | 47 | 7030 | .005 | -.019-.030 | .6607 | 47.700 | .403 | 3.565 |
| White ethnicity | 12 | 1885 | .157 | .092-.221 | <.0001 | 22.143 | .023 | 50.323 |
| Higher income | 7 | 1008 | .156 | -.024-.326 | .0890 | 48.791 | <.001 | 87.703 |
| Higher level of education | 44 | 5874 | .053 | .019-.086 | .0021 | 33.140 | .019 | 33.140 |
| Underweight | 8 | 1587 | -.014 | -.102-.074 | .7531 | 19.581 | .007 | 64.250 |
| Alzheimer’s (vs. other dementia subtypes) | 9 | 1552 | .136 | -.042-.305 | .1333 | 96.171 | <.001 | 91.681 |
| Longer disease duration | 12 | 1918 | -.012 | -.066-.041 | .6566 | 13.908 | .238 | 20.910 |
| More advanced dementia | 24 | 3548 | -.096 | -.146--.045 | .0002 | 48.410 | .001 | 52.489 |
| Global Deterioration Scale | 6 | 886 | -.103 | -.177--.029 | .0067 | 5.897 | .316 | 15.207 |
| Clinical Dementia Rating | 15 | 2184 | -.087 | -.161--.012 | .0232 | 40.148 | <.001 | 65.129 |
| Higher scores on cognitive screening measures | 93 | 13504 | .086 | .057-.115 | <.0001 | 218.065 | <.001 | 57.811 |
| Mini-Mental State Examination | 84 | 12046 | .081 | .050-.112 | <.0001 | 199.242 | <.001 | 58.342 |
| Alzheimer's Disease Assessment Scale-Cognitive Subscale | 5 | 3095 | .066 | .030-.100 | .0003 | 3.239 | .519 | 0 |
| Taking medication | 19 | 4606 | -.120 | -.168--.071 | <.0001 | 37.773 | .004 | 52.347 |
| Acetylcholinesterase inhibitors | 7 | 1141 | -.111 | -.178--.043 | .0014 | 7.058 | .316 | 14.990 |
| Polypharmacy | 8 | 1718 | -.106 | -.163--.049 | .0003 | 9.441 | .223 | 25.854 |
| Psychotropic drugs | 9 | 2518 | -.120 | -.203--.034 | .0061 | 21.104 | .007 | 62.093 |
| Longer duration of care home stay | 8 | 714 | -.096 | -.169--.021 | .0117 | 5.874 | .555 | 0 |
| Better functional ability | 79 | 13216 | .173 | .139-.206 | <.0001 | 262.432 | <.001 | 70.278 |
| Alzheimer's Disease Co-operative Study-Activities of Daily Living Inventory | 5 | 981 | .085 | -.069-.235 | .2773 | 22.156 | <.001 | 81.946 |
| Disability Assessment for Dementia | 5 | 3122 | .073 | -.007-.153 | .0751 | 11.492 | .022 | 65.192 |
| Basic activities of daily living | 50 | 8558 | .217 | .172-.261 | <.0001 | 179.342 | <.001 | 72.678 |
| Barthel Index | 17 | 2414 | .200 | .097-.299 | .0001 | 98.376 | <.001 | 83.736 |
| Katz Index of Independence in Activities of Daily Living | 11 | 1338 | .219 | .122-.312 | <.0001 | 25.762 | .004 | 61.183 |
| Physical Self-Maintenance Scale | 6 | 703 | .216 | .132-.297 | <.0001 | 6.403 | .269 | 21.917 |
| Basic activities of daily living measures excluding Barthel Index, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 18 | 4352 | .189 | .130-.246 | <.0001 | 41.009 | .001 | 58.545 |
| Instrumental activities of daily living | 25 | 3330 | .148 | .087-.208 | <.0001 | 65.771 | <.001 | 63.510 |
| Functional Activities Questionnaire | 5 | 398 | .176 | .077-.271 | .0005 | 2.319 | .678 | 0 |
| Lawton’s Instrumental Activities of Daily Living | 13 | 1660 | .115 | .059-.170 | <.0001 | 14.161 | .291 | 15.259 |
| Instrumental activities of daily living measures excluding Lawton’s Instrumental Activities of Daily Living & Functional Activities Questionnaire | 8 | 1372 | .208 | .059-.349 | .0066 | 50.192 | <.001 | 86.054 |
| Presence of unmet needs | 5 | 838 | -.204 | -.305--.100 | .0002 | 9.273 | .055 | 56.866 |
| More awareness | 10 | 1285 | .145 | .090-.198 | <.0001 | 7.769 | .558 | 0 |
| Better self-rated memory functioning | 9 | 1699 | .027 | -.021-.075 | .2681 | 6.595 | .581 | 0 |
| Depression | 80 | 11435 | -.315 | -.353--.276 | <.0001 | 363.600 | <.001 | 78.273 |
| Cornell Scale for Depression in Dementia | 27 | 5537 | -.245 | -.300--.189 | <.0001 | 102.956 | <.001 | 74.746 |
| Geriatric Depression Scale (all versions) | 28 | 2828 | -.436 | -.521--.342 | <.0001 | 212.993 | <.001 | 87.324 |
| Geriatric Depression Scale-15 | 16 | 1646 | -.490 | -.604--.357 | <.0001 | 155.722 | <.001 | 90.367 |
| Geriatric Depression Scale-30 | 11 | 1079 | -.320 | -.397--.240 | <.0001 | 15.873 | .103 | 36.999 |
| Neuropsychiatric Inventory-Depression | 12 | 1855 | -.262 | -.363--.154 | <.0001 | 55.863 | <.001 | 80.309 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 28 | 2802 | -.332 | -.401--.259 | <.0001 | 109.001 | <.001 | 75.229 |
| Anxiety | 21 | 3012 | -.237 | -.317--.154 | <.0001 | 98.595 | <.001 | 79.715 |
| Neuropsychiatric Inventory-Anxiety | 9 | 1503 | -.054 | -.105--.003 | .0382 | 7.068 | .529 | 0 |
| Rating of Anxiety in Dementia | 6 | 925 | -.328 | -.462--.180 | <.0001 | 21.077 | .001 | 76.278 |
| Anxiety measures excluding Rating of Anxiety in Dementia & Neuropsychiatric Inventory-Anxiety | 8 | 872 | -.351 | -.482--.204 | <.0001 | 35.812 | <.001 | 80.453 |
| Neuropsychiatric symptoms/BPSD | 56 | 9629 | -.110 | -.134--.086 | <.0001 | 64.570 | .177 | 14.821 |
| Neuropsychiatric Inventory | 41 | 8061 | -.108 | -.135--.080 | <.0001 | 50.662 | .120 | 21.045 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory | 17 | 1654 | -.127 | -.175--.078 | <.0001 | 13.292 | .651 | 0 |
| Pain | 10 | 2720 | -.157 | -.236--.077 | .0001 | 24.305 | .004 | 62.971 |
| Better self-rated health | 11 | 1702 | .269 | .167-.366 | <.0001 | 44.359 | <.001 | 77.457 |
| Presence of co-morbid conditions | 31 | 4188 | -.213 | -.268--.157 | <.0001 | 94.600 | <.001 | 68.288 |
| Better quality of relationship with carer | 6 | 802 | .384 | .148-.579 | .0019 | 62.659 | <.001 | 92.020 |
| Cared for by spouse (vs. other carer type) | 8 | 1775 | .124 | .060-.186 | .0001 | 11.873 | .105 | 41.044 |
| Being married | 22 | 2847 | .078 | .046-.110 | <.0001 | 18.132 | .641 | 0 |
| Living alone | 9 | 2129 | -.124 | . -.240--004 | .0436 | 58.329 | <.001 | 86.285 |
| Greater social engagement | 11 | 1035 | .314 | .121-.483 | .0017 | 94.157 | <.001 | 89.379 |
| Presence of religious beliefs/spirituality | 8 | 641 | .352 | .120-.547 | .0035 | 60.621 | <.001 | 88.453 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 13b: Factors associated with self-ratings of quality of life by people living with dementia – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 10 | 1808 | -.061 | -.121--.001 | .0453 | 12.653 | .179 | 28.870 |
| Female gender | 12 | 2242 | .017 | -.036-.070 | .5221 | 15.644 | .155 | 29.684 |
| Higher level of education | 11 | 1767 | .088 | .030-.144 | .0028 | 13.597 | .192 | 26.456 |
| Depression | 9 | 1008 | -.120 | -.199--.040 | .0034 | 12.445 | .132 | 35.715 |
| Center for Epidemiologic Studies Depression Scale | 5 | 564 | -.118 | -.244-.011 | .0738 | 9.181 | .057 | 56.432 |
| Distress at NPS symptoms | 9 | 1089 | -.140 | -.202--.078 | .0001 | 8.536 | .383 | 6.284 |
| Burden or stress | 20 | 2840 | -.146 | -.202--.089 | <.0001 | 38.857 | .005 | 51.103 |
| Zarit Burden Interview | 15 | 1808 | -.140 | -.217--.061 | .0006 | 33.997 | .002 | 58.820 |
| Burden or stress measures excluding Zarit Burden Interview | 5 | 1032 | -.166 | -.225--.105 | <.0001 | 3.010 | .556 | 0 |
| Poorer mental health (GHQ) | 5 | 702 | -.156 | -.275--.034 | .0126 | 6.753 | .150 | 40.767 |
| Carer quality of life (self-rated) | 6 | 667 | .253 | .081-.411 | .0043 | 23.736 | <.001 | 78.935 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 14a: Factors associated with informant ratings of the quality of life of the person with dementia – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 59 | 12017 | -.027 | -.055-.001 | .0581 | 121.613 | <.001 | 52.308 |
| Female gender | 49 | 10315 | -.003 | -.034-.028 | .8527 | 108.209 | <.001 | 55.642 |
| White ethnicity | 7 | 1486 | .101 | .042-.159 | .0008 | 7.612 | .268 | 21.180 |
| Higher level of education | 32 | 6092 | .037 | .012-.063 | .0038 | 29.143 | .562 | 0 |
| Underweight | 5 | 1755 | -.065 | -.129--.002 | .0447 | 7.119 | .130 | 43.809 |
| Alzheimer’s (vs. other dementia subtypes) | 9 | 2719 | .050 | -.027-.126 | .2054 | 27.443 | .001 | 70.849 |
| Longer disease duration | 12 | 1731 | -.066 | -.113--.019 | .0064 | 8.143 | .700 | 0 |
| More advanced dementia | 40 | 8094 | -.296 | -.371--.216 | <.0001 | 549.596 | <.001 | 92.904 |
| Clinical Dementia Rating | 25 | 5868 | -.266 | -.367--.160 | <.0001 | 417.838 | <.001 | 94.256 |
| Global Deterioration Scale | 6 | 910 | -.262 | -.383--.132 | <.0001 | 20.558 | .001 | 75.678 |
| Advanced dementia measures excluding Clinical Dementia Rating & Global Deterioration Scale | 9 | 1327 | -.388 | -.535--.216 | <.0001 | 86.493 | <.001 | 90.751 |
| Higher scores on cognitive screening measures | 87 | 14672 | .183 | .147-.218 | <.0001 | 377.741 | <.001 | 77.233 |
| Dementia Rating Scale | 6 | 602 | .266 | .091-.425 | .0032 | 22.092 | .001 | 77.367 |
| Mini-Mental State Examination | 77 | 12947 | .172 | .135-.210 | <.0001 | 321.090 | <.001 | 76.331 |
| Cognitive screening measures excluding Dementia Rating Scale & Mini-Mental State Examination | 15 | 4719 | 183 | .095-.269 | .0001 | 95.064 | <.001 | 85.273 |
| Taking medication | 21 | 6003 | -.054 | -.081--.027 | .0001 | 20.911 | .402 | 4.354 |
| Acetylcholinesterase inhibitors | 10 | 1892 | -.082 | -.147--.015 | .0156 | 17.145 | .046 | 47.508 |
| Polypharmacy | 9 | 1834 | -.060 | -.105--.014 | .0112 | 6.754 | .563 | 0 |
| Psychotropic drugs | 12 | 4043 | -.066 | -.112--.018 | .0064 | 19.261 | .057 | 42.889 |
| Antipsychotic | 5 | 1244 | -.171 | -.290--.047 | .0069 | 15.322 | .004 | 73.893 |
| Antidepressants | 6 | 1221 | -.098 | -.195--.000 | .0492 | 11.134 | .049 | 55.092 |
| Anxiolytics | 7 | 1617 | -.056 | -.149-.038 | .2459 | 17.494 | .008 | 65.702 |
| Longer duration of care home stay | 12 | 2312 | -.105 | -.162--.047 | .0004 | 18.574 | .069 | 40.778 |
| Degree to which residential care is person-centred | 6 | 1814 | .155 | .049-.257 | .0042 | 13.729 | .017 | 63.581 |
| Community dwelling (vs. residential care) | 5 | 1011 | .123 | .062-.184 | .0001 | 3.398 | .494 | 0 |
| Special dementia unit (vs. other residential facility) | 5 | 2366 | .114 | .069-.158 | <.0001 | 4.753 | .314 | 15.838 |
| Better functional ability | 87 | 18707 | .337 | .292-.380 | <.0001 | 893.737 | <.001 | 90.377 |
| Alzheimer's Disease Co-operative Study-Activities of Daily Living Inventory | 6 | 1264 | .346 | .223-.458 | <.0001 | 25.967 | <.001 | 80.745 |
| Bristol Activities of Daily Living Scale | 5 | 859 | .450 | .393-.504 | <.0001 | 4.094 | .393 | 2.296 |
| Disability Assessment for Dementia | 6 | 3206 | .249 | .110-.378 | .0005 | 45.745 | <.001 | 89.070 |
| Basic activities of daily living | 61 | 13149 | .371 | .317-.423 | <.0001 | 695.854 | <.001 | 91.378 |
| Barthel Index | 19 | 3429 | .484 | .372-.583 | <.0001 | 268.501 | <.001 | 93.296 |
| Dependence Scale | 7 | 3523 | .328 | .154-.483 | .0003 | 123.388 | <.001 | 95.137 |
| Katz Index of Independence in Activities of Daily Living | 16 | 2991 | .300 | .247-.354 | <.0001 | 31.816 | .007 | 52.854 |
| Physical Self-Maintenance Scale | 9 | 1494 | .333 | .265-.398 | <.0001 | 13.285 | .102 | 39.780 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 11 | 1859 | .300 | .208-.386 | <.0001 | 40.364 | <.001 | 75.225 |
| Instrumental activities of daily living | 24 | 3234 | .351 | .270-.428 | <.0001 | 134.793 | <.001 | 82.937 |
| Lawton’s Instrumental Activities of Daily Living | 15 | 2306 | .303 | .210-.390 | <.0001 | 72.120 | <.001 | 80.588 |
| Instrumental activities of daily living measures excluding Lawton’s Instrumental Activities of Daily Living | 10 | 1039 | .458 | .382-.528 | <.0001 | 16.148 | .064 | 44.267 |
| More awareness | 5 | 557 | .275 | .037-.484 | .0241 | 31.084 | <.001 | 87.132 |
| Better self-rated memory functioning | 8 | 1185 | .213 | .054-.363 | .0092 | 47.334 | <.001 | 85.211 |
| Depression | 68 | 12320 | -.304 | -.349--.259 | <.0001 | 459.021 | <.001 | 85.404 |
| Cornell Scale for Depression in Dementia | 28 | 6671 | -.339 | -.396--.280 | <.0001 | 171.626 | <.001 | 84.268 |
| Geriatric Depression Scale (all versions) | 19 | 1953 | -.259 | -.342--.172 | <.0001 | 64.056 | <.001 | 71.899 |
| Geriatric Depression Scale-30 | 10 | 1082 | -.289 | -.414--.154 | <.0001 | 40.764 | <.001 | 77.922 |
| Geriatric Depression Scale-15 | 8 | 837 | -.211 | -.324--.092 | .0006 | 19.448 | .007 | 64.006 |
| Neuropsychiatric Inventory-Depression | 12 | 2223 | -.263 | -.396--.118 | .0004 | 117.702 | <.001 | 90.654 |
| Other depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 19 | 2503 | -.309 | -.392--.221 | <.0001 | 93.689 | <.001 | 80.787 |
| Anxiety | 18 | 3143 | -.148 | -.189--.107 | <.0001 | 20.328 | .258 | 16.371 |
| Neuropsychiatric Inventory-Anxiety | 12 | 2128 | -.151 | -.209--.092 | <.0001 | 16.069 | .139 | 31.545 |
| Anxiety measures excluding Neuropsychiatric Inventory-Anxiety | 7 | 1201 | -.163 | -.235--.089 | <.0001 | 8.765 | .187 | 31.546 |
| Neuropsychiatric symptoms/BPSD | 76 | 15358 | -.329 | -.372--.285 | <.0001 | 630.810 | <.001 | 88.111 |
| Cohen-Mansfield Agitation Inventory | 9 | 1332 | -.150 | -.213--.085 | <.0001 | 10.839 | .211 | 26.191 |
| Neuropsychiatric Inventory | 51 | 11213 | -.338 | -.392--.282 | <.0001 | 487.984 | <.001 | 89.754 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory | 23 | 3685 | -.353 | -.417--.286 | <.0001 | 107.094 | <.001 | 79.457 |
| Pain | 13 | 4048 | -.203 | -.307--.095 | .0003 | 124.860 | <.001 | 90.389 |
| Better self-rated health | 8 | 1826 | .198 | .131-.263 | <.0001 | 12.123 | .097 | 42.260 |
| Presence of co-morbid conditions | 27 | 5349 | -.090 | -.126--.055 | <.0001 | 39.872 | .040 | 34.792 |
| Cared for by spouse (vs. other carer type) | 10 | 2139 | .117 | .053-.180 | .0004 | 17.386 | .043 | 48.234 |
| Being married | 18 | 3713 | .100 | .056-.143 | <.0001 | 28.012 | .045 | 39.311 |
| Living alone | 13 | 2396 | -.137 | -.193--.081 | <.0001 | 20.782 | .054 | 42.258 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 14b: Factors associated with informant ratings of the quality of life of the person with dementia – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 15 | 2500 | -.037 | -.020-.094 | .2006 | 24.345 | .042 | 42.494 |
| Female gender | 15 | 3089 | .046 | -.005-.096 | .0766 | 23.249 | .056 | 39.782 |
| Higher level of education | 12 | 2313 | .084 | .035-.132 | .0007 | 13.597 | .256 | 19.098 |
| More time spent caring (residential care only) | 6 | 772 | -.159 | -.253--.061 | .0016 | 9.538 | .089 | 47.578 |
| More time spent caring (community only) | 5 | 681 | -.137 | -.267--.002 | .0462 | 11.630 | .020 | 65.606 |
| Depression | 14 | 2694 | -.255 | -.338--.169 | <.0001 | 64.440 | <.001 | 79.826 |
| Center for Epidemiologic Studies Depression Scale | 6 | 905 | -.299 | -.458--.122 | .0012 | 32.272 | <.001 | 84.507 |
| Geriatric Depression Scale (all versions) | 5 | 591 | -.362 | -.496--.211 | <.0001 | 14.617 | .006 | 72.634 |
| Depression measures excluding Geriatric Depression Scale & Center for Epidemiologic Studies Depression Scale | 6 | 1449 | -.202 | -.313--.085 | .0008 | 22.218 | <.001 | 77.496 |
| Burden or stress | 25 | 4460 | -.324 | -.398--.247 | <.0001 | 180.102 | <.001 | 86.674 |
| Zarit Burden Interview | 18 | 3284 | -.345 | -.435--.248 | <.0001 | 148.814 | <.001 | 88.576 |
| Burden or stress measures excluding Zarit Burden Interview | 8 | 1247 | -.276 | -.391--.152 | <.0001 | 32.129 | <.001 | 78.213 |
| Distress at NPS symptoms | 10 | 1665 | -.320 | -.379--.258 | <.0001 | 15.219 | .085 | 40.863 |
| Poorer mental health (GHQ) | 6 | 715 | -.242 | -.311--.170 | <.0001 | 3.990 | .551 | 0 |
| Carer quality of life (self-rated) | 8 | 1509 | .314 | .212-.410 | <.0001 | 28.246 | <.001 | 75.218 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 15a: Factors associated with proxy ratings of the quality of life of the person with dementia – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 15 | 2283 | -.015 | -.113-.083 | .7650 | 71.987 | <.001 | 80.552 |
| Female gender | 12 | 2023 | -.003 | -.049-.043 | .8911 | 6.387 | .846 | 0 |
| More advanced dementia | 8 | 1421 | -.302 | -.413--.183 | <.0001 | 35.674 | <.001 | 80.378 |
| Higher scores on cognitive screening measures | 16 | 1978 | .104 | .018-.189 | .0185 | 50.789 | <.001 | 70.466 |
| Mini-Mental State Examination | 13 | 1557 | .062 | -.032-.154 | .1965 | 35.941 | <.001 | 66.612 |
| Taking medication | 7 | 1160 | -.099 | -.170--.026 | .0076 | 8.884 | .180 | 32.465 |
| Better functional ability | 15 | 2301 | .149 | .062-.233 | .0008 | 56.388 | <.001 | 75.172 |
| Basic activities of daily living | 12 | 1875 | .141 | .050-.230 | .0025 | 38.616 | <.001 | 71.514 |
| Basic activities of daily living measures excluding Barthel Index & Katz Index of Independence in Activities of Daily Living | 8 | 1249 | .166 | .058-.270 | .0027 | 22.654 | .002 | 69.100 |
| Depression | 13 | 1651 | -.317 | -.409--.219 | <.0001 | 47.495 | <.001 | 74.734 |
| Cornell Scale for Depression in Dementia | 5 | 811 | -.200 | -.361--.027 | .0235 | 19.089 | .001 | 79.046 |
| Geriatric Depression Scale | 5 | 466 | -.446 | -.608--.248 | <.0001 | 20.722 | <.001 | 80.697 |
| Neuropsychiatric symptoms/BPSD | 17 | 2559 | -.316 | -.373--.257 | <.0001 | 37.956 | .002 | 57.845 |
| Neuropsychiatric Inventory | 12 | 1645 | -.315 | -.387--.238 | <.0001 | 28.633 | .003 | 61.582 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory | 6 | 1120 | -.315 | -.396--.228 | <.0001 | 10.134 | .072 | 50.659 |
| Presence of co-morbid conditions | 6 | 873 | -.121 | -.186--.054 | .0004 | 3.383 | .641 | 0 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 15b: Factors associated with proxy ratings of the quality of life of the person with dementia – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 5 | 412 | -.017 | -.160-.126 | .8173 | 7.963 | .093 | 49.768 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 16a: Factors associated with the difference between self- and informant-rated quality of life for the person with dementia – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 12 | 2249 | -.042 | -.083--.000 | .0497 | 2.254 | .997 | 0 |
| Female gender | 11 | 2237 | .007 | -.052-.066 | .8093 | 16.622 | .083 | 39.840 |
| Higher level of education | 7 | 1212 | .027 | -.056-.110 | .5198 | 10.832 | .094 | 44.606 |
| Higher scores on cognitive screening measures | 23 | 3203 | .128 | .079-.175 | <.0001 | 35.229 | .037 | 37.552 |
| Mini-Mental State Examination | 21 | 2974 | .126 | .074-.177 | <.0001 | 33.508 | .030 | 40.312 |
| Better functional ability | 17 | 2080 | .221 | .147-.292 | <.0001 | 40.001 | .001 | 60.011 |
| Basic activities of daily living | 8 | 1207 | .204 | .115-.291 | <.0001 | 12.960 | .073 | 45.988 |
| Instrumental activities of daily living | 7 | 1019 | .099 | .037-.160 | .0018 | 1.227 | .976 | 0 |
| Lawton’s Instrumental Activities of Daily Living | 7 | 1019 | .099 | .037-.160 | .0018 | 1.227 | .976 | 0 |
| Depression | 11 | 1354 | -.277 | -.397--.148 | <.0001 | 46.807 | <.001 | 78.635 |
| Geriatric Depression Scale (all versions) | 9 | 1067 | -.337 | -.486--.168 | .0002 | 47.848 | <.001 | 83.281 |
| Neuropsychiatric symptoms/BPSD | 14 | 1700 | -.224 | -.289--.157 | <.0001 | 22.251 | .052 | 41.576 |
| Neuropsychiatric Inventory | 13 | 1580 | -.218 | -.287--.147 | <.0001 | 21.047 | .050 | 42.984 |
| Presence of co-morbid conditions | 5 | 467 | -.131 | -.311-.058 | .1739 | 15.201 | .004 | 73.686 |
| Being married | 6 | 668 | .075 | -.002-.151 | .0559 | 2.727 | .742 | 0 |
| Living alone | 7 | 1402 | -.061 | -.113--.008 | .0234 | 5.335 | .502 | 0 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 16b: Factors associated with the difference between self- and informant-rated quality of life of the person with dementia – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 7 | 1397 | -.038 | -.090-.015 | .1629 | 3.621 | .728 | 0 |
| Female gender | 8 | 1538 | .034 | -.036-.104 | .3398 | 11.970 | .102 | 41.519 |
| Burden or stress | 11 | 1753 | -.242 | -.317--.163 | <.0001 | 25.123 | .005 | 60.196 |
| Zarit Burden Interview | 10 | 1434 | -.259 | -.341--.174 | <.0001 | 21.812 | .009 | 58.738 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 17: Baseline factors associated with longitudinal quality of life ratings for the person with dementia – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 7 | 544 | -.079 | -.166-.009 | .0771 | 2.901 | .821 | 0 |
| Female gender | 7 | 583 | -.105 | -.226-.020 | .0984 | 11.330 | .079 | 47.045 |
| More advanced dementia | 6 | 561 | -.062 | -.147-.024 | .1600 | .879 | .972 | 0 |
| Clinical Dementia Rating | 5 | 439 | -.078 | -.175-.021 | .1227 | .459 | .977 | 0 |
| Higher scores on cognitive screening measures | 9 | 885 | .160 | .051-.265 | .0041 | 19.115 | .014 | 58.149 |
| Mini-Mental State Examination | 9 | 885 | .160 | .053-.265 | .0037 | 18.862 | .016 | 57.587 |
| Better functional ability | 5 | 371 | .115 | .012-.216 | .0287 | 2.867 | .580 | 0 |
| Depression | 5 | 447 | -.144 | -.255--.029 | .0144 | 5.052 | .282 | 20.826 |
| Neuropsychiatric symptoms/BPSD | 7 | 619 | -.120 | -.199--.041 | .0031 | 4.361 | .628 | 0 |
| Quality of life rating at baseline | 15 | 1782 | .280 | .140-.408 | .0001 | 117.942 | <.001 | 88.130 |
| Quality of Life-Alzheimer’s Disease rating at baseline | 10 | 1352 | .233 | .022-.425 | .0309 | 125.859 | <.001 | 92.849 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 18a: Correspondence between factor effect sizes for self-rated and informant-rated quality of life – factors pertaining to the person with dementia**

|  |  |  |
| --- | --- | --- |
| **Factor** | **Z** | **p** |
| Neuropsychiatric symptoms/BPSD | -17.7886 | <.0001 |
| Better functional ability | -15.4824 | <.0001 |
| More advanced dementia | -10.2832 | <.0001 |
| Higher scores on cognitive screening measures | -8.2902 | <.0001 |
| Better self-rated memory functioning | -4.9962 | <.0001 |
| More awareness | -2.6795 | .0074 |
| Pain | -1.9170 | .0552 |
| Longer disease duration | -1.6304 | .1030 |
| Being married | -.8898 | .3736 |
| Older age | -.5644 | .5725 |
| Living alone | -.4438 | .6572 |
| Longer duration of care home stay | -.2120 | .8321 |
| Cared for by spouse (vs. other carer type) | .2211 | .8251 |
| Female gender | .5959 | .5512 |
| Higher level of education | .8765 | .3807 |
| Depression | .9367 | .3489 |
| Underweight | 1.4736 | .1406 |
| White ethnicity | 1.6405 | .1009 |
| Better self-rated health | 2.2281 | .0259 |
| Alzheimer’s (vs. other dementia subtypes) | 2.7264 | .0064 |
| Taking medication | 3.3954 | .0007 |
| Anxiety | 3.6258 | .0003 |
| Presence of co-morbid conditions | 6.1080 | <.0001 |

Note: Negative Z score indicates that the informant rating effect size was higher than self-rating effect size, and vice versa.

**Supplementary Table 18b: Correspondence between factor effect sizes for self-rated and informant-rated quality of life – factors pertaining to the carer**

|  |  |  |
| --- | --- | --- |
| **Factor** | **Z** | **p** |
| Burden or stress | -7.8716 | <.0001 |
| Distress at NPS symptoms | -4.8879 | <.0001 |
| Depression | -3.7917 | .0002 |
| Poorer mental health (GHQ) | -1.6830 | .0924 |
| Carer quality of life (self-rated) | -1.4246 | .1543 |
| Female gender | -1.0457 | .2957 |
| Higher level of education | .1275 | .8986 |
| Older age | .7787 | .4361 |

Note: Negative Z score indicates that the informant rating effect size was higher than self-rating effect size, and vice versa.

**Supplementary Table 19a: Factors associated with self-ratings of quality of life by the person with dementia using the** **Quality of Life-Alzheimer’s Disease (QoL-AD) – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 35 | 5041 | -.014 | -.048-.020 | .4198 | 45.690 | .087 | 25.586 |
| Female gender | 30 | 4655 | -.004 | -.033-.025 | .7806 | 25.252 | .665 | 0 |
| White ethnicity | 5 | 777 | .194 | .104-.281 | <.0001 | 6.490 | .165 | 38.365 |
| Higher level of education | 28 | 4145 | .081 | .040-.121 | .0001 | 41.002 | .041 | 34.150 |
| Underweight | 5 | 1145 | -.043 | -.115-.029 | .2407 | 5.363 | .252 | 25.412 |
| Longer disease duration | 7 | 1225 | -.017 | -.103-.069 | .6956 | 10.641 | .100 | 43.616 |
| More advanced dementia | 18 | 2848 | -.100 | -.158--.042 | .0008 | 38.149 | .002 | 55.437 |
| Global Deterioration Scale | 5 | 853 | -.085 | -.152--.018 | .0135 | 1.561 | .816 | 0 |
| Clinical Dementia Rating | 10 | 1517 | -.108 | -.213--.001 | .0474 | 35.067 | <.001 | 74.335 |
| Higher scores on cognitive screening measures | 52 | 8809 | .064 | .033-.095 | .0001 | 83.982 | .002 | 39.272 |
| Mini-Mental State Examination | 47 | 8123 | .062 | .026-.097 | .0006 | 90.333 | <.001 | 49.077 |
| Taking medication | 12 | 3740 | -.100 | -.155--.045 | .0004 | 23.845 | .013 | 53.869 |
| Acetylcholinesterase inhibitors | 6 | 1029 | -.116 | -.196--.035 | .0051 | 6.909 | .228 | 27.627 |
| Polypharmacy | 5 | 1096 | -.118 | -.211--.022 | .0159 | 8.386 | .078 | 52.304 |
| Psychotropics | 5 | 2267 | -.066 | -.149-.018 | .1254 | 9.793 | .044 | 59.153 |
| Better functional ability | 48 | 8741 | .142 | .106-.177 | <.0001 | 106.485 | <.001 | 55.862 |
| Basic activities of daily living | 27 | 5159 | .160 | .109-.210 | <.0001 | 58.406 | <.001 | 55.484 |
| Physical Self-Maintenance Scale | 5 | 612 | .215 | .113-.312 | <.0001 | 6.338 | .175 | 36.884 |
| Katz Index of Independence in Activities of Daily Living | 8 | 1030 | .176 | .075-.273 | .0007 | 12.844 | .076 | 45.500 |
| Barthel Index | 10 | 990 | .112 | -.009-.230 | .0689 | 29.253 | .001 | 69.234 |
| Instrumental activities of daily living | 17 | 2165 | .124 | .067-.181 | <.0001 | 25.144 | .067 | 36.366 |
| Functional Activities Questionnaire | 5 | 398 | .176 | .077-.271 | .0005 | 2.319 | .678 | 0 |
| Lawton’s Instrumental Activities of Daily Living | 10 | 1421 | .114 | .037-.190 | .0038 | 15.646 | .075 | 42.476 |
| Presence of unmet needs\* | 5 | 838 | -.204 | -.305--.100 | .0002 | 9.273 | .055 | 56.866 |
| More awareness | 6 | 823 | .134 | .066-.201 | .0001 | 4.525 | .477 | 0 |
| Better self-rated memory functioning | 5 | 737 | .068 | -.005-.140 | .06763 | 3.274 | .513 | 0 |
| Depression | 50 | 8539 | -.287 | -.331--.241 | <.0001 | 218.287 | <.001 | 77.552 |
| Geriatric Depression Scale (all versions) | 12 | 1380 | -.386 | -.492--.268 | <.0001 | 57.174 | <.001 | 80.760 |
| Geriatric Depression Scale-30 | 7 | 902 | -.271 | -.357--.181 | <.0001 | 9.701 | .138 | 38.152 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 17 | 1911 | -.301 | -.387--.210 | <.0001 | 68.920 | <.001 | 76.785 |
| Neuropsychiatric Inventory-Depression | 9 | 1426 | -.263 | -.389--.126 | .0002 | 47.431 | <.001 | 83.133 |
| Cornell Scale for Depression in Dementia | 22 | 5013 | -.271 | -.333--.206 | <.0001 | 101.847 | <.001 | 79.381 |
| Anxiety | 16 | 2695 | -.190 | -.271--.106 | <.0001 | 65.530 | <.001 | 77.110 |
| Anxiety measures excluding Neuropsychiatric Inventory-Anxiety | 7 | 816 | -.299 | -.417--.170 | <.0001 | 20.940 | .002 | 71.347 |
| Neuropsychiatric Inventory-Anxiety | 8 | 1384 | -.048 | -.101-.005 | .0754 | 6.501 | .483 | 0 |
| Neuropsychiatric symptoms/BPSD | 40 | 7540 | -.106 | -.128--.083 | <.0001 | 38.582 | .489 | 0 |
| Neuropsychiatric Inventory | 31 | 6603 | -.112 | -.142--.082 | <.0001 | 35.850 | .213 | 16.317 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory | 11 | 1023 | -.103 | -.164--.041 | .0012 | 2.913 | .983 | 0 |
| Pain | 6 | 2495 | -.113 | -.187--.038 | .0032 | 11.852 | .037 | 57.812 |
| Presence of co-morbid conditions | 15 | 2321 | -.175 | -.253--.095 | <.0001 | 46.292 | <.001 | 69.757 |
| Better quality of relationship with carer | 5 | 583 | .311 | .114-.485 | .0024 | 23.547 | <.001 | 83.013 |
| Cared for by spouse (vs. other carer type) | 6 | 1199 | .159 | .103-.215 | <.0001 | 4.169 | .525 | 0 |
| Being married | 11 | 1991 | .087 | .042-.132 | .0002 | 10.351 | .410 | 3.388 |
| Living alone | 6 | 1553 | -.072 | -.127--.016 | .0113 | 5.762 | .330 | 13.222 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 19b: Factors associated with self-ratings of quality of life by the person with dementia using the Quality of Life-Alzheimer’s Disease (QoL-AD) – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 7 | 1410 | -.058 | -.103-.012 | .0137 | 7.859 | .447 | 0 |
| Female gender | 9 | 1844 | .067 | .016-.117 | .0104 | 9.082 | .335 | 11.916 |
| Higher level of education | 7 | 1154 | .112 | .023-.198 | .0135 | 11.511 | .074 | 47.874 |
| Depression | 6 | 687 | -.140 | -.299-.025 | .0963 | 22.061 | .001 | 77.336 |
| Distress at NPS symptoms | 8 | 918 | -.164 | -.227--.099 | <.0001 | 5.209 | .635 | 0 |
| Burden or stress | 16 | 2581 | -.127 | -.183--.071 | <.0001 | 27.663 | .024 | 45.776 |
| Burden or stress measures excluding Zarit Burden Interview | 5 | 1022 | -.191 | -.250--.131 | <.0001 | 2.177 | .703 | 0 |
| Zarit Burden Interview | 11 | 1559 | -.090 | -.164--.016 | .0172 | 18.530 | .047 | 46.034 |
| Carer quality of life (self-rated) | 5 | 521 | .297 | .087-.481 | .0060 | 21.397 | <.001 | 81.305 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 19c: Factors associated with self-ratings of quality of life made by the person with dementia using the Dementia Quality of Life Questionnaire (DEMQOL)**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 913 | -.063 | -.164-.039 | .2234 | 11.361 | .045 | 55.991 |
| Higher scores on cognitive screening measures | 8 | 919 | .019 | -.046-.085 | .5600 | 4.244 | .751 | 0 |
| Mini-Mental State Examination | 7 | 747 | .008 | -.065-.080 | .8358 | 3.710 | .716 | 0 |
| Better functional ability | 6 | 863 | .093 | -.060-.242 | .2341 | 24.110 | <.001 | 79.262 |
| Basic activities of daily living | 5 | 715 | .114 | -.065-.285 | .2117 | 21.256 | <.001 | 81.181 |
| Depression | 8 | 804 | -.417 | -.566--.243 | <.0001 | 47.237 | <.001 | 85.181 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 19d: Factors associated with self-ratings of quality of life made by the person with dementia quality of life using the EQ-5D**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 1234 | -.083 | -.224-.061 | .2587 | 28.510 | <.001 | 82.462 |
| Higher scores on cognitive screening measures | 12 | 2463 | .043 | -.011-.096 | .1229 | 18.879 | .063 | 41.733 |
| Mini-Mental State Examination | 11 | 2095 | .047 | -.015-.109 | .1338 | 19.118 | .039 | 47.694 |
| Better functional ability | 13 | 2858 | .194 | .067-.314 | .0028 | 135.774 | <.001 | 91.162 |
| Basic activities of daily living | 8 | 1474 | .331 | .190-.458 | <.0001 | 54.577 | <.001 | 87.174 |
| Depression | 7 | 1581 | -.225 | -.316--.131 | <.0001 | 18.998 | .004 | 68.418 |
| Geriatric Depression Scale (all versions) | 5 | 667 | -.264 | -.352--.171 | <.0001 | 5.251 | .263 | 23.823 |
| Neuropsychiatric symptoms/BPSD | 5 | 1511 | -.107 | -.159--.055 | .0001 | 4.327 | .363 | 7.568 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 19e: Factors associated with self-ratings of quality of life made by the person with dementia using the EQ-5D Visual Analogue Scale**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 879 | -.082 | -.222-.061 | .2600 | 28.479 | <.001 | 82.443 |
| Female gender | 5 | 749 | .010 | -.062-.083 | .7781 | 2.773 | .597 | 0 |
| Higher scores on cognitive screening measures | 8 | 1342 | .040 | -.022-.101 | .2031 | 8.411 | .298 | 16.778 |
| Mini-Mental State Examination | 7 | 980 | .012 | -.051-.076 | .6990 | 5.285 | .508 | 0 |
| Better functional ability | 6 | 1498 | .100 | -.032-.229 | .1356 | 29.328 | <.001 | 82.952 |
| Depression | 6 | 1379 | -.273 | -.375--.164 | <.0001 | 19.010 | .002 | 73.698 |
| Geriatric Depression Scale (all versions) | 5 | 730 | -.334 | -.443--.216 | <.0001 | 9.401 | .052 | 57.450 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 19f: Factors associated with self-ratings of quality of life made by the person with dementia using the Dementia Quality of Life instrument**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Higher scores on cognitive screening measures | 10 | 821 | .116 | .005-.225 | .0408 | 19.534 | .021 | 53.927 |
| Mini-Mental State Examination | 10 | 879 | .111 | -.001-.220 | .0518 | 20.508 | .015 | 56.115 |
| Better functional ability | 9 | 1070 | .134 | .044-.222 | .0037 | 14.919 | .061 | 46.379 |
| Basic activities of daily living | 8 | 766 | .168 | .077-.257 | .0003 | 10.021 | .187 | 30.143 |
| Depression | 10 | 898 | -.196 | -.287--.102 | .0001 | 16.782 | .052 | 46.370 |
| Cornell Scale for Depression in Dementia | 6 | 486 | -.119 | -.208--.029 | .0095 | 2.694 | .747 | 0 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 19g: Factors associated with self-ratings of quality of life made by the person with dementia using the 12-Item Short Form Health Survey (SF-12) and 36-Item Short Form Health Survey (SF-36)**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Higher scores on cognitive screening measures | 6 | 344 | .102 | -.174-.362 | .4715 | 31.812 | <.001 | 84.282 |
| Mini-Mental State Examination | 5 | 276 | .108 | -.234-.426 | .5409 | 31.763 | <.001 | 87.407 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 19h: Factors associated with self-ratings of quality of life by the person with dementia using dementia-specific quality of life measures – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 45 | 6547 | -.020 | -.044-.005 | .1148 | 35.842 | .801 | 0 |
| Female gender | 34 | 5198 | -.000 | -.028-.028 | .9913 | 33.321 | .452 | .963 |
| White ethnicity | 6 | 1052 | .168 | .083-.251 | .0001 | 9.681 | .085 | 48.351 |
| Higher level of education | 37 | 5075 | .063 | .024-.101 | .0017 | 61.494 | .005 | 41.458 |
| Underweight | 7 | 1462 | .000 | -.094-.095 | .9919 | 17.601 | .007 | 65.912 |
| Alzheimer’s (vs. other dementia subtypes) | 6 | 855 | .066 | -.065-.195 | .3222 | 16.836 | .005 | 70.302 |
| Longer disease duration | 10 | 1724 | -.009 | -.055-.073 | .7841 | 13.850 | .128 | 35.019 |
| More advanced dementia\* | 19 | 2904 | -.116 | -.173--.057 | .0001 | 41.359 | .001 | 56.478 |
| Global Deterioration Scale\* | 6 | 886 | -.103 | -.177--.029 | .0067 | 5.897 | .316 | 15.207 |
| Clinical Dementia Rating | 10 | 1540 | -.121 | -.223--.016 | .0236 | 34.106 | <.001 | 73.612 |
| Higher scores on cognitive screening measures | 71 | 10869 | .077 | .049-.106 | <.0001 | 126.989 | <.001 | 44.877 |
| Mini-Mental State Examination | 64 | 9792 | .077 | .043-.110 | <.0001 | 141.095 | <.001 | 55.349 |
| Alzheimer’s Disease Assessment Scale-Cognitive Subscale | 5 | 3095 | .068 | .033-.103 | .0002 | 3.369 | .498 | 0 |
| Taking medication | 17 | 4266 | -.122 | -.174--.068 | <.0001 | 36.857 | <.001 | 56.589 |
| Acetylcholinesterase inhibitors | 6 | 1029 | -.116 | -.196--.035 | .0051 | 6.909 | .228 | 27.627 |
| Polypharmacy | 8 | 1705 | -.108 | -.166--.049 | .0003 | 9.725 | .205 | 28.021 |
| Psychotropics\* | 9 | 2518 | -.120 | -.203--.034 | .0061 | 21.104 | .007 | 62.093 |
| Longer duration of care home stay\* | 8 | 714 | -.096 | -.169--.021 | .0117 | 5.874 | .555 | 0 |
| Better quality of relationship with carer\* | 5 | 583 | .311 | .114-.485 | .0024 | 23.547 | <.001 | 83.013 |
| Better functional ability | 63 | 10913 | .161 | .128-.194 | <.0001 | 159.449 | <.001 | 61.116 |
| Alzheimer's Disease Co-operative Study-Activities of Daily Living Inventory | 5 | 981 | .087 | -.064-.234 | .2584 | 21.346 | <.001 | 81.261 |
| Disability Assessment for Dementia | 5 | 3123 | .089 | .014-.162 | .0198 | 9.834 | .043 | 59.324 |
| Basic activities of daily living | 39 | 6821 | .193 | .149-.237 | <.0001 | 99.324 | <.001 | 61.741 |
| Physical Self-Maintenance Scale | 5 | 612 | .215 | .113-.312 | <.0001 | 6.338 | .175 | 36.884 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 13 | 3562 | .202 | .128-.274 | <.0001 | 33.612 | .001 | 64.299 |
| Katz Index of Independence in Activities of Daily Living | 8 | 1030 | .182 | .083-.277 | .0004 | 12.474 | .086 | 43.882 |
| Barthel Index | 14 | 1894 | .122 | .036-.206 | .0057 | 41.627 | <.001 | 68.770 |
| Instrumental activities of daily living | 18 | 2476 | .119 | .065-.172 | <.0001 | 26.861 | .060 | 36.711 |
| Functional Activities Questionnaire | 5 | 398 | .176 | .077-.271 | .0005 | 2.318 | .678 | 0 |
| Lawton’s Instrumental Activities of Daily Living | 10 | 1447 | .124 | .050-.196 | .0010 | 14.611 | .102 | 38.404 |
| Presence of unmet needs\* | 5 | 838 | -.204 | -.305--.100 | .0002 | 9.273 | .055 | 56.866 |
| More awareness | 8 | 1064 | .153 | .093-.212 | <.0001 | 6.798 | .450 | 0 |
| Better self-rated memory functioning | 7 | 1191 | .039 | -.018-.096 | .1820 | 5.203 | .518 | 0 |
| Depression | 66 | 10226 | -.302 | -.341--.261 | <.0001 | 278.686 | <.001 | 76.676 |
| Geriatric Depression Scale (all versions) | 17 | 1692 | -.424 | -.510--.329 | <.0001 | 71.101 | <.001 | 77.497 |
| Geriatric Depression Scale-15 | 8 | 651 | -.506 | -.630--.358 | <.0001 | 35.667 | <.001 | 80.374 |
| Geriatric Depression Scale-30 | 8 | 938 | -.319 | -.417--.214 | <.0001 | 15.531 | <.001 | 54.929 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 23 | 2515 | -.320 | -.391--.244 | <.0001 | 84.279 | <.001 | 73.896 |
| Neuropsychiatric Inventory-Depression | 11 | 1788 | -.274 | -.379--.162 | <.0001 | 54.205 | <.001 | 81.551 |
| Cornell Scale for Depression in Dementia | 25 | 5421 | -.253 | -.310--.194 | <.0001 | 104.748 | <.001 | 77.088 |
| Anxiety | 20 | 2946 | -.212 | -.286--.136 | <.0001 | 76.236 | <.001 | 75.077 |
| Rating of Anxiety in Dementia | 6 | 915 | -.330 | -.461--.184 | <.0001 | 20.357 | .001 | 75.439 |
| Anxiety measures excluding Rating of Anxiety in Dementia & Neuropsychiatric Inventory-Anxiety | 7 | 816 | -.299 | -.417--.170 | <.0001 | 20940 | .002 | 71.347 |
| Neuropsychiatric Inventory-Anxiety | 9 | 1503 | -.054 | -.105--.003 | .0382 | 7.068 | .529 | 0 |
| Neuropsychiatric symptoms/BPSD | 48 | 8660 | -.117 | -.143--.091 | <.0001 | 58.786 | .116 | 20.049 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory | 13 | 1127 | -.113 | -.171--.054 | .0002 | 8.956 | .707 | 0 |
| Neuropsychiatric Inventory | 37 | 7621 | -.119 | -.149--.089 | <.0001 | 50.020 | .060 | 28.028 |
| Pain | 9 | 2595 | -.134 | -.210--.056 | .0008 | 18.287 | .019 | 56.253 |
| Better self-rated health | 6 | 1115 | .269 | .101-.422 | .0020 | 36.456 | <.001 | 86.285 |
| Presence of co-morbid conditions | 23 | 3155 | -.216 | -.283--.147 | <.0001 | 75.635 | <.001 | 70.913 |
| Cared for by spouse (vs. other carer type) | 7 | 1345 | .144 | .083-.204 | <.0001 | 7.461 | .280 | 19.578 |
| Being married | 16 | 2848 | .085 | .048-.122 | <.0001 | 12.931 | .608 | 0 |
| Living alone | 7 | 1699 | -.064 | -.114--.014 | .0125 | 6.380 | .382 | 5.958 |
| Presence of religious beliefs/spirituality | 7 | 619 | .349 | .102-.556 | .0064 | 58.178 | <.001 | 89.687 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 19i: Factors associated with self-ratings of quality of life made by the person with dementia using dementia-specific quality of life measures – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 8 | 1556 | -.051 | -.024-.125 | .1845 | 12.269 | .092 | 42.944 |
| Female gender | 10 | 1990 | .054 | .009-.098 | .0176 | 8.303 | .504 | 0 |
| Higher level of education | 8 | 1300 | .096 | .017-.174 | .0178 | 12.475 | .086 | 43.886 |
| Depression | 7 | 758 | -.178 | -.323--.025 | .0229 | 25.505 | <.001 | 76.476 |
| Distress at NPS symptoms\* | 8 | 918 | -.164 | -.227--.099 | <.0001 | 5.209 | .635 | 0 |
| Burden or stress | 19 | 2751 | -.154 | -.213--.093 | <.0001 | 40.152 | .002 | 55.171 |
| Burden/stress measures excluding Zarit Burden Interview | 5 | 1022 | -.191 | -.250--.131 | <.0001 | 2.177 | .703 | 0 |
| Zarit Burden Interview | 14 | 1729 | -.143 | -.225--.059 | .0009 | 33.991 | .001 | 61.755 |
| Carer quality of life (self-rated)\* | 6 | 667 | .253 | .081-.411 | .0043 | 23.736 | <.001 | 78.935 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 19j: Factors associated with self-ratings of quality of life made by the person with dementia using health related quality of life measures**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 13 | 2005 | -.032 | -.117-.053 | .4620 | 38.657 | <.001 | 68.957 |
| Female gender | 11 | 1504 | .010 | -.041-.061 | .6939 | 7.602 | .668 | 0 |
| Higher level of education | 6 | 885 | .030 | -.036-.097 | .3715 | 4.383 | .496 | 0 |
| Higher scores on cognitive screening measures | 22 | 3316 | .043 | -.016-.101 | .1503 | 52.682 | <.001 | 60.138 |
| Mini-Mental State Examination | 21 | 2957 | .043 | -.021-.105 | .1864 | 52.908 | <.001 | 62.199 |
| Better functional ability | 18 | 3469 | .140 | .051-.227 | .0021 | 111.365 | <.001 | 84.735 |
| Basic activities of daily living | 10 | 1633 | .257 | .147-.361 | <.0001 | 44.408 | <.001 | 79.733 |
| Instrumental activities of daily living | 7 | 884 | .143 | -.010-.290 | .0667 | 27.452 | <.001 | 78.143 |
| Depression | 12 | 1924 | -.277 | -.354--.196 | <.0001 | 31.847 | .001 | 65.460 |
| Geriatric Depression Scale (all versions) | 8 | 882 | -.324 | -.416--.225 | <.0001 | 14.021 | .051 | 50.074 |
| Geriatric Depression Scale-30 | 5 | 575 | -.236 | -.312--.156 | <.0001 | 2.630 | .622 | 0 |
| Neuropsychiatric symptoms/BPSD | 8 | 1954 | -.082 | -.127--.036 | .0005 | 7.352 | .393 | 4.788 |
| Neuropsychiatric Inventory | 6 | 1529 | -.062 | -.112--.012 | .0150 | 3.754 | .585 | 0 |
| Presence of co-morbid conditions | 6 | 1009 | -.166 | -.265--.064 | .0015 | 12.257 | .031 | 59.208 |
| Being married | 5 | 1259 | .059 | .004-.114 | .0364 | 3.749 | .441 | 0 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 19k: Factors associated with self-ratings of quality of life made by the person with dementia using generic quality of life measures**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 7 | 1033 | -.026 | -.087-.036 | .4107 | 4.238 | .645 | 0 |
| Higher scores on cognitive screening measures | 9 | 1116 | .173 | .027-.311 | .0201 | 39.800 | <.001 | 79.900 |
| Mini-Mental State Examination | 6 | 361 | .161 | .006-.308 | .0421 | 9.776 | .082 | 48.857 |
| Better functional ability | 7 | 968 | .218 | .018-.401 | .0333 | 50.832 | <.001 | 88.196 |
| Basic activities of daily living | 5 | 472 | .301 | .154-.435 | .0001 | 9.221 | .056 | 56.621 |
| Depression | 10 | 1091 | -.409 | -.544--.253 | <.0001 | 60.277 | <.001 | 85.069 |
| Geriatric Depression Scale (all versions) | 8 | 1087 | -.475 | -.665--.227 | .0004 | 138.284 | <.001 | 94.938 |
| Geriatric Depression Scale-15 | 6 | 665 | -.508 | -.710--.231 | .0007 | 80.499 | <.001 | 93.789 |
| Presence of co-morbid conditions | 5 | 819 | -.156 | -.305-.000 | .0507 | 17.053 | .002 | 76.544 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 19l: Factors associated with self-ratings of quality of life made by the people with dementia diagnosed with Alzheimer’s disease – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 22 | 3277 | .006 | -.028-.041 | .7153 | 19.720 | .539 | 0 |
| Female gender | 16 | 2281 | .003 | -.039-.044 | .8932 | 12.019 | .678 | 0 |
| Higher level of education | 23 | 2825 | .027 | -.011-.064 | .1616 | 10.054 | .986 | 0 |
| Longer disease duration | 5 | 1018 | -.030 | -.134-.075 | .5743 | 8.912 | .063 | 55.115 |
| Higher scores on cognitive screening measures | 37 | 6846 | .114 | .073-.155 | <.0001 | 76.809 | <.001 | 53.130 |
| Mini-Mental State Examination | 33 | 5956 | .107 | .058-.155 | <.0001 | 81.391 | <.001 | 60.684 |
| Taking medication | 9 | 1386 | -.167 | -.247--.084 | <.0001 | 15.618 | .048 | 48.778 |
| Psychotropics | 6 | 433 | -.206 | -.312--.094 | .0004 | 6.723 | .242 | 25.633 |
| Better functional ability | 33 | 6763 | .165 | .121-.209 | <.0001 | 81.629 | <.001 | 60.798 |
| Basic activities of daily living | 20 | 5051 | .190 | .145-.234 | <.0001 | 33.568 | .021 | 43.399 |
| Physical Self-Maintenance Scale | 5 | 636 | .248 | .173-.320 | <.0001 | 1.067 | .899 | 0 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 9 | 3328 | .198 | .119-.274 | <.0001 | 21.083 | .007 | 62.055 |
| Instrumental activities of daily living | 11 | 1383 | .098 | .045-.151 | .0003 | 4.619 | .915 | 0 |
| Lawton’s Instrumental Activities of Daily Living | 8 | 1184 | .093 | .036-.150 | .0015 | 3.270 | .859 | 0 |
| More awareness | 6 | 850 | .149 | .082-.214 | .0002 | 3.309 | .652 | 0 |
| Depression | 31 | 3841 | -.350 | -.410--.288 | <.0001 | 123.201 | <.001 | 75.650 |
| Geriatric Depression Scale (all versions) | 14 | 1658 | -.398 | -.496--.291 | <.0001 | 73.145 | <.001 | 82.227 |
| Geriatric Depression Scale-15 | 7 | 665 | -.482 | -.646--.275 | <.0001 | 54.511 | <.001 | 88.993 |
| Geriatric Depression Scale-30 | 6 | 889 | -.285 | -.367--.198 | <.0001 | 7.967 | .158 | 37.243 |
| Neuropsychiatric Inventory-Depression | 5 | 1051 | -.351 | -.529--.144 | .0012 | 43.027 | <.001 | 90.704 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 11 | 1116 | -.325 | -.413--.231 | <.0001 | 23.635 | .009 | 57.690 |
| Cornell Scale for Depression in Dementia | 7 | 871 | -.316 | -.445--.174 | <.0001 | 28.599 | <.001 | 79.020 |
| Anxiety | 11 | 1510 | -.164 | -.265--.059 | .0023 | 35.155 | <.001 | 71.554 |
| Neuropsychiatric Inventory-Anxiety | 5 | 1008 | -.026 | -.088-.036 | .4102 | 3.012 | .556 | 0 |
| Neuropsychiatric symptoms/BPSD | 23 | 5718 | -.096 | -.130--.062 | <.0001 | 28.140 | .171 | 21.820 |
| Neuropsychiatric Inventory | 19 | 5101 | -.092 | -.132--.053 | <.0001 | 25.724 | .106 | 30.026 |
| Presence of co-morbid conditions | 12 | 1632 | -.152 | -.229--.074 | .0002 | 21.616 | .028 | 49.112 |
| Being married | 8 | 1334 | .059 | .005-.113 | .0331 | 3.159 | .870 | 0 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 19m: Factors associated with self-ratings of quality of life made by the people with dementia diagnosed with Alzheimer’s disease – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 968 | -.053 | -.169-.065 | .3810 | 12.295 | .031 | 59.335 |
| Female gender | 7 | 1151 | .039 | -.019-.097 | .1857 | 3.733 | .713 | 0 |
| Depression | 5 | 554 | -.160 | -.290--.023 | .0220 | 9.247 | .055 | 56.741 |
| Burden or stress | 11 | 1559 | -.109 | -.171--.047 | .0007 | 13.870 | .179 | 27.902 |
| Zarit Burden Interview | 9 | 1209 | -.075 | -.133--.016 | .0127 | 8.305 | .404 | 3.674 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 19n: Factors associated with self-ratings of quality of life by people with dementia, excluding studies that focused specifically on people diagnosed with Alzheimer’s disease – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 36 | 5205 | -.043 | -.077--.009 | .0124 | 49.150 | .057 | 28.789 |
| Female gender | 31 | 4749 | .007 | -.025-.039 | .6684 | 35.667 | .219 | 15.888 |
| White ethnicity | 8 | 1428 | .146 | .070-.220 | .0002 | 14.655 | .041 | 52.234 |
| Higher level of education | 20 | 3034 | .072 | .013-.131 | .0161 | 46.331 | <.001 | 58.991 |
| Underweight | 5 | 863 | .003 | -.131-.125 | .9587 | 14.084 | .007 | 71.600 |
| Alzheimer’s (vs. other dementia subtypes) | 8 | 1233 | .058 | -.035-.150 | .2250 | 17.733 | .013 | 60.525 |
| Longer disease duration | 7 | 900 | .033 | -.034-.098 | .3348 | 2.872 | .825 | 0 |
| More advanced dementia | 19 | 2731 | -.095 | -.156--.034 | .0024 | 42.107 | .001 | 57.252 |
| Global Deterioration Scale | 5 | 665 | -.106 | -.204--.006 | .0377 | 5.700 | .223 | 29.828 |
| Clinical Dementia Rating | 12 | 1783 | -.088 | -.175-.001 | .0516 | 34.818 | <.001 | 68.407 |
| Higher scores on cognitive screening measures | 56 | 6657 | .066 | .025-.107 | .0017 | 139.605 | <.001 | 60.603 |
| Mini-Mental State Examination | 51 | 6090 | .054 | .015-.092 | .0059 | 99.527 | <.001 | 49.762 |
| Taking medication | 10 | 3220 | -.086 | -.140--.031 | .0022 | 16.385 | .059 | 45.072 |
| Polypharmacy | 5 | 972 | -.149 | -.210--.087 | <.0001 | .982 | .913 | 0 |
| Longer duration of care home stay | 5 | 582 | -.062 | -.144-.020 | .1380 | .614 | .961 | 0 |
| Better functional ability | 46 | 6454 | .174 | .124-.223 | <.0001 | 170.431 | <.001 | 73.596 |
| Basic activities of daily living | 29 | 3452 | .202 | .130-.271 | <.0001 | 118.961 | <.001 | 76.463 |
| Katz Index of Independence in Activities of Daily Living | 7 | 536 | .296 | .161-.420 | <.0001 | 13.647 | .034 | 56.034 |
| Barthel Index | 15 | 2263 | .197 | .079-.309 | .0012 | 105.346 | <.001 | 86.710 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 9 | 1024 | .180 | .083-.274 | .0003 | 18.425 | .018 | 56.580 |
| Instrumental activities of daily living | 14 | 1948 | .188 | .089-.283 | .0002 | 57.590 | <.001 | 77.427 |
| Instrumental activities of daily living measures excluding IADL & FAQ | 8 | 1372 | .208 | .059-.349 | .0066 | 50.192 | <.001 | 86.054 |
| Lawton’s Instrumental Activities of Daily Living | 5 | 477 | .178 | .024-.324 | .0241 | 9.822 | .044 | 59.274 |
| Presence of unmet needs\* | 5 | 838 | -.204 | -.305--.100 | .0002 | 9.273 | .055 | 56.866 |
| Better self-rated memory functioning | 5 | 1100 | .036 | -.037-.109 | .3328 | 5.335 | .255 | 25.022 |
| Depression | 49 | 7594 | -.293 | -.342--.242 | <.0001 | 233.321 | <.001 | 79.428 |
| Geriatric Depression Scale (all versions) | 14 | 1170 | -.468 | -.588--.327 | <.0001 | 94.727 | <.001 | 86.276 |
| Geriatric Depression Scale-15 | 9 | 980 | -.496 | -.640--.318 | <.0001 | 84.433 | <.001 | 90.525 |
| Geriatric Depression Scale-30 | 5 | 190 | -.407 | -.531--.266 | <.0001 | 4.295 | .368 | 6.863 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 17 | 1686 | -.324 | -.423--.218 | <.0001 | 83.732 | <.001 | 80.891 |
| Cornell Scale for Depression in Dementia | 20 | 4666 | -.220 | -.276--.162 | <.0001 | 61.713 | <.001 | 69.212 |
| Neuropsychiatric Inventory-Depression | 7 | 804 | -.203 | -.305--.097 | .0002 | 12.299 | .056 | 51.215 |
| Anxiety | 10 | 1502 | -.256 | -.368--.137 | <.0001 | 44.750 | <.001 | 79.888 |
| Neuropsychiatric symptoms/BPSD | 33 | 3911 | -.126 | -.158--.093 | <.0001 | 33.928 | .375 | 5.683 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory | 13 | 1037 | -.123 | -.183--.061 | .0001 | 11.947 | .450 | 0 |
| Neuropsychiatric Inventory | 22 | 2960 | -.127 | -.164--.089 | <.0001 | 22.137 | .392 | 5.135 |
| Pain | 8 | 2639 | -.158 | -.242--.071 | .0004 | 22.538 | .002 | 68.942 |
| Better self-rated health | 9 | 1447 | .231 | .123-.333 | <.0001 | 31.509 | <.001 | 74.610 |
| Presence of co-morbid conditions | 19 | 2557 | -.210 | -.270--.148 | <.0001 | 43.338 | .001 | 58.466 |
| Better quality of relationship with carer | 5 | 682 | .453 | .235-.627 | .0001 | 39.223 | <.001 | 89.802 |
| Cared for by spouse (vs. other carer type) | 5 | 1129 | .178 | .052-.298 | .0056 | 17.025 | .002 | 76.506 |
| Being married | 14 | 2514 | .090 | .048-.0131 | <.0001 | 14.215 | .359 | 8.545 |
| Living alone | 5 | 1258 | -.200 | -.371--.015 | .0339 | 42.488 | <.001 | 90.585 |
| Greater social engagement\* | 8 | 903 | .345 | .102-.549 | .0061 | 92.625 | <.001 | 92.443 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 19o: Factors associated with self-ratings of quality of life by people with dementia, excluding studies that focused specifically on people diagnosed with Alzheimer’s disease – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Female gender | 5 | 1091 | .085 | .004-.166 | .0394 | 6.555 | .161 | 38.982 |
| Higher level of education | 7 | 1257 | .110 | .029-.190 | .0077 | 10.968 | .089 | 45.295 |
| Distress at NPS symptoms | 5 | 711 | -.150 | -.248--.049 | .0036 | 6.313 | .177 | 36.636 |
| Burden or stress | 9 | 1281 | -.144 | -.215--.071 | .0001 | 11.674 | .166 | 31.472 |
| Zarit Burden Interview | 6 | 599 | -.151 | -.271--.027 | .0175 | 10.098 | .072 | 50.487 |
| Poorer mental health (GHQ)\* | 5 | 702 | -.156 | -.275--.034 | .0126 | 6.753 | .150 | 40.767 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 19p: Factors associated with self-ratings of quality of life by people with dementia living in the community – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 29 | 4624 | -.023 | -.058-.012 | .1969 | 36.584 | .128 | 23.464 |
| Female gender | 27 | 4437 | .004 | -.028.037 | .7994 | 29.075 | .308 | 10.576 |
| White ethnicity | 7 | 1026 | .237 | .177-.294 | <.0001 | 3.186 | .785 | 0 |
| Higher level of education | 24 | 3945 | .062 | .025-.099 | .0010 | 28.830 | .186 | 20.221 |
| Alzheimer’s (vs. other dementia subtypes) | 5 | 625 | .137 | .029-.241 | .0130 | 6.938 | .139 | 42.345 |
| Longer disease duration | 6 | 1185 | .015 | -.078-.107 | .7575 | 10.245 | .069 | 51.196 |
| More advanced dementia | 8 | 1481 | -.144 | -.248--.036 | .0089 | 28.005 | <.001 | 75.005 |
| Clinical Dementia Rating | 5 | 983 | -.183 | -.348--.006 | .0425 | 26.814 | <.001 | 85.083 |
| Higher scores on cognitive screening measures | 48 | 8542 | .067 | .040-.094 | <.0001 | 59.157 | .002 | 20.550 |
| Mini-Mental State Examination | 41 | 7476 | .063 | .029-.096 | .0003 | 62.786 | .012 | 36.292 |
| Taking medication | 8 | 2664 | -.083 | -.139--.025 | .0047 | 11.573 | .116 | 39.512 |
| Polypharmacy | 5 | 1288 | -.104 | -.181--.026 | .0087 | 7.178 | .127 | 44.273 |
| Better functional ability | 38 | 8470 | .182 | .131-.232 | <.0001 | 174.584 | <.001 | 78.807 |
| Basic activities of daily living | 20 | 5126 | .236 | .161-.309 | <.0001 | 104.875 | <.001 | 81.883 |
| Katz Index of Independence in Activities of Daily Living | 5 | 833 | .293 | .100-.465 | .0034 | 20.200 | <.001 | 80.198 |
| Barthel Index | 7 | 1055 | .243 | .064-.407 | .0083 | 47.165 | <.001 | 87.279 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 6 | 2903 | .198 | .091-.301 | .0003 | 18.004 | .003 | 72.228 |
| Instrumental activities of daily living | 16 | 2657 | .176 | .094-.256 | <.0001 | 61.289 | <.001 | 75.526 |
| Instrumental ADL measures excluding IADL & FAQ | 7 | 1260 | .232 | .066-.386 | .0065 | 48.642 | <.001 | 87.662 |
| Lawton’s Instrumental Activities of Daily Living | 6 | 1168 | .132 | .034-.228 | .0088 | 11.810 | .037 | 57.661 |
| Better self-rated memory functioning | 5 | 741 | .050 | -.026-.126 | .1990 | 4.126 | .389 | 3.062 |
| Depression | 40 | 6743 | -.315 | -.369--.260 | <.0001 | 201.589 | <.001 | 80.654 |
| Geriatric Depression Scale (all versions) | 17 | 1761 | -.393 | -.481--.298 | <.0001 | 72.052 | <.001 | 77.794 |
| Geriatric Depression Scale-15 | 9 | 780 | -.474 | -.590--.340 | <.0001 | 36.822 | <.001 | 78.274 |
| Geriatric Depression Scale-30 | 8 | 981 | -.275 | -.341--.206 | <.0001 | 8.135 | .321 | 13.955 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 15 | 1724 | -.357 | -.447--.259 | <.0001 | 62.906 | <.001 | 77.745 |
| Neuropsychiatric Inventory-Depression | 6 | 1092 | -.289 | -.463--.093 | .0043 | 44.993 | <.001 | 88.887 |
| Cornell Scale for Depression in Dementia | 8 | 2840 | -.213 | -.288--.136 | <.0001 | 25.401 | .001 | 72.442 |
| Anxiety | 11 | 2051 | -.196 | -.289--.099 | .0001 | 43.156 | <.001 | 76.828 |
| Anxiety measures excluding Rating of Anxiety in Dementia & Neuropsychiatric Inventory-Anxiety | 5 | 598 | -.360 | -.464--.247 | <.0001 | 9.065 | .060 | 55.873 |
| Neuropsychiatric Inventory-Anxiety | 6 | 1077 | -.057 | -.131-.017 | .1302 | 6.268 | .281 | 20.233 |
| Neuropsychiatric symptoms/BPSD | 29 | 6006 | -.110 | -.138--.081 | <.0001 | 29.851 | .370 | 6.199 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory | 8 | 539 | -.130 | -.214--.045 | .0029 | 4.586 | .710 | 0 |
| Neuropsychiatric Inventory | 22 | 5513 | -.111 | -.144--.077 | <.0001 | 25.108 | .243 | 16.362 |
| Pain | 5 | 1481 | -.138 | -.247--.026 | .0157 | 6.944 | .139 | 42.400 |
| Presence of co-morbid conditions | 14 | 2196 | -.217 | -.301--.131 | <.0001 | 48.928 | <.001 | 73.430 |
| Cared for by spouse (vs. other carer type) | 6 | 1523 | .149 | .056-.239 | .0018 | 15.511 | .008 | 67.764 |
| Being married | 14 | 2567 | .079 | .039-.118 | .0001 | 13.225 | .431 | 1.698 |
| Living alone | 6 | 1553 | -.072 | -.127--.016 | .0113 | 5.762 | .330 | 13.222 |
| Greater social engagement | 5 | 409 | .287 | .070-.478 | .0102 | 15.481 | .004 | 74.161 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 19q: Factors associated with self-ratings of quality of life by people with dementia living in the community – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 7 | 1496 | -.057 | -.132-.018 | .1368 | 10.398 | .109 | 42.297 |
| Female gender | 9 | 1849 | .051 | .005-.097 | .0296 | 6.975 | .539 | 0 |
| Higher level of education | 7 | 1242 | .076 | -.001-.153 | .0523 | 9.789 | .134 | 38.704 |
| Depression | 6 | 771 | -.106 | -.178--.033 | .0045 | 5.182 | .394 | 3.508 |
| Distress at NPS symptoms | 6 | 667 | -.175 | -.265--.082 | .0002 | 6.637 | .249 | 24.660 |
| Burden or stress | 13 | 2358 | -.137 | -.192--.080 | <.0001 | 20.709 | .055 | 42.056 |
| Zarit Burden Interview | 8 | 1326 | -.113 | -.199--.026 | .0108 | 15.403 | .031 | 54.555 |
| Burden/stress measures excluding Zarit Burden Interview | 5 | 1032 | -.166 | -.225--.105 | <.0001 | 3.010 | .556 | 0 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 19r: Factors associated with self-ratings of quality of life by people with dementia living in residential care – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **Number of participants** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 1052 | -.008 | -.068-.053 | .8060 | 2.385 | .794 | 0 |
| Female gender | 6 | 1052 | .015 | -.070-.100 | .7245 | 9.295 | .098 | 46.209 |
| More advanced dementia | 7 | 893 | -.052 | -.159-.055 | .3412 | 13.555 | .035 | 55.735 |
| Higher scores on cognitive screening measures | 14 | 1197 | .102 | -.015-.216 | .0873 | 46.304 | <.001 | 71.925 |
| Mini-Mental State Examination | 14 | 1197 | .115 | -.011-.238 | .0739 | 54.900 | <.001 | 76.321 |
| Taking medication | 9 | 1746 | -.154 | -.238--.069 | .0004 | 18.922 | .015 | 57.721 |
| Psychotropics | 5 | 994 | -.231 | -.408--.036 | .0207 | 15.908 | .003 | 74.855 |
| Longer duration of care home stay | 7 | 665 | -.069 | -.146-.008 | .0783 | .793 | .992 | 0 |
| Better functional ability | 13 | 1211 | .206 | .096-.312 | .0003 | 40.820 | <.001 | 70.603 |
| Basic activities of daily living | 13 | 1211 | .207 | .097-.313 | .0003 | 40.974 | <.001 | 70.713 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 5 | 301 | .178 | .064-.287 | .0024 | 3.007 | .557 | 0 |
| Barthel Index | 6 | 860 | .120 | -.069-.300 | .2126 | 35.449 | <.001 | 85.895 |
| Depression | 14 | 1756 | -.244 | -.336--.147 | <.0001 | 40.746 | <.001 | 68.095 |
| Cornell Scale for Depression in Dementia | 9 | 1470 | -.201 | -.320-.074 | .0020 | 32.210 | <.001 | 75.163 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 6 | 330 | -.325 | -.439--.200 | <.0001 | 7.146 | .210 | 30.031 |
| Anxiety | 5 | 367 | -.225 | -.430-.001 | .0511 | 17.665 | .001 | 77.356 |
| Neuropsychiatric symptoms/BPSD | 9 | 873 | -.086 | -.154--.018 | .0135 | 8.212 | .413 | 2.583 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory | 6 | 464 | -.097 | -.209-.017 | .0937 | 7.187 | .207 | 30.434 |
| Presence of co-morbid conditions | 8 | 747 | -.177 | -.247--.106 | <.0001 | 5.159 | .641 | 0 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 20a: Factors associated with informant ratings of quality of life for the person with dementia made by family carers only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 41 | 7101 | -.033 | -.066-.001 | .0544 | 72.245 | .001 | 44.633 |
| Female gender | 36 | 6465 | -.020 | -.060-.020 | .3197 | 80.622 | <.001 | 56.588 |
| Higher level of education | 28 | 4841 | .047 | .019-.075 | .0012 | 19.449 | .853 | 0 |
| Longer disease duration | 10 | 1504 | -.071 | -.122--.020 | .0061 | 7.556 | .579 | 0 |
| More advanced dementia | 20 | 3696 | -.296 | -.431--.148 | .0001 | 413.353 | <.001 | 95.403 |
| Global Deterioration Scale | 5 | 767 | -.288 | -.388--.181 | <.0001 | 9.593 | .048 | 58.301 |
| Clinical Dementia Rating | 16 | 2933 | -.252 | -.408--.081 | .0042 | 325.168 | <.001 | 95.387 |
| Higher scores on cognitive screening measures | 64 | 11057 | .155 | .115-.195 | <.0001 | 247.699 | <.001 | 74.566 |
| Mini-Mental State Examination | 56 | 9836 | .148 | .104-.191 | <.0001 | 223.071 | <.001 | 75.344 |
| Cognitive screening measures excluding Dementia Rating Scale & Mini-Mental State Examination | 16 | 4304 | .174 | .086-.259 | .0001 | 81.672 | <.001 | 81.634 |
| Taking medication | 14 | 3586 | -.060 | -.092--.027 | .0004 | 11.910 | .535 | 0 |
| Acetylcholinesterase inhibitors | 7 | 1317 | -.055 | -.122-.013 | .1131 | 8.134 | .228 | 26.235 |
| Polypharmacy | 8 | 1652 | -.064 | -.115--.013 | .0140 | 7.536 | .375 | 7.116 |
| Psychotropics | 6 | 1731 | -.093 | -.163--.022 | .0100 | 6.640 | .249 | 24.696 |
| Better functional ability | 60 | 11082 | .328 | .275-.378 | <.0001 | 476.001 | <.001 | 87.605 |
| Bristol Activities of Daily Living Scale | 5 | 859 | .443 | .387-.496 | <.0001 | 2.642 | .619 | 0 |
| Alzheimer's Disease Co-operative Study-Activities of Daily Living Inventory | 5 | 1172 | .341 | .199-.468 | <.0001 | 25.946 | <.001 | 84.583 |
| Disability Assessment for Dementia\* | 5 | 3172 | .231 | .085-.367 | .0021 | 42.953 | <.001 | 90.687 |
| Basic activities of daily living | 35 | 6833 | .369 | .295-.438 | <.0001 | 334.697 | <.001 | 89.842 |
| Barthel Index | 10 | 1021 | .522 | .377-.642 | <.0001 | 63.199 | <.001 | 85.759 |
| Dependence scale | 5 | 3182 | .342 | .112-.537 | .0041 | 117.287 | <.001 | 96.850 |
| Physical Self-Maintenance Scale | 6 | 622 | .310 | .214-.401 | <.0001 | 8.025 | .155 | 37.696 |
| Katz Index of Independence in Activities of Daily Living | 9 | 1581 | .298 | .212-.380 | <.0001 | 23.071 | .003 | 65.324 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 6 | 611 | .271 | .157-.378 | <.0001 | 9.812 | .081 | 49.044 |
| Instrumental activities of daily living | 24 | 3234 | .350 | .269-.426 | <.0001 | 134.795 | <.001 | 82.937 |
| Lawton’s Instrumental Activities of Daily Living\* | 15 | 2306 | .303 | .210-.390 | <.0001 | 72.120 | <.001 | 80.588 |
| Instrumental activities of daily living measures excluding Lawton’s Instrumental Activities of Daily Living | 10 | 1039 | .453 | .373-.526 | <.0001 | 17.506 | .041 | 48.590 |
| Better self-rated memory functioning | 6 | 515 | .177 | -.000-.343 | .0503 | 19.765 | .001 | 74.703 |
| Depression | 49 | 8469 | -.301 | -.352--.248 | <.0001 | 292.145 | <.001 | 83.570 |
| Cornell Scale for Depression in Dementia | 16 | 3601 | -.364 | -.435--.289 | <.0001 | 79.254 | <.001 | 81.074 |
| Geriatric Depression Scale (all versions) | 18 | 1919 | -.253 | -.338--.164 | <.0001 | 62.570 | <.001 | 72.830 |
| Geriatric Depression Scale-30 | 10 | 1082 | -.294 | -.419--.158 | <.0001 | 41.161 | <.001 | 78.135 |
| Geriatric Depression Scale-15 | 8 | 837 | -.200 | -.308--.087 | .0006 | 17.439 | .015 | 59.861 |
| Neuropsychiatric Inventory-Depression | 8 | 1877 | -.291 | -.462--.098 | .0036 | 115.445 | <.001 | 93.937 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 15 | 1612 | -.287 | -.350--.221 | <.0001 | 29.273 | .010 | 52.174 |
| Anxiety | 13 | 2675 | -.148 | -.194--.102 | <.0001 | 15.224 | .229 | 21.178 |
| Neuropsychiatric Inventory-Anxiety | 8 | 1877 | -.168 | -.232--.101 | <.0001 | 12.173 | .095 | 42.495 |
| Neuropsychiatric symptoms/BPSD | 53 | 10716 | -.354 | -.406--.301 | <.0001 | 448.528 | <.001 | 88.407 |
| Neuropsychiatric Inventory | 39 | 8635 | -.363 | -.425--.296 | <.0001 | 396.376 | <.001 | 90.413 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory | 15 | 2209 | -.364 | -.430--.294 | <.0001 | 43.166 | <.001 | 67.567 |
| Better self-rated health | 6 | 1031 | .232 | .140-.320 | <.0001 | 9.258 | .099 | 45.992 |
| Presence of co-morbid conditions | 17 | 2873 | -.107 | -.154--.061 | <.0001 | 22.593 | .125 | 29.182 |
| Cared for by spouse (vs. other carer type)\* | 10 | 2139 | .117 | .053-.180 | .0004 | 17.386 | .043 | 48.234 |
| Being married | 14 | 2998 | .117 | .073-.161 | <.0001 | 17.980 | .158 | 27.699 |
| Living alone | 12 | 2271 | -.120 | -.176--.063 | <.0001 | 18.067 | .080 | 39.114 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20b: Factors associated with informant ratings of quality of life for the person with dementia made by family carers only – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 12 | 2158 | -.059 | -.111--.006 | .0303 | 14.758 | .194 | 25.464 |
| Female gender | 14 | 2466 | .040 | -.014-.093 | .1498 | 20.256 | .089 | 35.821 |
| Higher level of education | 11 | 1676 | .077 | .018-.134 | .0102 | 13.080 | .219 | 23.550 |
| More time spent caring (community only)\* | 5 | 681 | -.137 | -.267--.002 | .0462 | 11.630 | .020 | 65.606 |
| Depression\* | 14 | 2694 | -.255 | -.338--.169 | <.0001 | 64.440 | <.001 | 79.826 |
| Center for Epidemiologic Studies Depression Scale\* | 6 | 905 | -.299 | -.458--.122 | .0012 | 32.272 | <.001 | 84.507 |
| Geriatric Depression Scale\* | 5 | 591 | -.362 | -.496--.211 | <.0001 | 14.617 | .006 | 72.634 |
| Depression measures excluding Geriatric Depression Scale & Center for Epidemiologic Studies Depression Scale\* | 6 | 1449 | -.202 | -.313--.085 | .0008 | 22.218 | <.001 | 77.496 |
| Distress at NPS symptoms | 10 | 1645 | -.319 | -.388--.246 | <.0001 | 21.052 | .012 | 57.248 |
| Burden or stress | 23 | 4207 | -.328 | -.406--.246 | <.0001 | 176.692 | <.001 | 87.549 |
| Zarit Burden Interview | 18 | 3275 | -.343 | -.433--.246 | <.0001 | 148.656 | <.001 | 88.564 |
| Burden or stress measures excluding Zarit Burden Interview | 6 | 1003 | -.280 | -.428--.118 | .0009 | 29.333 | <.001 | 82.954 |
| Poorer mental health (GHQ)\* | 6 | 715 | -.242 | -.311--.170 | <.0001 | 3.990 | .551 | 0 |
| Carer quality of life (self-rated) | 7 | 1409 | .315 | .201-.421 | <.0001 | 27.700 | <.001 | 78.339 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20c: Factors associated with informant ratings of quality of life for the person with dementia made by health care professionals only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 18 | 3966 | -.050 | -.103-.005 | .0726 | 43.490 | <.001 | 60.910 |
| Female gender | 18 | 4155 | .021 | -.019-.062 | .3022 | 25.920 | .076 | 34.413 |
| Higher level of education | 5 | 928 | -.008 | -.116-.101 | .8868 | 9.172 | .057 | 56.388 |
| More advanced dementia | 13 | 3043 | -.333 | -.427--.231 | <.0001 | 99.998 | <.001 | 88.000 |
| Clinical Dementia Rating | 5 | 2053 | -.327 | -.487--.146 | .0006 | 71.904 | <.001 | 94.437 |
| Advanced dementia measures excluding Clinical Dementia Rating | 8 | 990 | -.338 | -.448--.217 | <.0001 | 28.062 | <.001 | 75.055 |
| Higher scores on cognitive screening measures | 25 | 3237 | .244 | .180-.306 | <.0001 | 81.605 | <.001 | 70.590 |
| Mini-Mental State Examination | 25 | 3228 | .247 | .182-.309 | <.0001 | 84.364 | <.001 | 71.552 |
| Taking medication | 11 | 3108 | -.049 | -.085--.012 | .0085 | 10.092 | .432 | .908 |
| Acetylcholinesterase inhibitors | 5 | 766 | -.105 | -.211-.003 | .0556 | 8.699 | .069 | 54.018 |
| Psychotropics | 8 | 2503 | -.051 | -.109-.007 | .0852 | 12.423 | .087 | 43.655 |
| Antidepressants | 5 | 1076 | -.126 | -.244--.004 | .0432 | 11.384 | .023 | 64.864 |
| Longer duration of care home stay | 10 | 1804 | -.088 | -.150--.025 | .0062 | 14.138 | .117 | 36.344 |
| Degree to which residential care is person-centred | 6 | 1814 | .154 | .049-.256 | .0042 | 13.718 | .018 | 63.551 |
| Special dementia unit (vs. other residential facility) | 5 | 2372 | .120 | .071-.168 | <.0001 | 5.528 | .237 | 27.641 |
| Better functional ability | 29 | 6176 | .368 | .277-.452 | <.0001 | 406 | <.001 | 93.109 |
| Basic activities of daily living | 25 | 4654 | .363 | .268-.451 | <.0001 | 297.994 | <.001 | 91.946 |
| Barthel Index | 12 | 2329 | .425 | .264-.563 | <.0001 | 207.202 | <.001 | 94.691 |
| Katz Index of Independence in Activities of Daily Living | 5 | 474 | .371 | .290-.447 | <.0001 | 2.532 | .639 | 0 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 7 | 1345 | .280 | .166-.386 | <.0001 | 27.152 | <.001 | 77.903 |
| Depression | 19 | 3176 | -.310 | -.400--.214 | <.0001 | 133.102 | <.001 | 86.476 |
| Cornell Scale for Depression in Dementia | 11 | 2506 | -.262 | -.350--.168 | <.0001 | 52.375 | <.001 | 80.907 |
| Neuropsychiatric Inventory-Depression | 7 | 489 | -.304 | -.457--.133 | .0006 | 20.521 | .002 | 70.762 |
| Anxiety | 9 | 761 | -.215 | -.314--.110 | <.0001 | 14.794 | .063 | 45.923 |
| Neuropsychiatric Inventory-Anxiety | 7 | 489 | -.199 | -.336--.053 | .0078 | 13.914 | .031 | 56.877 |
| Neuropsychiatric symptoms/BPSD | 24 | 3714 | -.331 | -.402--.255 | <.0001 | 131.451 | <.001 | 82.503 |
| Cohen-Mansfield Agitation Inventory | 6 | 776 | -.201 | -.284--.115 | <.0001 | 6.847 | .232 | 26.980 |
| Neuropsychiatric Inventory | 12 | 1794 | -.311 | -.404--.211 | <.0001 | 43.189 | <.001 | 74.531 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory | 9 | 1472 | -.371 | -.497--.230 | <.0001 | 69.911 | <.001 | 88.557 |
| Pain | 9 | 2443 | -.255 | -.403--.095 | .0021 | 115.216 | <.001 | 93.057 |
| Presence of co-morbid conditions | 8 | 1781 | -.099 | -.152--.046 | .0003 | 8.528 | .288 | 17.914 |
| Being married | 5 | 917 | .055 | -.037-.146 | .2428 | 6.578 | .160 | 39.188 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 20d: Factors associated with informant ratings of quality of life for the person with dementia made by mixed groups of informants including both family carers and health care professionals – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 5 | 1719 | -.039 | .014--.092 | .1493 | 4.829 | .305 | 17.170 |
| Higher scores on cognitive screening measures | 5 | 1246 | .225 | .016-.414 | .0350 | 52.030 | <.001 | 92.312 |
| Better functional ability | 9 | 2515 | .339 | .272-.403 | <.0001 | 26.525 | .001 | 69.840 |
| Basic activities of daily living\* | 8 | 2324 | .330 | .258-.399 | <.0001 | 24.499 | .001 | 71.427 |
| Neuropsychiatric symptoms/BPSD | 5 | 1345 | -.157 | -.301--.006 | .0415 | 29.669 | <.001 | 86.518 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20e: Factors associated with informant ratings of quality of life for the person with dementia made using the Quality of Life-Alzheimer’s Disease (QoL-AD) - factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 31 | 6501 | -.011 | -.047-.025 | .5574 | 57.365 | .002 | 47.703 |
| Female gender | 25 | 5286 | -.034 | -.082-.014 | .1658 | 65.922 | <.001 | 63.593 |
| Higher level of education | 19 | 3371 | .061 | .027-.095 | .0004 | 17.493 | .489 | 0 |
| Longer disease duration | 6 | 1137 | -.063 | -.132-.006 | .0754 | 6.184 | .289 | 19.145 |
| More advanced dementia | 18 | 3466 | -.249 | -.308-.188 | <.0001 | 55.453 | <.001 | 69.344 |
| Clinical Dementia Rating | 12 | 2555 | -.210 | -.285-.134 | <.0001 | 39.043 | <.001 | 71.826 |
| Advanced dementia measures excluding Clinical Dementia Rating | 6 | 911 | -.330 | -.387-.270 | <.0001 | 4.064 | .540 | 0 |
| Higher scores on cognitive screening measures | 43 | 8818 | .165 | .120-.210 | <.0001 | 164.917 | <.001 | 74.533 |
| Mini-Mental State Examination | 38 | 8113 | .164 | .116-.210 | <.0001 | 142.608 | <.001 | 74.055 |
| Cognitive screening measures excluding Dementia Rating Scale & Mini-Mental State Examination | 8 | 3165 | .127 | .017-.235 | .0242 | 30.856 | <.001 | 77.314 |
| Taking medication | 11 | 4033 | -.047 | -.079--.016 | .0033 | 10.179 | .425 | 1.754 |
| Acetylcholinesterase inhibitors | 5 | 1116 | -.054 | -.135-.028 | .1947 | 6.465 | .167 | 38.125 |
| Polypharmacy | 6 | 1509 | -.072 | -.129--.014 | .0148 | 6.109 | .296 | 18.148 |
| Psychotropics | 5 | 2437 | -.032 | -.072-.008 | .1128 | 1.317 | .859 | 0 |
| Better functional ability | 44 | 9961 | .303 | .255-.349 | <.0001 | 248.081 | <.001 | 82.667 |
| Basic activities of daily living | 27 | 7002 | .317 | .255-.376 | <.0001 | 169.842 | <.001 | 84.692 |
| Barthel Index | 10 | 1885 | .395 | .326-.461 | <.0001 | 22.776 | .007 | 60.485 |
| Katz Index of Independence in Activities of Daily Living | 9 | 2023 | .286 | .196-.370 | <.0001 | 31.683 | <.001 | 74.750 |
| Instrumental activities of daily living | 15 | 1997 | .320 | .212-.421 | <.0001 | 85.817 | <.001 | 83.686 |
| Lawton’s Instrumental Activities of Daily Living | 10 | 1567 | .295 | .158-.421 | <.0001 | 66.351 | <.001 | 86.436 |
| Instrumental activities of daily living measures excluding Lawton’s Instrumental Activities of Daily Living | 6 | 540 | .412 | .319-.498 | <.0001 | 7.164 | .209 | 30.203 |
| Better self-rated memory functioning | 5 | 442 | .213 | .020-.390 | .0308 | 16.079 | .003 | 75.122 |
| Depression | 43 | 9336 | -.301 | -.353--.248 | <.0001 | 296.306 | <.001 | 85.825 |
| Cornell Scale for Depression in Dementia | 20 | 5720 | -.339 | -.399--.275 | <.0001 | 118.105 | <.001 | 83.913 |
| Geriatric Depression Scale (all versions) | 12 | 1475 | -.280 | -.383--.170 | <.0001 | 48.505 | <.001 | 77.322 |
| Geriatric Depression Scale-30 | 8 | 983 | -.314 | -.453--.161 | .0001 | 37.641 | <.001 | 81.403 |
| Neuropsychiatric Inventory-Depression | 8 | 1881 | -.257 | -.431--.064 | .0096 | 107.576 | <.001 | 93.493 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 10 | 956 | -.301 | -.372--.226 | <.0001 | 13.416 | .145 | 32.914 |
| Anxiety | 14 | 2884 | -.183 | -.254--.111 | <.0001 | 41.720 | <.001 | 68.840 |
| Anxiety measures excluding Neuropsychiatric Inventory-Anxiety | 7 | 1188 | -.196 | -.305--.082 | .0008 | 20.326 | .002 | 70.481 |
| Neuropsychiatric symptoms/BPSD | 41 | 9369 | -.332 | -.392--.268 | <.0001 | 405.962 | <.001 | 90.147 |
| Neuropsychiatric Inventory | 32 | 8095 | -.330 | -.400--.257 | <.0001 | 353.242 | <.001 | 91.224 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory | 9 | 1126 | -.401 | -.513--.275 | <.0001 | 44.122 | <.001 | 81.869 |
| Pain | 6 | 2764 | -.049 | -.086--.012 | .0100 | 2.694 | .747 | 0 |
| Presence of co-morbid conditions | 13 | 2489 | -.118 | -.167--.068 | <.0001 | 16.284 | .179 | 26.310 |
| Cared for by spouse (vs. other carer type) | 7 | 1835 | .115 | .021-.206 | .0162 | 21.684 | .001 | 72.330 |
| Being married | 10 | 2020 | .132 | .082-.182 | <.0001 | 11.222 | .261 | 19.797 |
| Living alone | 7 | 1657 | -.158 | -.240--.073 | .0003 | 15.874 | .014 | 62.202 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 20f: Factors associated with informant ratings of quality of life for the person with dementia made using the Quality of Life-Alzheimer’s Disease (QoL-AD) - factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 9 | 1845 | -.014 | -.115-.088 | .7905 | 32.842 | <.001 | 75.641 |
| Female gender | 12 | 2282 | .045 | -.012-.101 | .1206 | 17.642 | .090 | 37.650 |
| Higher level of education | 8 | 1357 | .072 | .001-.142 | .0461 | 10.469 | .164 | 33.136 |
| Depression | 10 | 2003 | -.254 | -.338--.166 | <.0001 | 34.194 | <.001 | 73.680 |
| Distress at NPS symptoms | 8 | 1097 | -.302 | -.373--.227 | <.0001 | 11.291 | .126 | 38.003 |
| Burden or stress | 19 | 3544 | -.327 | -.427--.220 | <.0001 | 208.780 | <.001 | 91.379 |
| Zarit Burden Interview | 14 | 2592 | -.341 | -.450--.223 | <.0001 | 132.637 | <.001 | 90.199 |
| Burden or stress measures excluding Zarit Burden Interview | 5 | 952 | -.286 | -.529-.001 | .0506 | 72.363 | <.001 | 94.472 |
| Poorer mental health (GHQ) | 6 | 742 | -.286 | -.392--.172 | <.0001 | 8.442 | .133 | 40.774 |
| Carer quality of life (self-rated) | 7 | 1408 | .323 | .212-.427 | <.0001 | 26.792 | <.001 | 77.605 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 20g: Factors associated with informant ratings of quality of life for the person with dementia made using the Alzheimer's Disease Related Quality of Life (ADRQL) – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 12 | 2495 | -.049 | -.097--.001 | .0443 | 14.699 | .197 | 25.164 |
| Female gender | 8 | 2085 | .057 | .014-.100 | .0096 | 6.141 | .523 | 0 |
| More advanced dementia | 9 | 1596 | -.383 | -.487--.267 | <.0001 | 46.370 | <.001 | 82.747 |
| Higher scores on cognitive screening measures | 14 | 2508 | .295 | .223-.363 | <.0001 | 43.364 | <.001 | 70.021 |
| Mini-Mental State Examination | 14 | 2510 | .295 | .223-.365 | <.0001 | 45.213 | <.001 | 71.247 |
| Taking medication | 6 | 1190 | -.027 | -.086-.032 | .3690 | 5.295 | .381 | 5.569 |
| Better functional ability | 14 | 4069 | .342 | .233-.442 | <.0001 | 161.125 | <.001 | 91.932 |
| Basic activities of daily living | 9 | 1339 | .361 | .267-.448 | <.0001 | 26.861 | .001 | 70.217 |
| Katz Index of Independence in Activities of Daily Living | 7 | 989 | .344 | .274-.410 | <.0001 | 8.170 | .226 | 26.558 |
| Depression | 10 | 1320 | -.328 | -.441--.204 | <.0001 | 50.806 | <.001 | 82.285 |
| Cornell Scale for Depression in Dementia | 9 | 1186 | -.353 | -.470--.225 | <.0001 | 44.614 | <.001 | 82.068 |
| Neuropsychiatric symptoms/BPSD | 14 | 2618 | -.379 | -.473--.276 | <.0001 | 110.040 | <.001 | 88.186 |
| Neuropsychiatric Inventory | 8 | 1589 | -.421 | -.536--.291 | <.0001 | 59.180 | <.001 | 88.172 |
| Presence of co-morbid conditions | 7 | 929 | -.006 | -.071-.059 | .8511 | 6.011 | .422 | .185 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 20h: Factors associated with informant ratings of quality of life for the person with dementia made using the EQ-5D – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 7 | 2051 | .018 | -.065-.101 | .6721 | 19.691 | .003 | 69.529 |
| Female gender | 6 | 1902 | -.057 | -.101-.011 | .0140 | 2.363 | .797 | 0 |
| Higher scores on cognitive screening measures | 14 | 2839 | .196 | .100-.289 | .0001 | 79.568 | <.001 | 83.662 |
| Mini-Mental State Examination | 13 | 2429 | .215 | .119-.308 | <.0001 | 63.367 | <.001 | 81.063 |
| Better functional ability | 18 | 3551 | .531 | .409-.634 | <.0001 | 342.597 | <.001 | 95.038 |
| Basic activities of daily living | 11 | 1981 | .613 | .481-.718 | <.0001 | 152.400 | <.001 | 93.438 |
| Barthel Index | 6 | 1448 | .723 | .646-.785 | <.0001 | 25.778 | <.001 | 80.603 |
| Instrumental activities of daily living | 5 | 636 | .459 | .330-.572 | <.0001 | 11.179 | .025 | 64.220 |
| Depression | 8 | 2074 | -.167 | -.260--.070 | .0007 | 29.949 | <.001 | 76.627 |
| Neuropsychiatric symptoms/BPSD | 8 | 1624 | -.293 | -.420--.154 | .0001 | 54.199 | <.001 | 87.085 |
| Neuropsychiatric Inventory\* | 8 | 1624 | -.293 | -.420--.154 | .0001 | 54.199 | <.001 | 87.085 |
| Presence of co-morbid conditions | 6 | 1677 | -.116 | -.209--.021 | .0164 | 15.527 | .008 | 67.798 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20i: Factors associated with informant ratings of quality of life for the person with dementia made using the EQ-5D Visual Analogue Scale – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 1689 | -.020 | -.118-.078 | .6867 | 16.603 | .005 | 69.884 |
| Female gender | 5 | 1211 | -.056 | -.137-.027 | .1878 | 6.622 | .157 | 39.600 |
| Higher scores on cognitive screening measures | 7 | 1763 | .111 | -.029-.246 | .1204 | 46.034 | <.001 | 86.966 |
| Mini-Mental State Examination | 6 | 1356 | .135 | -.037-.300 | .1233 | 43.564 | <.001 | 88.523 |
| Better functional ability | 6 | 1857 | .285 | .201-.365 | <.0001 | 16.183 | .006 | 69.104 |
| Depression | 6 | 1740 | -.178 | -.279--.074 | .0009 | 20.593 | .001 | 75.720 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 20j: Factors associated with informant ratings of quality of life for the person with dementia made using the** **Quality of Life in Late Stage Dementia Scale (QUALID) – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 1765 | -.022 | -.094-.050 | .5496 | 9.849 | .080 | 49.234 |
| Female gender | 7 | 2057 | -.011 | -.054-.033 | .6271 | 5.064 | .536 | 0 |
| More advanced dementia | 5 | 1537 | -.245 | -.348--.135 | <.0001 | 15.096 | .005 | 73.504 |
| Higher scores on cognitive screening measures | 6 | 1213 | .091 | -.084-.261 | .3093 | 40.592 | <.001 | 87.682 |
| Mini-Mental State Examination\* | 6 | 1213 | .091 | -.084-.261 | .3093 | 40.592 | <.001 | 87.682 |
| Taking medication | 5 | 1319 | -.087 | -.169--.004 | .0392 | 7.165 | .127 | 44.176 |
| Better functional ability | 9 | 2355 | .203 | .011-.381 | .0388 | 165.249 | <.001 | 95.159 |
| Basic activities of daily living\* | 9 | 2355 | .203 | .011-.381 | .0388 | 165.249 | <.001 | 95.159 |
| Depression | 6 | 1058 | -.526 | -.664--.352 | <.0001 | 48.065 | <.001 | 89.597 |
| Neuropsychiatric symptoms/BPSD | 8 | 1651 | -.395 | -.535--.234 | <.0001 | 77.089 | <.001 | 90.920 |
| Neuropsychiatric Inventory | 5 | 1063 | -.352 | -.514--.165 | .0003 | 27.454 | <.001 | 85.430 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20k: Factors associated with informant ratings of quality of life for the person with dementia made using the** **Health Utility Index (HUI) 2 and/or 3 – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Higher scores on cognitive screening measures | 6 | 3336 | .208 | .025-.378 | .0264 | 89.599 | <.001 | 94.420 |
| Mini-Mental State Examination | 5 | 2920 | .240 | -.032-.479 | .0834 | 112.324 | <.001 | 96.439 |
| Better functional ability | 6 | 3338 | .375 | .158-.558 | .0010 | 145.386 | <.001 | 96.561 |
| Basic activities of daily living | 5 | 2917 | .385 | .111-.604 | .0070 | 126.927 | <.001 | 96.849 |
| Presence of co-morbid conditions | 5 | 1337 | -.135 | -.209--.060 | .0005 | 7.097 | .131 | 43.637 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 20l: Factors associated with informant ratings of quality of life for the person with dementia made using dementia-specific quality of life measures – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 49 | 10112 | -.029 | -.057--.001 | .0428 | 85.287 | .001 | 43.719 |
| Female gender | 37 | 8320 | .000 | -.036-.036 | .9987 | 88.710 | <.001 | 59.418 |
| White ethnicity | 5 | 906 | .066 | .000-.131 | .0490 | 2.029 | .730 | 0 |
| Higher level of education | 24 | 3930 | .042 | .007-.077 | .0187 | 26.544 | .276 | 13.350 |
| Underweight\* | 5 | 1755 | -.065 | -.129--.002 | .0447 | 7.119 | .130 | 43.809 |
| Alzheimer’s (vs. other dementia subtypes) | 8 | 2624 | .067 | -.010-.143 | .0885 | 23.568 | .001 | 70.298 |
| Longer disease duration | 8 | 1356 | -.070 | -.123--.016 | .0107 | 6.674 | .464 | 0 |
| More advanced dementia | 33 | 6532 | -.281 | -.336--.225 | <.0001 | 176.330 | <.001 | 81.852 |
| Clinical Dementia Rating | 19 | 4715 | -.261 | -.337--.180 | <.0001 | 142.262 | <.001 | 87.347 |
| Global Deterioration Scale | 6 | 898 | -.283 | -.379--.182 | <.0001 | 12.740 | .026 | 60.755 |
| Advanced dementia measures excluding Clinical Dementia Rating & Global Deterioration Scale | 8 | 919 | -.337 | -.429--.238 | <.0001 | 17.240 | .016 | 59.396 |
| Higher scores on cognitive screening measures | 68 | 12491 | .190 | .152-.228 | <.0001 | 285.747 | <.001 | 76.553 |
| Mini-Mental State Examination | 59 | 10906 | .183 | .143-.222 | <.0001 | 227.086 | <.001 | 74.459 |
| Cognitive screening measures excluding Dementia Rating Scale & Mini-Mental State Examination | 17 | 5004 | .211 | .120-.299 | <.0001 | 132.416 | <.001 | 87.917 |
| Taking medication | 19 | 5737 | -.057 | -.086--.028 | .0001 | 20.097 | .327 | 10.434 |
| Acetylcholinesterase inhibitors | 9 | 1684 | -.093 | -.165--.020 | .0122 | 16.171 | .040 | 50.527 |
| Polypharmacy | 8 | 1776 | -.058 | -.104--.011 | .0154 | 6.564 | .476 | 0 |
| Psychotropics | 12 | 4043 | -.066 | -.112--.018 | .0064 | 19.261 | .057 | 42.889 |
| Antipsychotics\* | 5 | 1244 | -.171 | -.290--.047 | .0069 | 15.322 | .004 | 73.893 |
| Antidepressants\* | 6 | 1221 | -.098 | -.195--.000 | .0492 | 11.134 | .049 | 55.092 |
| Anxiolytics \* | 7 | 1617 | -.056 | -.149-.038 | .2459 | 17.494 | .008 | 65.702 |
| Longer duration of care home stay | 11 | 2217 | -.103 | -.164--.041 | .0011 | 18.521 | .047 | 46.008 |
| Degree to which residential care is person-centred\* | 6 | 1814 | .155 | .049-.257 | .0042 | 13.729 | .017 | 63.581 |
| Special dementia unit (vs. other residential facility)\* | 5 | 2366 | .114 | .069-.158 | <.0001 | 4.753 | .314 | 15.838 |
| Better functional ability | 70 | 16702 | .283 | .246-.320 | <.0001 | 414.271 | <.001 | 83.344 |
| Alzheimer's Disease Co-operative Study-Activities of Daily Living Inventory | 6 | 1176 | .354 | .225-.470 | <.0001 | 22.915 | <.001 | 78.181 |
| Disability Assessment for Dementia | 5 | 3172 | .214 | .067-.353 | .0047 | 43.709 | <.001 | 90.849 |
| Basic activities of daily living | 48 | 11109 | .294 | .255-.333 | <.0001 | 206.491 | <.001 | 77.239 |
| Barthel Index | 13 | 2424 | .331 | .251-.406 | <.0001 | 50.285 | <.001 | 76.136 |
| Dependence Scale | 5 | 2967 | .217 | .068-.356 | .0045 | 36.368 | <.001 | 89.001 |
| Katz Index of Independence in Activities of Daily Living | 14 | 2840 | .295 | .239-.348 | <.0001 | 29.224 | .006 | 55.515 |
| Physical Self-Maintenance Scale | 10 | 1716 | .321 | .237-.399 | <.0001 | 25.638 | .002 | 64.896 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 10 | 1777 | .292 | .195-.384 | <.0001 | 38.905 | <.001 | 76.867 |
| Instrumental activities of daily living | 18 | 2610 | .337 | .244-.423 | <.0001 | 103.639 | <.001 | 83.597 |
| Lawton’s Instrumental Activities of Daily Living | 12 | 2089 | .303 | .190-.409 | <.0001 | 77.671 | <.001 | 85.838 |
| Instrumental activities of daily living measures excluding Lawton’s Instrumental Activities of Daily Living | 7 | 63 | .433 | .347-.511 | <.0001 | 8.967 | .175 | 33.091 |
| More awareness\* | 5 | 557 | .275 | .037-.484 | .0241 | 31.084 | <.001 | 87.132 |
| Better self-rated memory functioning | 7 | 710 | .170 | .030-.304 | .0177 | 20.382 | .002 | 70.562 |
| Depression | 59 | 11196 | -.321 | -.369--.271 | <.0001 | 442.334 | <.001 | 86.888 |
| Cornell Scale for Depression in Dementia | 27 | 6439 | -.358 | -.415--.299 | <.0001 | 165.413 | <.001 | 84.282 |
| Geriatric Depression Scale (all versions) | 13 | 1509 | -.284 | -.383--.179 | <.0001 | 49.013 | <.001 | 75.517 |
| Geriatric Depression Scale-30 | 8 | 983 | -.314 | -.453--.161 | <.0001 | 37.641 | <.001 | 81.403 |
| Neuropsychiatric Inventory-Depression | 11 | 2087 | -.259 | -.404--.102 | .0015 | 113.249 | <.001 | 91.170 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 17 | 1998 | -.314 | -.408--.213 | <.0001 | 88.394 | <.001 | 81.899 |
| Anxiety | 17 | 3090 | -.178 | -.243--.112 | <.0001 | 44.849 | <.001 | 64.324 |
| Neuropsychiatric Inventory-Anxiety | 11 | 2087 | -.150 | -.211--.088 | <.0001 | 15.735 | .107 | 36.447 |
| Anxiety measures excluding Neuropsychiatric Inventory-Anxiety | 7 | 1188 | -.219 | -.316--.118 | <.0001 | 16.338 | .012 | 63.275 |
| Neuropsychiatric symptoms/BPSD | 66 | 13851 | -.335 | -.383--.285 | <.0001 | 625.716 | <.001 | 89.612 |
| Cohen-Mansfield Agitation Inventory | 9 | 1332 | -.150 | -.213--.085 | <.0001 | 10.839 | .211 | 26.191 |
| Neuropsychiatric Inventory | 43 | 10216 | -.348 | -.409--.283 | <.0001 | 495.411 | <.001 | 91.522 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory | 20 | 3079 | -.353 | -.425-.276 | <.0001 | 103.081 | <.001 | 81.568 |
| Pain\* | 13 | 4048 | -.203 | -.307--.095 | .0003 | 124.860 | <.001 | 90.389 |
| Presence of co-morbid conditions | 21 | 3888 | -.072 | -.111--.034 | .0002 | 26.380 | .154 | 24.185 |
| Cared for by spouse (vs. other carer type) | 9 | 2068 | .121 | .046-.194 | .0016 | 20.652 | .008 | 62.263 |
| Being married | 13 | 2407 | .122 | .076-.168 | <.0001 | 14.966 | .243 | 19.821 |
| Living alone | 10 | 2066 | -.141 | -.206--.074 | <.0001 | 18.676 | .028 | 51.811 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20m: Factors associated with informant ratings of quality of life for the person with dementia made using dementia-specific quality of life measures – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 13 | 2318 | -.013 | -.088-.061 | .7257 | 33.985 | .001 | 64.691 |
| Female gender | 14 | 3066 | .054 | .006-.102 | .0283 | 21.214 | .090 | 35.689 |
| Higher level of education | 11 | 2231 | .087 | .035-.138 | .0010 | 13.164 | .215 | 24.034 |
| More time spent caring (community only)\* | 5 | 681 | -.137 | -.267--.002 | .0462 | 11.630 | .020 | 65.606 |
| Depression | 12 | 2215 | -.266 | -.342--.187 | <.0001 | 37.599 | <.001 | 70.744 |
| Center for Epidemiologic Studies Depression Scale | 5 | 865 | -.274 | -.439--.091 | .0037 | 26.446 | <.001 | 84.875 |
| Depression measures excluding Geriatric Depression Scale & Center for Epidemiologic Studies Depression Scale | 5 | 1041 | -.236 | -.293--.178 | <.0001 | 1.918 | .751 | 0 |
| Distress at NPS symptoms | 7 | 1027 | -.331 | -.419--.236 | <.0001 | 14.753 | .022 | 59.330 |
| Burden or stress | 22 | 3827 | -.336 | -.425--.239 | <.0001 | 211.743 | <.001 | 90.082 |
| Zarit Burden Interview | 17 | 2875 | -.351 | -.445--.250 | <.0001 | 135.079 | <.001 | 88.155 |
| Poorer mental health (GHQ)\* | 6 | 742 | -.286 | -.392--.172 | <.0001 | 8.442 | .133 | 40.774 |
| Carer quality of life (self-rated) | 8 | 1508 | .317 | .217-.410 | <.0001 | 26.916 | <.001 | 73.993 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20n: Factors associated with informant ratings of quality of life for the person with dementia made using dementia-specific quality of life measures by family carers – factors pertaining to the person with dementia factors**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 33 | 5786 | -.030 | -.064-.004 | .0789 | 48.532 | .031 | 34.064 |
| Female gender | 26 | 5059 | -.025 | -.072-.023 | .3037 | 63.531 | <.001 | 60.649 |
| Higher level of education | 22 | 3679 | .052 | .019-.084 | .0018 | 18.091 | .643 | 0 |
| Longer disease duration | 6 | 1133 | -.068 | -.135-.001 | .0520 | 5.966 | .310 | 16.194 |
| More advanced dementia | 18 | 2754 | -.263 | -.327--.196 | <.0001 | 55.213 | <.001 | 69.210 |
| Clinical Dementia Rating | 10 | 1632 | -.225 | -.322--.124 | <.0001 | 36.719 | <.001 | 75.490 |
| Global Deterioration Scale | 5 | 767 | -.288 | -.388--.181 | <.0001 | 9.593 | .048 | 58.301 |
| Higher scores on cognitive screening measures | 46 | 8976 | .161 | .117-.204 | <.0001 | 163.119 | <.001 | 72.413 |
| Mini-Mental State Examination | 39 | 7896 | .160 | .112-.206 | <.0001 | 140.566 | <.001 | 72.966 |
| Cognitive screening measures excluding Dementia Rating Scale & Mini-Mental State Examination | 12 | 987 | .171 | .069-.269 | .0010 | 73.164 | <.001 | 84.965 |
| Taking medication | 12 | 3320 | -.062 | -.096--.028 | .0003 | 10.969 | .446 | 0 |
| Acetylcholinesterase inhibitors | 6 | 1109 | -.070 | -.150-.011 | .0904 | 7.653 | .176 | 34.667 |
| Polypharmacy | 7 | 1594 | -.066 | -.122--.009 | .0232 | 7.360 | .289 | 18.476 |
| Psychotropics | 6 | 1731 | -.093 | -.163--.022 | .0099 | 6.640 | .249 | 24.696 |
| Better functional ability | 44 | 9500 | .275 | .222-.327 | <.0001 | 283.292 | <.001 | 84.821 |
| Alzheimer's Disease Co-operative Study-Activities of Daily Living Inventory | 5 | 1179 | .344 | .213-.462 | <.0001 | 22.319 | <.001 | 82.078 |
| Disability Assessment for Dementia | 5 | 3172 | .214 | .067-.353 | .0047 | 43.709 | <.001 | 90.849 |
| Basic activities of daily living | 25 | 5531 | .292 | .229-.353 | <.0001 | 113.668 | <.001 | 78.886 |
| Barthel Index | 6 | 587 | .388 | .296-.472 | <.0001 | 7.489 | .187 | 33.233 |
| Katz Index of Independence in Activities of Daily Living | 7 | 1434 | .289 | .191-.382 | <.0001 | 20.106 | .003 | 70.158 |
| Physical Self-Maintenance Scale | 7 | 844 | .296 | .172-.411 | <.0001 | 20.564 | .002 | 70.823 |
| Basic activities of daily living measures excluding Barthel Index, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 5 | 543 | .271 | .135-.397 | .0001 | 9.632 | .047 | 58.472 |
| Instrumental activities of daily living | 18 | 2610 | .335 | .242-.422 | <.0001 | 103.328 | <.001 | 83.548 |
| Lawton’s Instrumental Activities of Daily Living\* | 12 | 2089 | .282 | .171-.387 | <.0001 | 73.362 | <.001 | 85.006 |
| Instrumental activities of daily living measures excluding Lawton’s Instrumental Activities of Daily Living | 7 | 632 | .426 | .335-.510 | <.0001 | 9.893 | .129 | 39.351 |
| More awareness\* | 5 | 557 | .275 | .037-.484 | .0241 | 31.084 | <.001 | 87.132 |
| Better self-rated memory functioning\* | 6 | 515 | .177 | -.000-.343 | .0503 | 19.765 | .001 | 74.703 |
| Depression | 40 | 7346 | -.319 | -.377--.258 | <.0001 | 282.918 | <.001 | 86.215 |
| Cornell Scale for Depression in Dementia | 15 | 3371 | -.394 | -.468--.314 | <.0001 | 80.048 | <.001 | 82.511 |
| Geriatric Depression Scale (all versions) | 12 | 1475 | -.278 | -.381--.168 | <.0001 | 47.937 | <.001 | 77.053 |
| Geriatric Depression Scale-30 | 8 | 983 | -.320 | -.458--.166 | <.0001 | 37.958 | <.001 | 81.558 |
| Neuropsychiatric Inventory-Depression | 6 | 1669 | -.267 | -.473--.033 | .0258 | 105.110 | <.001 | 95.243 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 12 | 1240 | -.289 | -.366--.208 | <.0001 | 23.239 | .016 | 52.665 |
| Anxiety | 12 | 2621 | -.183 | -.260--.104 | <.0001 | 39.398 | <.001 | 72.080 |
| Neuropsychiatric Inventory-Anxiety | 7 | 1836 | -.168 | -.237--.097 | <.0001 | 11.997 | .062 | 49.986 |
| Anxiety measures excluding Neuropsychiatric Inventory-Anxiety | 6 | 964 | -.190 | -.318--.055 | .0061 | 18.114 | .003 | 72.397 |
| Neuropsychiatric symptoms/BPSD | 42 | 9113 | -.368 | -.430--.304 | <.0001 | 443.809 | <.001 | 90.762 |
| Neuropsychiatric Inventory | 31 | 7638 | -.383 | -.456--.304 | <.0001 | 403.246 | <.001 | 92.560 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory | 13 | 1692 | -.350 | -.435--.258 | <.0001 | 48.078 | <.001 | 78.041 |
| Presence of co-morbid conditions | 13 | 2208 | -.097 | -.149--.044 | .0003 | 16.661 | .163 | 27.974 |
| Cared for by spouse (vs. other carer type)\* | 9 | 2068 | .121 | .046-.194 | .0016 | 20.652 | .008 | 62.263 |
| Being married | 11 | 2162 | .126 | .071-.181 | <.0001 | 15.335 | .120 | 34.789 |
| Living alone | 9 | 1944 | -.125 | -.190--.060 | .0002 | 15.001 | .059 | 46.670 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20o: Factors associated with informant ratings of quality of life for the person with dementia made using dementia-specific quality of life measures by family carers only – factors pertaining to the carer factors**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 10 | 1976 | -.037 | -.121-.047 | .3861 | 27.028 | .001 | 66.701 |
| Female gender | 13 | 2443 | .037 | -.019-.093 | .1896 | 20.272 | .062 | 40.806 |
| Higher level of education | 10 | 1608 | .080 | .018-.142 | .0120 | 12.749 | .147 | 29.404 |
| More time spent caring (community only)\* | 5 | 681 | -.137 | -.267--.002 | .0462 | 11.630 | .020 | 65.606 |
| Depression\* | 12 | 2215 | -.266 | -.342--.187 | <.0001 | 37.599 | <.001 | 70.744 |
| Center for Epidemiologic Studies Depression Scale\* | 5 | 865 | -.274 | -.439--.091 | .0037 | 26.446 | <.001 | 84.875 |
| Depression measures excluding Geriatric Depression Scale & Center for Epidemiologic Studies Depression Scale\* | 5 | 1041 | -.236 | -.293--.178 | <.0001 | 1.918 | .751 | 0 |
| Distress at NPS symptoms | 7 | 1007 | -.330 | -.434--.216 | <.0001 | 20.691 | .002 | 71.002 |
| Burden or stress | 20 | 3574 | -.341 | -.437--.238 | <.0001 | 206.746 | <.001 | 90.810 |
| Zarit Burden Interview | 17 | 2866 | -.349 | -.443--.247 | <.0001 | 135.117 | <.001 | 88.158 |
| Poorer mental health (GHQ)\* | 6 | 742 | -.286 | -.392--.172 | <.0001 | 8.442 | .133 | 40.774 |
| Carer quality of life (self-rated) | 7 | 1408 | .318 | .207-.421 | <.0001 | 26.485 | <.001 | 77.346 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20p: Factors associated with informant ratings of quality of life for the person with dementia made using dementia-specific quality of life measures by health care professionals only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 14 | 3205 | -.062 | -.111--.012 | .0152 | 22.767 | .045 | 42.900 |
| Female gender | 14 | 3394 | .027 | -.018-.072 | .2415 | 20.523 | .083 | 36.657 |
| More advanced dementia | 13 | 3043 | -.333 | -.427--.231 | <.0001 | 99.998 | <.001 | 88.000 |
| Clinical Dementia Rating | 5 | 2053 | -.327 | -.487--.146 | .0006 | 71.904 | <.001 | 94.437 |
| Advanced dementia measures excluding Clinical Dementia Rating | 8 | 990 | -.338 | -.448--.217 | <.0001 | 28.062 | <.001 | 75.055 |
| Higher scores on cognitive screening measures | 23 | 3047 | .239 | .172-.305 | <.0001 | 78.324 | <.001 | 71.912 |
| Mini-Mental State Examination | 23 | 3038 | .242 | .173-.309 | <.0001 | 81.160 | <.001 | 72.893 |
| Taking medication | 11 | 3108 | -.049 | -.085--.012 | .0085 | 10.092 | .432 | .908 |
| Acetylcholinesterase inhibitors | 5 | 766 | -.105 | -.211-.003 | .0556 | 8.699 | .069 | 54.018 |
| Psychotropics | 8 | 2503 | -.051 | -.109-.007 | .0852 | 12.423 | .087 | 43.655 |
| Antidepressants | 5 | 1076 | -.126 | -.244--.004 | .0432 | 11.384 | .023 | 64.864 |
| Longer duration of care home stay | 9 | 1709 | -.085 | -.153--.016 | .0152 | 13.936 | .083 | 42.596 |
| Degree to which residential care is person-centred\* | 6 | 1814 | .154 | .049-.256 | .0042 | 13.718 | .018 | 63.551 |
| Special dementia unit (vs. other residential facility)\* | 5 | 2372 | .120 | .071-.168 | <.0001 | 5.528 | .237 | 27.641 |
| Better functional ability | 23 | 5328 | .292 | .234-.349 | <.0001 | 97.626 | <.001 | 77.465 |
| Basic activities of daily living | 21 | 3894 | .303 | .252-.353 | <.0001 | 54.478 | <.001 | 63.288 |
| Barthel Index | 10 | 1759 | .336 | .258-.410 | <.0001 | 27.120 | .001 | 66.814 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 6 | 1249 | .249 | .137-.354 | <.0001 | 19.768 | <.001 | 74.707 |
| Depression | 18 | 3135 | -.315 | -.407--.216 | <.0001 | 132.695 | <.001 | 87.189 |
| Cornell Scale for Depression in Dementia | 11 | 2506 | -.262 | -.350--.168 | <.0001 | 52.375 | <.001 | 80.907 |
| Neuropsychiatric Inventory-Depression | 5 | 424 | -.318 | -.508--.099 | .0049 | 20.146 | <.001 | 80.145 |
| Anxiety | 8 | 720 | -.213 | -.322--.098 | .0003 | 14.760 | .039 | 52.575 |
| Neuropsychiatric Inventory-Anxiety | 6 | 448 | -.194 | -.350--.026 | .0236 | 13.790 | .017 | 63.743 |
| Neuropsychiatric symptoms/BPSD | 23 | 3673 | -.326 | -.399--.249 | <.0001 | 130.165 | <.001 | 83.098 |
| Neuropsychiatric Inventory | 11 | 1753 | -.300 | -.398--.196 | <.0001 | 41.346 | <.001 | 75.814 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory | 14 | 2288 | -.327 | -.426--.221 | <.0001 | 93.038 | <.001 | 86.027 |
| Pain\* | 9 | 2443 | -.255 | -.403--.095 | .0021 | 115.216 | <.001 | 93.057 |
| Presence of co-morbid conditions | 6 | 987 | -.065 | -.129-.000 | .0508 | 5.193 | .393 | 3.723 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20q: Factors associated with informant ratings of quality of life for the person with dementia made using dementia-specific quality of life measures by mixed groups of carers including both family carers and health care professionals – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 5 | 1717 | .040 | -.013-.092 | .1369 | 4.748 | .314 | 15.746 |
| Better functional ability | 9 | 2513 | .311 | .224-.394 | <.0001 | 43.255 | <.001 | 81.505 |
| Basic activities of daily living\* | 8 | 2322 | .298 | .206-.385 | <.0001 | 38.411 | <.001 | 81.776 |
| Neuropsychiatric symptoms/BPSD | 6 | 1536 | -.209 | -.362--.046 | .0126 | 51.817 | <.001 | 90.351 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20r: Factors associated with informant ratings of quality of life for the person with dementia made using health-related quality of life measures – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 13 | 3160 | -.050 | -.118-.019 | .1538 | 38.056 | <.001 | 68.468 |
| Female gender | 11 | 2533 | -.031 | -.080-.018 | .2195 | 13.666 | .189 | 26.826 |
| Higher level of education | 5 | 1764 | .024 | -.023-.071 | .3165 | 1.726 | .786 | 0 |
| More advanced dementia | 8 | 2257 | -.424 | -.624.--171 | .0015 | 284.268 | <.001 | 97.538 |
| Clinical Dementia Rating | 7 | 1849 | -.375 | -.608--.083 | .0131 | 237.791 | <.001 | 97.477 |
| Higher scores on cognitive screening measures | 22 | 5828 | .154 | .078-.228 | <.0001 | 135.888 | <.001 | 84.546 |
| Mini-Mental State Examination | 21 | 5438 | .151 | .060-.239 | .0011 | 172.057 | <.001 | 88.376 |
| Better functional ability | 23 | 6347 | .452 | .331-.558 | <.0001 | 601.300 | <.001 | 96.341 |
| Basic activities of daily living | 15 | 4710 | .517 | .345-.655 | <.0001 | 572.421 | <.001 | 97.554 |
| Barthel Index | 7 | 1475 | .664 | .546-.756 | <.0001 | 53.911 | <.001 | 88.871 |
| Instrumental activities of daily living | 6 | 711 | .353 | .164-.516 | .0004 | 28.980 | <.001 | 82.747 |
| Depression | 13 | 2715 | -.240 | -.320--.157 | <.0001 | 50.222 | <.001 | 76.106 |
| Geriatric Depression Scale (all versions) | 7 | 795 | -.228 | -.361--.086 | .0018 | 18.927 | .004 | 68.299 |
| Geriatric Depression Scale-30 | 5 | 589 | -.306 | -.481--.107 | .0030 | 15.260 | .004 | 73.788 |
| Neuropsychiatric symptoms/BPSD | 12 | 4688 | -.320 | -.422--.209 | <.0001 | 137.811 | <.001 | 92.018 |
| Neuropsychiatric Inventory | 10 | 4234 | -.290 | -.400--.172 | <.0001 | 106.540 | <.001 | 91.552 |
| Presence of co-morbid conditions | 8 | 2393 | -.114 | -.189--.038 | .0035 | 21.962 | .003 | 68.127 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 20s: Factors associated with informant ratings of quality of life for the person with dementia made using health-related quality of life measures – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Burden or stress | 5 | 1515 | -.267 | -.402--.121 | .0004 | 32.132 | <.001 | 87.551 |

**Supplementary Table 20t: Factors associated with informant ratings of quality of life for the person with dementia made using health-related quality of life measures by family carers only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 11 | 2157 | -.060 | -.142-.023 | .1596 | 31.177 | .001 | 67.925 |
| Female gender | 9 | 1530 | -.005 | -.065-.055 | .8692 | 9.930 | .270 | 19.434 |
| More advanced dementia | 7 | 2030 | -.469 | -.664--.215 | .0006 | 237.789 | <.001 | 97.477 |
| Clinical Dementia Rating | 6 | 1622 | -.422 | -.657--.112 | .0090 | 202.966 | <.001 | 97.537 |
| Higher scores on cognitive screening measures | 21 | 5300 | .162 | .081-.240 | <.0001 | 128.786 | <.001 | 84.470 |
| Mini-Mental State Examination | 20 | 4909 | .158 | .060-.253 | .0016 | 168.151 | <.001 | 88.701 |
| Better functional ability | 23 | 6347 | .452 | .331-.558 | <.0001 | 601.300 | <.001 | 96.341 |
| Basic activities of daily living | 13 | 3692 | .475 | .300-.619 | <.0001 | 298.154 | <.001 | 95.975 |
| Barthel Index | 7 | 1475 | .664 | .546-.756 | <.0001 | 53.911 | <.001 | 88.871 |
| Instrumental activities of daily living\* | 6 | 711 | .353 | .164-.516 | .0004 | 28.980 | <.001 | 82.747 |
| Depression | 12 | 2190 | -.267 | -.343--.187 | <.0001 | 34.677 | <.001 | 68.278 |
| Geriatric Depression Scale (all versions) | 7 | 795 | -.228 | -.361--.086 | .0018 | 18.927 | .004 | 68.299 |
| Geriatric Depression Scale-30 | 5 | 589 | -.306 | -.481--.107 | .0030 | 15.260 | .004 | 73.788 |
| Neuropsychiatric symptoms/BPSD | 12 | 4688 | -.315 | -.418--.204 | <.0001 | 136.816 | <.001 | 91.960 |
| Neuropsychiatric Inventory | 10 | 4234 | -.285 | -.394--.167 | <.0001 | 105.366 | <.001 | 91.458 |
| Presence of co-morbid conditions | 5 | 1074 | -.139 | -.228--.047 | .0032 | 7.514 | .111 | 46.769 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20u: Factors associated with informant ratings of quality of life for the person with dementia made using health-related quality of life measures by family carers only – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Burden or stress\* | 5 | 1515 | -.267 | -.402--.121 | .0004 | 32.132 | <.001 | 87.551 |

Note: those asterisked are unchanged from previous analyses.

**Supplementary Table 20v: Factors associated with informant ratings of quality of life for the person with dementia made using generic quality of life measures – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Higher scores on cognitive screening measures | 8 | 1045 | .214 | .019-.393 | .0316 | 61.342 | <.001 | 88.589 |
| Mini-Mental State Examination | 6 | 476 | .204 | .027-.368 | .0240 | 17.476 | .004 | 71.389 |
| Better functional ability | 6 | 818 | .462 | .252-.630 | .0001 | 46.481 | <.001 | 89.243 |
| Depression | 5 | 625 | -.168 | -.328-.002 | .0529 | 11.694 | .020 | 65.795 |
| Geriatric Depression Scale (all versions) | 5 | 625 | -.288 | -.477--.074 | .0090 | 19.971 | .001 | 79.971 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 20w: Factors associated with informant ratings of quality of life for the person with dementia made using generic quality of life measures by family carers only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Higher scores on cognitive screening measures | 7 | 950 | .186 | -.031-.386 | .0922 | 56.747 | <.001 | 89.427 |
| Mini-Mental State Examination | 5 | 381 | .157 | -.053-.353 | .1423 | 14.947 | .005 | 73.238 |
| Better functional ability | 5 | 709 | .360 | .187-.512 | .0001 | 17.072 | .002 | 76.570 |
| Depression\* | 5 | 625 | -.168 | -.328-.002 | .0529 | 11.694 | .020 | 65.795 |
| Geriatric Depression Scale (all versions)\* | 5 | 625 | -.288 | -.477--.074 | .0090 | 19.971 | .001 | 79.971 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20x: Factors associated with informant ratings of quality of life for people with dementia diagnosed with Alzheimer’s disease – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 20 | 3202 | -.013 | -.067-.041 | .6383 | 38.724 | .005 | 50.935 |
| Female gender | 15 | 2646 | -.005 | -.076-.066 | .8896 | 40.263 | <.001 | 65.229 |
| Higher level of education | 15 | 2364 | .013 | -.028-.053 | .5462 | 6.844 | .941 | 0 |
| More advanced dementia | 9 | 1325 | -.217 | -.328--.099 | .0003 | 37.128 | <.001 | 78.453 |
| Clinical Dementia Rating | 7 | 1073 | -.195 | -.326--.057 | .0058 | 32.036 | <.001 | 81.271 |
| Higher scores on cognitive screening measures | 31 | 6659 | .157 | .102-.211 | <.0001 | 117.522 | <.001 | 74.473 |
| Mini-Mental State Examination | 26 | 5640 | .130 | .073-.185 | <.0001 | 80.492 | <.001 | 68.941 |
| Cognitive screening measures excluding Dementia Rating Scale & Mini-Mental State Examination | 8 | 3416 | .231 | .105-.350 | .0004 | 59.180 | <.001 | 88.172 |
| Taking medication | 8 | 1401 | -.087 | -.149--.025 | .0063 | 8.752 | .271 | 20.019 |
| Acetylcholinesterase inhibitors | 5 | 1083 | -.055 | -.138-.028 | .1909 | 6.409 | .171 | 37.587 |
| Better functional ability | 28 | 6218 | .289 | .221-.354 | <.0001 | 172.427 | <.001 | 84.341 |
| Basic activities of daily living | 18 | 4845 | .294 | .214-.369 | <.0001 | 107.216 | <.001 | 84.144 |
| Dependence Scale | 6 | 3374 | .263 | .108-.407 | .0011 | 71.667 | <.001 | 93.023 |
| Katz Index of Independence in Activities of Daily Living | 5 | 877 | .272 | .138-.397 | .0001 | 12.267 | .015 | 67.391 |
| Physical Self-Maintenance Scale | 5 | 441 | .343 | .238-.441 | <.0001 | 5.561 | .234 | 28.069 |
| Instrumental activities of daily living | 11 | 1420 | .334 | .200-.456 | <.0001 | 64.787 | <.001 | 84.565 |
| Lawton’s Instrumental Activities of Daily Living | 8 | 1157 | .317 | .151-.466 | .0003 | 51.773 | <.001 | 86.479 |
| Depression | 26 | 3464 | -.274 | -.328--.218 | <.0001 | 66.994 | <.001 | 62.683 |
| Cornell Scale for Depression in Dementia | 7 | 826 | -.414 | -.532--.279 | <.0001 | 26.831 | <.001 | 77.638 |
| Geriatric Depression Scale (all versions) | 12 | 1539 | -.237 | -.338--.129 | <.0001 | 46.065 | <.001 | 76.121 |
| Geriatric Depression Scale-30 | 7 | 949 | -.245 | -.396--.081 | .0037 | 34.026 | <.001 | 82.366 |
| Neuropsychiatric Inventory-Depression | 6 | 953 | -.332 | -.471--.177 | .0001 | 22.630 | <.001 | 77.905 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 8 | 931 | -.249 | -.309--.187 | <.0001 | 3.701 | .813 | 0 |
| Anxiety | 9 | 1126 | -.170 | -.261--.076 | .0004 | 14.112 | .079 | 43.312 |
| Neuropsychiatric Inventory-Anxiety | 6 | 858 | -.218 | -.354--.074 | .0033 | 12.607 | .027 | 60.340 |
| Neuropsychiatric symptoms/BPSD | 32 | 6928 | -.339 | -.408--.267 | <.0001 | 285.405 | <.001 | 89.138 |
| Neuropsychiatric Inventory | 22 | 5643 | -.344 | -.432--.251 | <.0001 | 252.974 | <.001 | 91.699 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory | 8 | 999 | -.343 | -.404--.279 | <.0001 | 8.369 | .301 | 16.359 |
| Presence of co-morbid conditions | 8 | 1456 | -.073 | -.124--.021 | .0056 | 2.547 | .924 | 0 |
| Being married | 8 | 1595 | .101 | .052-.149 | <.0001 | 5.600 | .587 | 0 |
| Living alone | 5 | 1017 | -.100 | -.191--.007 | .0349 | 7.193 | .126 | 44.389 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 20y: Factors associated with informant ratings of quality of life for people with dementia diagnosed with Alzheimer’s disease – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 5 | 807 | -.119 | -.187--.050 | .0008 | 1.386 | .847 | 0 |
| Female gender | 7 | 1018 | -.012 | -.074-.050 | .7102 | 3.032 | .805 | 0 |
| Depression | 7 | 1343 | -.205 | -.316--.088 | .0007 | 23.207 | .001 | 74.146 |
| Burden or stress | 13 | 2464 | -.258 | -.357--.153 | <.0001 | 80.475 | <.001 | 85.089 |
| Zarit Burden Interview | 10 | 2149 | -.288 | -.399--.170 | <.0001 | 68.951 | <.001 | 86.947 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 20z: Factors associated with informant ratings of quality of life for people with dementia diagnosed with Alzheimer’s disease made by family carers only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 19 | 3094 | -.013 | -.070-.044 | .6540 | 38.623 | .003 | 53.395 |
| Female gender | 15 | 2646 | -.006 | -.077-.066 | .8724 | 40.543 | <.001 | 65.468 |
| Higher level of education | 15 | 2356 | .010 | -.031-.051 | .6370 | 5.733 | .973 | 0 |
| More advanced dementia | 6 | 953 | -.207 | -.366--.038 | .0169 | 35.737 | <.001 | 86.009 |
| Clinical Dementia Rating | 5 | 732 | -.175 | -.360-.023 | .0833 | 29.546 | <.001 | 86.463 |
| Higher scores on cognitive screening measures | 32 | 6719 | .163 | .109-.217 | <.0001 | 123.055 | <.001 | 74.808 |
| Mini-Mental State Examination | 27 | 5700 | .138 | .081-.194 | <.0001 | 87.152 | <.001 | 70.167 |
| Cognitive screening measures excluding Dementia Rating Scale & Mini-Mental State Examination | 8 | 3416 | .231 | .105-.350 | .0004 | 59.180 | <.001 | 88.172 |
| Taking medication | 8 | 1401 | -.087 | -.148--.024 | .0067 | 8.775 | .269 | 20.228 |
| Acetylcholinesterase inhibitors | 5 | 1083 | -.055 | -.138-.028 | .1909 | 6.409 | .171 | 37.587 |
| Better functional ability | 25 | 5907 | .288 | .216-.358 | <.0001 | 171.226 | <.001 | 85.983 |
| Instrumental activities of daily living | 11 | 1420 | .331 | .197-.453 | <.0001 | 64.186 | <.001 | 84.420 |
| Lawton’s Instrumental Activities of Daily Living\* | 8 | 1157 | .317 | .151-.466 | .0003 | 51.773 | <.001 | 86.479 |
| Basic activities of daily living | 15 | 4462 | .297 | .207-.382 | <.0001 | 101.437 | <.001 | 86.198 |
| Katz Index of Independence in Activities of Daily Living\* | 5 | 877 | .272 | .138-.397 | .0001 | 12.267 | .015 | 67.391 |
| Depression | 22 | 3142 | -.272 | -.332--.210 | <.0001 | 63.114 | <.001 | 66.727 |
| Cornell Scale for Depression in Dementia | 6 | 630 | -.427 | -.572--.256 | <.0001 | 27.013 | <.001 | 81.490 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 7 | 850 | -.256 | -.319--.191 | <.0001 | 3.217 | .781 | 0 |
| Geriatric Depression Scale (all versions) | 11 | 1505 | -.223 | -.328--.113 | .0001 | 43.658 | <.001 | 77.094 |
| Geriatric Depression Scale-30 | 7 | 949 | -.245 | -.396--.081 | .0037 | 34.026 | <.001 | 82.366 |
| Anxiety | 7 | 1131 | -.171 | -.265--.073 | .0007 | 13.331 | .038 | 54.992 |
| Neuropsychiatric symptoms/BPSD | 26 | 6228 | -.348 | -.425--.266 | <.0001 | 262.972 | <.001 | 90.493 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory | 7 | 849 | -.359 | -.418--.297 | <.0001 | 6.142 | .407 | 2.316 |
| Neuropsychiatric Inventory | 19 | 5379 | -.340 | -.434--.239 | <.0001 | 239.349 | <.001 | 92.480 |
| Presence of co-morbid conditions\* | 8 | 1456 | -.073 | -.124--.021 | .0056 | 2.547 | .924 | 0 |
| Being married | 8 | 1595 | .107 | .057-.158 | <.0001 | 7.302 | .398 | 4.132 |
| Living alone\* | 5 | 1017 | -.100 | -.191--.007 | .0349 | 7.193 | .126 | 44.389 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20aa: Factors associated with informant ratings of quality of life for people with dementia diagnosed with Alzheimer’s disease made by family carers only – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age\* | 5 | 807 | -.119 | -.187--.050 | .0008 | 1.386 | .847 | 0 |
| Female gender | 7 | 1018 | -.019 | -.081-.043 | .5396 | 4.215 | .648 | 0 |
| Depression\* | 7 | 1343 | -.205 | -.316--.088 | .0007 | 23.207 | .001 | 74.146 |
| Burden or stress | 13 | 2455 | -.250 | -.350--.145 | <.0001 | 81.036 | <.001 | 85.192 |
| Zarit Burden Interview | 10 | 2140 | -.279 | -.391--.159 | <.0001 | 70.006 | <.001 | 87.144 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20ab: Factors associated with informant ratings of quality of life for the person with dementia, excluding studies that focused specifically on people diagnosed with Alzheimer’s disease – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 39 | 8815 | -.032 | -.065-.001 | .0561 | 82.818 | <.001 | 54.116 |
| Female gender | 34 | 7669 | -.005 | -.039-.029 | .7701 | 65.909 | .001 | 49.931 |
| White ethnicity\* | 5 | 906 | .066 | .000-.131 | .0490 | 2.029 | .730 | 0 |
| Higher level of education | 16 | 3253 | .061 | .023-.100 | .0017 | 17.403 | .295 | 13.807 |
| Alzheimer’s (vs. other dementia subtypes)\* | 9 | 2719 | .050 | -.027-.126 | .2054 | 27.443 | .001 | 70.849 |
| Longer disease duration | 8 | 983 | -.053 | -.116-.010 | .1016 | 1.605 | .978 | 0 |
| More advanced dementia | 31 | 6769 | -.318 | -.405--.225 | <.0001 | 485.325 | <.001 | 93.819 |
| Clinical Dementia Rating | 18 | 4796 | -.293 | -.413--.163 | <.0001 | 361.339 | <.001 | 95.295 |
| Global Deterioration Scale | 5 | 677 | -.265 | -.382--.141 | <.0001 | 11.376 | .023 | 64.839 |
| Advanced dementia measures excluding Global Deterioration Scale & Clinical Dementia Rating | 8 | 1296 | -.403 | -.555--.224 | <.0001 | 84.093 | <.001 | 91.676 |
| Higher scores on cognitive screening measures | 55 | 7858 | .195 | .147-.242 | <.0001 | 240.569 | <.001 | 77.553 |
| Mini-Mental State Examination | 50 | 7152 | .192 | .142-.240 | <.0001 | 211.931 | <.001 | 76.879 |
| Cognitive screening measures excluding Dementia Rating Scale & Mini-Mental State Examination | 9 | 1033 | .124 | .011-.234 | .0319 | 21.125 | .007 | 62.131 |
| Taking medication | 13 | 4602 | -.046 | -.075--.016 | .0023 | 11.196 | .512 | 0 |
| Acetylcholinesterase inhibitors | 5 | 809 | -.109 | -.215--.000 | .0498 | 9.371 | .052 | 57.314 |
| Psychotropics | 9 | 3769 | -.050 | -.096--.004 | .0314 | 12.960 | .113 | 38.270 |
| Antidepressants | 5 | 1119 | -.074 | -.171-.025 | .1416 | 7.923 | .094 | 49.513 |
| Anxiolytics | 6 | 1515 | -.064 | -.168-.042 | .2363 | 17.125 | .004 | 70.802 |
| Longer duration of care home stay\* | 12 | 2312 | -.105 | -.162--.047 | .0004 | 18.574 | .069 | 40.778 |
| Degree to which residential care is person-centred\* | 6 | 1814 | .155 | .049-.257 | .0042 | 13.729 | .017 | 63.581 |
| Special dementia unit (vs. other residential facility)\* | 5 | 2372 | .120 | .071-.168 | <.0001 | 5.528 | .237 | 27.641 |
| Better functional ability | 59 | 12394 | .360 | .303-.413 | <.0001 | 669.188 | <.001 | 91.333 |
| Basic activities of daily living | 41 | 8103 | .394 | .327-.457 | <.0001 | 455.482 | <.001 | 91.218 |
| Barthel Index | 18 | 3327 | .498 | .384-.596 | <.0001 | 259.016 | <.001 | 93.437 |
| Katz Index of Independence in Activities of Daily Living | 11 | 2114 | .310 | .256-.363 | <.0001 | 16.416 | .088 | 39.082 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 10 | 1808 | .287 | .193-.376 | <.0001 | 37.609 | <.001 | 76.070 |
| Instrumental activities of daily living | 13 | 1814 | .348 | .243-.445 | <.0001 | 60.784 | <.001 | 80.258 |
| Lawton’s Instrumental Activities of Daily Living | 7 | 1149 | .261 | .166-.351 | <.0001 | 15.567 | .016 | 61.456 |
| Instrumental activities of daily living measures excluding Lawton’s Instrumental Activities of Daily Living | 7 | 776 | .517 | .462-.567 | <.0001 | 5.640 | .465 | 0 |
| Depression | 42 | 8856 | -.318 | -.379--.256 | <.0001 | 388.227 | <.001 | 89.439 |
| Cornell Scale for Depression in Dementia | 21 | 5844 | -.318 | -.382--.250 | <.0001 | 140.453 | <.001 | 85.760 |
| Geriatric Depression Scale (all versions) | 7 | 414 | -.307 | -.455--.144 | .0003 | 16.548 | .011 | 63.742 |
| Neuropsychiatric Inventory-Depression | 6 | 1270 | -.192 | -.408-.043 | .1084 | 73.543 | <.001 | 93.201 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 11 | 1572 | -.346 | -.468--.211 | <.0001 | 79.163 | <.001 | 87.368 |
| Anxiety | 9 | 2018 | -.143 | -.186--.100 | <.0001 | 6.214 | .623 | 0 |
| Neuropsychiatric Inventory-Anxiety | 6 | 1270 | -.122 | -.176--.067 | <.0001 | 2.888 | .717 | 0 |
| Neuropsychiatric symptoms/BPSD | 44 | 8430 | -.322 | -.377--.265 | <.0001 | 332.965 | <.001 | 87.086 |
| Cohen-Mansfield Agitation Inventory | 6 | 1015 | -.141 | -.201--.080 | <.0001 | 3.448 | .631 | 0 |
| Neuropsychiatric Inventory | 29 | 5570 | -.333 | -.403--.260 | <.0001 | 226.724 | <.001 | 87.650 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory | 14 | 2517 | -.322 | -.398--.242 | <.0001 | 59.110 | <.001 | 78.007 |
| Pain\* | 13 | 4048 | -.203 | -.307-.095 | .0003 | 124.860 | <.001 | 90.389 |
| Presence of co-morbid conditions | 196 | 3893 | -.101 | -.148--.053 | <.0001 | 36.917 | .005 | 51.242 |
| Cared for by spouse (vs. other carer type) | 7 | 1453 | .129 | .066-.191 | <.0001 | 8.234 | .221 | 27.130 |
| Being married | 6 | 1303 | .115 | .033-.197 | .0064 | 10.267 | .068 | 51.298 |
| Living alone | 8 | 1379 | -.161 | -.220--.101 | <.0001 | 8.540 | .287 | 18.033 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20ac: Factors associated with informant ratings of quality of life for the person with dementia, excluding studies that focused specifically on people diagnosed with Alzheimer’s disease – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 10 | 1693 | -.004 | -.062-.070 | .9088 | 15.187 | .086 | 40.737 |
| Female gender | 8 | 2071 | .098 | .049-.147 | .0001 | 8.376 | .301 | 16.424 |
| Higher level of education | 9 | 2094 | .098 | .043-.152 | .0005 | 11.342 | .183 | 29.463 |
| More time spent caring (residential care only) | 5 | 605 | -.166 | -.284--.043 | .0082 | 9.436 | .051 | 57.609 |
| Depression | 7 | 1350 | -.290 | -.376--.199 | <.0001 | 17.128 | .009 | 64.970 |
| Distress at NPS symptoms | 5 | 878 | -.331 | -.436--.216 | <.0001 | 12.111 | .017 | 66.973 |
| Burden or stress | 12 | 1996 | -.373 | -.477--.260 | <.0001 | 82.666 | <.001 | 86.693 |
| Zarit Burden Interview | 8 | 1135 | -.385 | -.538--.206 | <.0001 | 73.232 | <.001 | 90.441 |
| Poorer mental health (GHQ)\* | 6 | 715 | -.242 | -.311--.170 | <.0001 | 3.990 | .551 | 0 |
| Carer quality of life (self-rated) | 6 | 1228 | .330 | .209-.441 | <.0001 | 22.844 | <.001 | 78.112 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20ad: Factors associated with informant ratings of quality of life for the person with dementia made by family carers only, excluding studies that focused specifically on people diagnosed with Alzheimer’s disease – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 22 | 4007 | -.045 | -.086--.004 | .0326 | 33.375 | .042 | 37.078 |
| Female gender | 21 | 3819 | -.034 | -.079-.011 | .1336 | 34.792 | .021 | 42.516 |
| Higher level of education | 13 | 2485 | .082 | .043-.121 | <.0001 | 7.481 | .824 | 0 |
| Longer disease duration | 6 | 756 | -.059 | -.131-.013 | .1074 | 1.194 | .945 | 0 |
| More advanced dementia | 19 | 3510 | -.322 | -.453--.178 | <.0001 | 361.331 | <.001 | 95.018 |
| Clinical Dementia Rating | 11 | 2202 | -.286 | -.481--.064 | .0120 | 265.365 | <.001 | 96.232 |
| Higher scores on cognitive screening measures | 34 | 4456 | .154 | .093-.214 | <.0001 | 127.116 | <.001 | 74.040 |
| Mini-Mental State Examination | 30 | 4109 | .161 | .093-.227 | <.0001 | 127.011 | <.001 | 77.167 |
| Cognitive screening measures excluding Dementia Rating Scale & Mini-Mental State Examination | 6 | 869 | .120 | -.025-.260 | .1036 | 18.060 | .003 | 72.315 |
| Taking medication | 6 | 2185 | -.050 | -.092--.008 | .0207 | 2.569 | .766 | 0 |
| Better functional ability | 35 | 5176 | .358 | .284-.427 | <.0001 | 267.710 | <.001 | 87.300 |
| Basic activities of daily living | 19 | 2319 | .423 | .313-.521 | <.0001 | 153.424 | <.001 | 88.268 |
| Barthel Index | 9 | 919 | .550 | .408-.666 | <.0001 | 50.258 | <.001 | 84.082 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 5 | 560 | .238 | .130-.341 | <.0001 | 6.437 | .169 | 37.861 |
| Instrumental activities of daily living\* | 13 | 1814 | .348 | .243-.445 | <.0001 | 60.784 | <.001 | 80.258 |
| Lawton’s Instrumental Activities of Daily Living | 7 | 1149 | .261 | .166-.351 | <.0001 | 15.567 | .016 | 61.456 |
| Instrumental activities of daily living measures excluding Lawton’s Instrumental Activities of Daily Living\* | 7 | 776 | .517 | .462-.567 | <.0001 | 5.640 | .465 | 0 |
| Depression | 27 | 5327 | -.320 | -.396--.240 | <.0001 | 226.800 | <.001 | 88.536 |
| Cornell Scale for Depression in Dementia | 10 | 2972 | -.336 | -.419--.247 | <.0001 | 50.641 | <.001 | 82.228 |
| Geriatric Depression Scale (all versions) | 7 | 414 | -.315 | -.462--.151 | .0003 | 16.856 | .010 | 64.404 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 8 | 1062 | -.300 | -.404--.188 | <.0001 | 22.755 | .002 | 69.237 |
| Anxiety | 6 | 1544 | -.137 | -.185--.087 | <.0001 | 1.810 | .875 | 0 |
| Neuropsychiatric symptoms/BPSD | 26 | 4321 | -.357 | -.421--.289 | <.0001 | 140.919 | <.001 | 82.259 |
| Neuropsychiatric Inventory | 20 | 3256 | -.384 | -.457--.306 | <.0001 | 109.702 | <.001 | 82.680 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory | 8 | 1360 | -.358 | -.467--.239 | <.0001 | 36.806 | <.001 | 80.981 |
| Presence of co-morbid conditions | 9 | 1417 | -.152 | -.232--.070 | .0003 | 17.530 | .025 | 54.363 |
| Cared for by spouse (vs. other carer type)\* | 7 | 1453 | .129 | .066-.191 | <.0001 | 8.234 | .221 | 27.130 |
| Being married\* | 6 | 1303 | .115 | .033-.197 | .0064 | 10.267 | .068 | 51.298 |
| Living alone | 7 | 1254 | -.139 | -.204--.073 | <.0001 | 7.783 | .254 | 22.906 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20ae: Factors associated with informant ratings of quality of life for the person with dementia made by family carers only, excluding studies that focused specifically on people diagnosed with Alzheimer’s disease – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 7 | 1351 | -.026 | -.093-.040 | .4394 | 8.258 | .220 | 27.341 |
| Female gender | 7 | 1448 | .088 | .025-.151 | .0066 | 8.198 | .224 | 26.813 |
| Higher level of education | 8 | 1457 | .095 | .026-.164 | .0074 | 11.161 | .132 | 37.281 |
| More time spent caring (residential care only)\* | 5 | 605 | -.166 | -.284--.043 | .0082 | 9.436 | .051 | 57.609 |
| Depression\* | 7 | 1350 | -.290 | -.376--.199 | <.0001 | 17.128 | .009 | 64.970 |
| Distress at NPS symptoms | 5 | 858 | -.322 | -.446--.186 | <.0001 | 16.515 | .002 | 75.780 |
| Burden or stress | 10 | 1752 | -.401 | -.511--.277 | <.0001 | 71.985 | <.001 | 87.497 |
| Zarit Burden Interview | 8 | 1135 | -.392 | -.542--.218 | <.0001 | 70.434 | <.001 | 90.062 |
| Poorer mental health (GHQ)\* | 6 | 715 | -.242 | -.311--.170 | <.0001 | 3.990 | .551 | 0 |
| Carer quality of life (self-rated) | 5 | 1128 | .335 | .194-.462 | <.0001 | 22.438 | <.001 | 82.173 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20af: Factors associated with informant ratings of quality of life for the person with dementia made by health care professionals only, excluding studies that focused specifically on people diagnosed with Alzheimer’s disease – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 17 | 3858 | -.052 | -.108-.005 | .0713 | 43.123 | <.001 | 62.897 |
| Female gender | 17 | 4053 | .025 | -.017-.066 | .2393 | 25.050 | .069 | 36.127 |
| More advanced dementia | 12 | 3012 | -.338 | -.435--.234 | <.0001 | 99.396 | <.001 | 88.933 |
| Clinical Dementia Rating | 5 | 2053 | -.327 | -.487--.146 | .0006 | 71.904 | <.001 | 94.437 |
| Advanced dementia measures excluding Clinical Dementia Rating | 7 | 959 | -.347 | -.463--.219 | <.0001 | 27.406 | <.001 | 78.107 |
| Higher scores on cognitive screening measures | 21 | 2965 | .242 | .176-.305 | <.0001 | 67.722 | <.001 | 70.468 |
| Mini-Mental State Examination | 21 | 2956 | .245 | .177-.310 | <.0001 | 70.495 | <.001 | 71.629 |
| Taking medication | 10 | 3006 | -.050 | .010-.090 | .0136 | 10.069 | .345 | 10.619 |
| Psychotropics | 7 | 2401 | -.050 | -.113-.014 | .1281 | 12.273 | .056 | 51.112 |
| Anxiolytics | 5 | 1370 | -.104 | -.240-.036 | .1449 | 21.632 | <.001 | 81.509 |
| Longer duration of care home stay\* | 10 | 1804 | -.088 | -.150--.025 | .0062 | 14.138 | .117 | 36.344 |
| Degree to which residential care is person-centred\* | 6 | 1814 | .154 | .049-.256 | .0042 | 13.718 | .018 | 63.551 |
| Special dementia unit (vs. other residential facility)\* | 5 | 2372 | .120 | .071-.168 | <.0001 | 5.528 | .237 | 27.641 |
| Better functional ability | 26 | 6008 | .367 | .271-.456 | <.0001 | 403.300 | <.001 | 93.801 |
| Basic activities of daily living | 23 | 4510 | .372 | .272-.463 | <.0001 | 294.753 | <.001 | 92.536 |
| Barthel Index | 11 | 2227 | .443 | .276-.583 | <.0001 | 197.598 | <.001 | 94.939 |
| Katz Index of Independence in Activities of Daily Living | 5 | 474 | .371 | .290-.447 | <.0001 | 2.532 | .639 | 0 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 7 | 1345 | .280 | .166-.386 | <.0001 | 27.152 | <.001 | 77.903 |
| Depression | 15 | 2897 | -.283 | -.387--.172 | <.0001 | 123.916 | <.001 | 88.702 |
| Cornell Scale for Depression in Dementia | 10 | 2398 | -.244 | -.337--.147 | <.0001 | 47.726 | <.001 | 81.142 |
| Anxiety | 5 | 563 | -.165 | -.264--.061 | .0019 | 5.630 | .229 | 28.950 |
| Neuropsychiatric symptoms/BPSD | 19 | 3466 | -.330 | -.411--.245 | <.0001 | 127.793 | <.001 | 85.915 |
| Neuropsychiatric Inventory | 9 | 1619 | -.320 | -.431--.199 | <.0001 | 41.768 | <.001 | 80.847 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory | 8 | 1303 | -.318 | -.419--.209 | <.0001 | 30.289 | <.001 | 76.889 |
| Pain\* | 9 | 2443 | -.255 | -.403--.095 | .0021 | 115.216 | <.001 | 93.057 |
| Presence of co-morbid conditions | 8 | 1781 | -.099 | -.152--.046 | .0003 | 8.528 | .288 | 17.914 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20ag: Factors associated with informant ratings of quality of life for the person with dementia made by mixed groups of informants including family carers and health care professionals, excluding studies that focused specifically on people diagnosed with Alzheimer’s disease – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 5 | 1719 | -.039 | -.092-.014 | .1493 | 4.829 | .305 | 17.170 |
| Better functional ability | 6 | 1983 | .341 | .257-.420 | <.0001 | 20.398 | .001 | 75.488 |
| Basic activities of daily living\* | 6 | 1983 | .341 | .257-.420 | <.0001 | 20.398 | .001 | 75.488 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20ah: Factors associated with informant ratings of quality of life for people with dementia living in the community – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 27 | 4932 | -.020 | -.067-.027 | .4077 | 63.551 | <.001 | 59.088 |
| Female gender | 20 | 3894 | .015 | -.041-.070 | .6052 | 49.788 | <.001 | 61.838 |
| Higher level of education | 19 | 3597 | .043 | .011-.076 | .0097 | 13.919 | .734 | 0 |
| Longer disease duration | 5 | 1067 | -.088 | -.148--.028 | .0041 | 2.156 | .707 | 0 |
| More advanced dementia | 10 | 1681 | -.232 | -.333--.125 | <.0001 | 43.127 | <.001 | 79.131 |
| Clinical Dementia Rating | 6 | 1122 | -.220 | -.372--.055 | .0091 | 35.013 | <.001 | 85.719 |
| Higher scores on cognitive screening measures | 40 | 8097 | .148 | .098-.196 | <.0001 | 158.260 | <.001 | 75.357 |
| Mini-Mental State Examination | 34 | 6956 | .127 | .074-.179 | <.0001 | 122.962 | <.001 | 73.976 |
| Cognitive screening measures excluding Dementia Rating Scale & Mini-Mental State Examination | 14 | 3868 | .165 | .074-.253 | .0004 | 61.744 | <.001 | 78.945 |
| Taking medication | 9 | 2377 | -.040 | -.080-.001 | .0545 | 7.754 | .458 | 0 |
| Acetylcholinesterase inhibitors | 5 | 1077 | -.012 | -.072-.048 | .6899 | 2.037 | .729 | 0 |
| Polypharmacy | 5 | 1115 | -.068 | -.145-.010 | .0855 | 5.905 | .206 | 32.264 |
| Psychotropics | 5 | 1226 | -.104 | -.202--.004 | .0425 | 8.195 | .085 | 51.192 |
| Better functional ability | 34 | 7799 | .339 | .272-.402 | <.0001 | 288.900 | <.001 | 88.577 |
| Bristol Activities of Daily Living Scale | 5 | 769 | .419 | .322-.507 | <.0001 | 6.973 | .137 | 42.637 |
| Disability Assessment for Dementia | 5 | 3042 | .208 | .071-.337 | .0030 | 29.842 | <.001 | 86.596 |
| Basic activities of daily living | 17 | 5108 | .329 | .223-.428 | <.0001 | 217.392 | <.001 | 92.640 |
| Katz Index of Independence in Activities of Daily Living | 6 | 1059 | .335 | .226-.436 | <.0001 | 15.098 | .010 | 66.883 |
| Instrumental activities of daily living | 15 | 2215 | .402 | .291-.503 | <.0001 | 108.271 | <.001 | 87.070 |
| Lawton’s Instrumental Activities of Daily Living | 7 | 1356 | .343 | .182-.487 | .0001 | 54.793 | <.001 | 89.050 |
| Instrumental activities of daily living measures excluding Lawton’s Instrumental Activities of Daily Living | 9 | 970 | .491 | .431-.547 | <.0001 | 9.859 | .275 | 18.860 |
| Depression | 31 | 5694 | -.321 | -.369--.272 | <.0001 | 103.915 | <.001 | 71.130 |
| Cornell Scale for Depression in Dementia | 9 | 2823 | -.362 | -.438--.282 | <.0001 | 36.031 | <.001 | 77.797 |
| Geriatric Depression Scale (all versions) | 12 | 1262 | -.270 | -.389--.142 | .0001 | 52.200 | <.001 | 78.927 |
| Geriatric Depression Scale-30 | 8 | 912 | -.281 | -.433--.113 | .0012 | 39.036 | <.001 | 82.068 |
| Neuropsychiatric Inventory-Depression | 6 | 1083 | -.351 | -.481--.205 | <.0001 | 26.160 | <.001 | 80.887 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression | 8 | 888 | -.297 | -.382--.207 | <.0001 | 12.997 | .072 | 46.143 |
| Anxiety | 10 | 1821 | -.159 | -.221--.096 | <.0001 | 14.064 | .120 | 36.007 |
| Neuropsychiatric Inventory-Anxiety | 6 | 1083 | -.201 | -.304--.095 | .0003 | 12.322 | .031 | 59.424 |
| Neuropsychiatric symptoms/BPSD | 33 | 7104 | -.371 | -.438--.301 | <.0001 | 300.843 | <.001 | 89.363 |
| Neuropsychiatric Inventory | 25 | 6113 | -.374 | -.455--.288 | <.0001 | 283.585 | <.001 | 91.537 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory | 8 | 1018 | -.402 | -.478--.320 | <.0001 | 14.457 | .044 | 51.579 |
| Presence of co-morbid conditions | 9 | 1746 | -.105 | -.176--.032 | .0046 | 15.523 | .050 | 48.463 |
| Cared for by spouse (vs. other carer type) | 6 | 1761 | .116 | .041-.191 | .0027 | 11.823 | .037 | 57.709 |
| Being married | 12 | 2575 | .111 | .066-.155 | <.0001 | 13.808 | .244 | 20.338 |
| Living alone | 10 | 2030 | -.126 | -.190--.061 | .0002 | 16.828 | .051 | 46.519 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 20ai: Factors associated with informant ratings of quality of life for people with dementia living in the community - factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 9 | 1750 | -.048 | -.101-.005 | .0785 | 9.216 | .324 | 13.193 |
| Female gender | 9 | 1584 | .029 | -.023-.081 | .2783 | 8.470 | .289 | 5.550 |
| Higher level of education | 6 | 1316 | .090 | .000-.179 | .0495 | 12.327 | .031 | 59.439 |
| More time spent caring (community only)\* | 5 | 681 | -.137 | -.267--.002 | .0462 | 11.630 | .020 | 65.606 |
| Depression | 9 | 2050 | -.237 | -.340--.130 | <.0001 | 45.312 | <.001 | 82.345 |
| Center for Epidemiologic Studies Depression Scale | 5 | 854 | -.273 | -.446--.081 | .0059 | 28.229 | <.001 | 85.830 |
| Distress at NPS symptoms | 5 | 925 | -.364 | -.442--.281 | <.0001 | 6.681 | .143 | 41.697 |
| Burden or stress | 17 | 3469 | -.358 | -.440--.270 | <.0001 | 124.683 | <.001 | 87.167 |
| Zarit Burden Interview | 12 | 2575 | -.397 | -.494--.291 | <.0001 | 96.649 | <.001 | 88.619 |
| Burden or stress measures excluding Zarit Burden Interview | 5 | 894 | -.255 | -.427--.066 | .0086 | 27.271 | <.001 | 85.332 |
| Carer quality of life (self-rated) | 5 | 1108 | .306 | .176-.425 | <.0001 | 17.771 | .001 | 77.492 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20aj: Factors associated with informant ratings of quality of life for people with dementia living in the community made by family carers only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 25 | 4724 | -.020 | -.070-.029 | .4200 | 63.230 | <.001 | 62.043 |
| Female gender | 20 | 3894 | .014 | -.042-.070 | .6186 | 50.065 | <.001 | 62.049 |
| Higher level of education | 18 | 3489 | .043 | .010-.077 | .0112 | 12.856 | .746 | 0 |
| More advanced dementia\* | 10 | 1681 | -.232 | -.333--.125 | <.0001 | 43.127 | <.001 | 79.131 |
| Clinical Dementia Rating\* | 6 | 1122 | -.220 | -.372--.055 | .0091 | 35.013 | <.001 | 85.719 |
| Higher scores on cognitive screening measures | 38 | 7912 | .147 | .096-.197 | <.0001 | 154.127 | <.001 | 75.994 |
| Mini-Mental State Examination | 30 | 6671 | .129 | .073-.184 | <.0001 | 117.460 | <.001 | 75.311 |
| Cognitive screening measures excluding Dementia Rating Scale & Mini-Mental State Examination\* | 14 | 3868 | .165 | .074-.253 | .0004 | 61.744 | <.001 | 78.945 |
| Taking medication | 8 | 1586 | -.053 | -.102--.003 | .0372 | 6.905 | .439 | 0 |
| Acetylcholinesterase inhibitors | 5 | 1077 | -.012 | -.072-.048 | .6899 | 2.037 | .729 | 0 |
| Polypharmacy\* | 5 | 1115 | -.068 | -.145-.010 | .0855 | 5.905 | .206 | 32.264 |
| Better functional ability | 32 | 7631 | .337 | .268-.402 | <.0001 | 284.355 | <.001 | 89.098 |
| Disability Assessment for Dementia\* | 5 | 3042 | .208 | .071-.337 | .0030 | 29.842 | <.001 | 86.596 |
| Basic activities of daily living | 16 | 5008 | .334 | .222-.436 | <.0001 | 217.457 | <.001 | 93.102 |
| Katz Index of Independence in Activities of Daily Living | 5 | 959 | .345 | .214-.464 | <.0001 | 15.089 | .005 | 73.491 |
| Instrumental activities of daily living | 15 | 2215 | .400 | .288-.501 | <.0001 | 108.533 | <.001 | 87.101 |
| Lawton’s Instrumental Activities of Daily Living\* | 7 | 1356 | .343 | .182-.487 | .0001 | 54.793 | <.001 | 89.050 |
| Instrumental activities of daily living measures excluding Lawton’s Instrumental Activities of Daily Living | 9 | 970 | .482 | .415-.544 | <.0001 | 11.367 | .182 | 29.619 |
| Depression | 30 | 5588 | -.328 | -.377--.277 | <.0001 | 103.831 | <.001 | 72.070 |
| Cornell Scale for Depression in Dementia | 8 | 2717 | -.380 | -.459--.296 | <.0001 | 34.170 | <.001 | 79.514 |
| Geriatric Depression Scale (all versions)\* | 8 | 912 | -.281 | -.433--.113 | .0012 | 39.036 | <.001 | 82.068 |
| Geriatric Depression Scale-30\* | 8 | 888 | -.297 | -.382--.207 | <.0001 | 12.997 | .072 | 46.143 |
| Neuropsychiatric Inventory-Depression | 6 | 1083 | -.368 | -.500--.220 | <.0001 | 28.020 | <.001 | 82.156 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression\* | 8 | 888 | -.297 | -.382--.207 | <.0001 | 12.997 | .072 | 46.143 |
| Anxiety | 10 | 1821 | -.155 | -.213--.096 | <.0001 | 12.508 | .186 | 28.044 |
| Neuropsychiatric Inventory-Anxiety | 6 | 1083 | -.194 | -.290--.094 | .0002 | 10.851 | .054 | 53.923 |
| Neuropsychiatric symptoms/BPSD | 32 | 7004 | -.378 | -.446--.305 | <.0001 | 306.693 | <.001 | 89.892 |
| Neuropsychiatric Inventory | 24 | 6013 | -.380 | -.462--.291 | <.0001 | 282.294 | <.001 | 91.852 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory | 8 | 1018 | -.414 | -.500--.319 | <.0001 | 19.533 | .007 | 64.162 |
| Presence of co-morbid conditions\* | 9 | 1746 | -.105 | -.176--.032 | .0046 | 15.523 | .050 | 48.463 |
| Cared for by spouse (vs. other carer type)\* | 6 | 1761 | .116 | .041-.191 | .0027 | 11.823 | .037 | 57.709 |
| Being married | 11 | 2464 | .118 | .068-.168 | <.0001 | 15.003 | .132 | 33.344 |
| Living alone\* | 10 | 2030 | -.126 | -.190--.061 | .0002 | 16.828 | .051 | 46.519 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20ak: Factors associated with informant ratings of quality of life for people with dementia living in the community made by family carers only – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 8 | 1650 | -.052 | -.112-.007 | .0863 | 8.978 | .254 | 22.034 |
| Female gender | 9 | 1584 | .022 | -.038-.083 | .4646 | 10.292 | .245 | 22.273 |
| Higher level of education\* | 6 | 1316 | .090 | .000-.179 | .0495 | 12.327 | .031 | 59.439 |
| More time spent caring (community only)\* | 5 | 681 | -.137 | -.267--.002 | .0462 | 11.630 | .020 | 65.606 |
| Depression\* | 9 | 2050 | -.237 | -.340--.130 | <.0001 | 45.312 | <.001 | 82.345 |
| Center for Epidemiologic Studies Depression Scale\* | 5 | 854 | -.273 | -.446--.081 | .0059 | 28.229 | <.001 | 85.830 |
| Distress at NPS symptoms | 5 | 925 | -.372 | -.454--.283 | <.0001 | 7.747 | .101 | 48.368 |
| Burden or stress | 16 | 3349 | -.355 | -.442--.261 | <.0001 | 126.936 | <.001 | 88.183 |
| Zarit Burden Interview | 12 | 2566 | -.390 | -.489--.282 | <.0001 | 99.191 | <.001 | 88.910 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20al: Factors associated with informant ratings of quality of life for people with dementia living in the community made by health care professionals only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Higher scores on cognitive screening measures | 5 | 489 | .132 | -.031-.288 | .1129 | 13.060 | .011 | 69.373 |
| Mini-Mental State Examination\* | 5 | 489 | .132 | -.031-.288 | .1129 | 13.060 | .011 | 69.373 |
| Better functional ability | 5 | 438 | .380 | .243-.502 | <.0001 | 9.983 | .041 | 59.933 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20am: Factors associated with informant ratings of quality of life for people with dementia living in residential care settings – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 18 | 4208 | -.026 | -.074-.023 | .2967 | 37.041 | .003 | 54.105 |
| Female gender | 17 | 4120 | -.006 | -.049-.038 | .7906 | 27.808 | .033 | 42.462 |
| Higher level of education | 5 | 1672 | .012 | -.081-.104 | .8077 | 13.001 | .011 | 69.234 |
| More advanced dementia | 14 | 2948 | -.288 | -.358--.214 | <.0001 | 50.995 | <.001 | 74.507 |
| Clinical Dementia Rating | 6 | 1971 | -.250 | -.340--.155 | <.0001 | 20.781 | .001 | 78.939 |
| Advanced dementia measures excluding Global Deterioration Scale | 8 | 979 | -.321 | -.426--.208 | <.0001 | 23.752 | .001 | 70.529 |
| Higher scores on cognitive screening measures | 19 | 3313 | .239 | .169-.306 | <.0001 | 75.494 | <.001 | 76.157 |
| Mini-Mental State Examination | 18 | 3118 | .246 | .171-.319 | <.0001 | 78.566 | <.001 | 78.362 |
| Taking medication | 9 | 3007 | -.062 | -.098--.025 | .0009 | 7.993 | .434 | 0 |
| Psychotropics | 6 | 2423 | -.065 | -.132-.003 | .0609 | 9.789 | .081 | 48.920 |
| Longer duration of care home stay\* | 12 | 2312 | -.105 | -.162--.047 | .0004 | 18.574 | .069 | 40.778 |
| Better functional ability | 25 | 5927 | .399 | .300-.490 | <.0001 | 411.991 | <.001 | 94.175 |
| Basic activities of daily living | 24 | 4562 | .419 | .325-.506 | <.0001 | 294.635 | <.001 | 92.194 |
| Barthel Index | 14 | 2790 | .504 | .371-.616 | <.0001 | 226.725 | <.001 | 94.266 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 12 | 2067 | .322 | .251-.390 | <.0001 | 28.818 | .002 | 61.829 |
| Depression | 18 | 3738 | -.309 | -.406--.206 | <.0001 | 176.913 | <.001 | 90.391 |
| Cornell Scale for Depression in Dementia | 11 | 2957 | -.287 | -.394--.172 | <.0001 | 99.990 | <.001 | 89.999 |
| Anxiety | 5 | 546 | -.158 | -.257--.056 | .0025 | 5.284 | .259 | 24.293 |
| Neuropsychiatric symptoms/BPSD | 20 | 3777 | -.303 | -.381--.221 | <.0001 | 130.068 | <.001 | 85.392 |
| Cohen-Mansfield Agitation Inventory | 8 | 1243 | -.149 | -.219--.077 | .0001 | 10.594 | .157 | 33.928 |
| Neuropsychiatric Inventory | 7 | 1483 | -.338 | -.447--.218 | <.0001 | 28.326 | <.001 | 78.818 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory | 10 | 1684 | -.317 | -.442--.181 | <.0001 | 79.560 | <.001 | 88.688 |
| Pain | 9 | 2199 | -.268 | -.422--.099 | .0021 | 114.141 | <.001 | 92.991 |
| Presence of co-morbid conditions | 8 | 1763 | -.044 | -.110-.021 | .1846 | 11.657 | .112 | 39.950 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 20an: Factors associated with informant ratings of quality of life for people with dementia living in residential care settings made by family carers only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 1153 | -.032 | -.090-.027 | .2868 | 2.273 | .810 | 0 |
| Female gender | 6 | 1182 | -.063 | -.120--.006 | .0309 | 2.801 | .731 | 0 |
| Better functional ability | 7 | 523 | .464 | .237-.643 | .0002 | 46.736 | <.001 | 87.162 |
| Basic activities of daily living | 7 | 523 | .487 | .248-.670 | .0002 | 53.503 | <.001 | 88.786 |
| Barthel Index | 5 | 382 | .614 | .395-.767 | <.0001 | 26.443 | <.001 | 84.873 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 20zo: Factors associated with informant ratings of quality of life for people with dementia living in residential care settings made by health care professionals only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 14 | 3040 | -.033 | -.094-.028 | .2889 | 32.792 | .002 | 60.356 |
| Female gender | 14 | 3049 | .010 | -.037-.057 | .6787 | 20.158 | .091 | 35.510 |
| More advanced dementia | 12 | 2420 | -.309 | -.389--.225 | <.0001 | 48.344 | <.001 | 77.246 |
| Higher scores on cognitive screening measures | 16 | 2543 | .253 | .181-.323 | <.0001 | 53.642 | <.001 | 72.037 |
| Mini-Mental State Examination | 16 | 2534 | .257 | .183-.328 | <.0001 | 56.286 | <.001 | 73.350 |
| Taking medication | 8 | 1821 | -.075 | -.123--.028 | .0019 | 6.916 | .438 | 0 |
| Psychotropics | 5 | 1216 | -.080 | -.177-.019 | .1140 | 9.203 | .056 | 56.538 |
| Longer duration of care home stay\* | 10 | 1804 | -.088 | -.150--.025 | .0062 | 14.138 | .117 | 36.344 |
| Special dementia unit (vs. other residential facility)\* | 5 | 2372 | .120 | .071-.168 | <.0001 | 5.528 | .237 | 27.641 |
| Better functional ability | 20 | 5178 | .365 | .249-.471 | <.0001 | 373.509 | <.001 | 94.913 |
| Basic activities of daily living | 19 | 3812 | .386 | .275-.488 | <.0001 | 258.544 | <.001 | 93.038 |
| Barthel Index | 9 | 2075 | .455 | .266-.610 | <.0001 | 192.570 | <.001 | 95.846 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 11 | 1934 | .328 | .256-.397 | <.0001 | 25.263 | <.001 | 60.417 |
| Depression | 14 | 2785 | -.305 | -.413--.189 | <.0001 | 122.925 | <.001 | 89.424 |
| Cornell Scale for Depression in Dementia | 9 | 2298 | -.251 | -.349--.146 | <.0001 | 47.214 | <.001 | 83.056 |
| Anxiety\* | 5 | 546 | -.158 | -.257--.056 | .0025 | 5.284 | .259 | 24.293 |
| Neuropsychiatric symptoms/BPSD | 16 | 3056 | -.331 | -.419--.238 | <.0001 | 109.008 | <.001 | 86.240 |
| Neuropsychiatric Inventory | 5 | 1230 | -.353 | -.509--.175 | <.0001 | 31.678 | <.001 | 87.373 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory | 8 | 1368 | -.348 | -.484--.195 | <.0001 | 64.515 | <.001 | 89.150 |
| Cohen-Mansfield Agitation Inventory | 6 | 776 | -.201 | -.284--.115 | <.0001 | 6.847 | .232 | 26.980 |
| Pain | 8 | 2049 | -.271 | -.443--.081 | .0057 | 114.980 | <.001 | 93.912 |
| Presence of co-morbid conditions | 6 | 1068 | -.074 | -.150-.002 | .0577 | 6.961 | .224 | 28.176 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 21a: Factors associated with proxy ratings of quality of life for the person with dementia made by family carers only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 8 | 865 | .059 | -.061-.177 | .3383 | 20.802 | .004 | 66.349 |
| Female gender | 5 | 428 | .061 | -.035-.156 | .2148 | 1.637 | .802 | 0 |
| Higher scores on cognitive screening measures | 10 | 1145 | .002 | -.066-.071 | .9452 | 11.337 | .253 | 20.614 |
| Mini-Mental State Examination\* | 10 | 1145 | .002 | -.066-.071 | .9452 | 11.337 | .253 | 20.614 |
| Better functional ability | 8 | 1124 | .139 | .009-.265 | .0361 | 32.947 | <.001 | 78.754 |
| Basic activities of daily living | 5 | 699 | .114 | -.038-.261 | .1423 | 15.249 | .004 | 73.768 |
| Depression | 7 | 761 | -.362 | -.494--.215 | <.0001 | 26.611 | <.001 | 77.453 |
| Geriatric Depression Scale (all versions)\* | 5 | 466 | -.446 | -.608--.248 | <.0001 | 20.722 | <.001 | 80.697 |
| Neuropsychiatric symptoms/BPSD | 10 | 1267 | -.356 | -.437--.270 | <.0001 | 23.112 | .006 | 61.060 |
| Neuropsychiatric Inventory | 8 | 1033 | -.349 | -.444--.247 | <.0001 | 20.217 | .005 | 65.376 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 21b: Factors associated with proxy ratings of quality of life for the person with dementia made by family carers only – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age\* | 5 | 412 | -.017 | -.160-.126 | .8173 | 7.963 | .093 | 49.768 |

Note: those asterisked are unchanged from previous analyses.

**Supplementary Table 21c: Factors associated with proxy ratings of quality of life for the person with dementia made by health care professionals only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 5 | 989 | -.095 | -.290-.107 | .3569 | 34.171 | <.001 | 88.294 |
| Female gender | 5 | 1166 | .027 | -.031-.084 | .3682 | 1.430 | .839 | 0 |
| Taking medication | 5 | 886 | -.120 | -.207--.030 | .0088 | 6.916 | .140 | 42.161 |
| Better functional ability | 6 | 862 | .082 | .008-.156 | .0300 | 5.544 | .353 | 9.808 |
| Basic activities of daily living | 6 | 862 | .082 | .008-.156 | .0300 | 5.544 | .353 | 9.808 |
| Depression | 5 | 583 | -.347 | -.417--.272 | <.0001 | 3.665 | .453 | 0 |
| Neuropsychiatric symptoms/BPSD | 5 | 1005 | -.295 | -.382--.203 | <.0001 | 8.874 | .064 | 54.926 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 21d: Factors associated with proxy ratings of quality of life for the person with dementia made using the Dementia Quality of Life Questionnaire (DEMQOL) – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 826 | .094 | -.042-.227 | .1753 | 18.263 | .003 | 72.622 |
| Higher scores on cognitive screening measures | 8 | 875 | .003 | -.086-.091 | .9553 | 11.111 | .134 | 36.997 |
| Mini-Mental State Examination\* | 8 | 875 | .003 | -.086-.091 | .9553 | 11.111 | .134 | 36.997 |
| Better functional ability | 8 | 1134 | .097 | -.030-.220 | .1334 | 28.953 | <.001 | 75.823 |
| Basic activities of daily living | 5 | 727 | .041 | -.033-.114 | .2753 | 2.655 | .617 | 0 |
| Depression | 5 | 487 | -.386 | -.577--.155 | .0015 | 26.266 | <.001 | 84.771 |
| Neuropsychiatric symptoms/BPSD | 7 | 898 | -.404 | -.491--.311 | <.0001 | 13.860 | .031 | 56.711 |
| Neuropsychiatric Inventory\* | 7 | 898 | -.404 | -.491--.311 | <.0001 | 13.860 | .031 | 56.711 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 21e: Factors associated with proxy ratings of quality of life for the person with dementia made using dementia-specific quality of life measures – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 14 | 2243 | -.016 | -.118-.087 | .7643 | 71.886 | <.001 | 81.916 |
| Female gender | 11 | 1832 | .037 | -.009-.083 | .1184 | 3.351 | .972 | 0 |
| More advanced dementia | 7 | 1381 | -.307 | -.425--.179 | <.0001 | 35.663 | <.001 | 83.176 |
| Higher scores on cognitive screening measures | 15 | 1903 | .112 | .022-.199 | .0144 | 49.267 | <.001 | 71.584 |
| Mini-Mental State Examination | 12 | 1482 | .068 | -.030-.165 | .1718 | 35.146 | <.001 | 68.702 |
| Taking medication\* | 7 | 1160 | -.099 | -.170--.026 | .0076 | 8.884 | .180 | 32.465 |
| Better functional ability | 15 | 2284 | .139 | .051-.224 | .0019 | 56.667 | <.001 | 75.294 |
| Basic activities of daily living | 12 | 1878 | .124 | .039-.208 | .0042 | 33.337 | <.001 | 67.004 |
| Basic activities of daily living measures excluding Barthel Index & Katz Index of Independence in Activities of Daily Living | 8 | 1251 | .141 | .039-.240 | .0066 | 19.852 | .006 | 64.739 |
| Depression\* | 13 | 1651 | -.317 | -.409--.219 | <.0001 | 47.495 | <.001 | 74.734 |
| Geriatric Depression Scale (all versions)\* | 5 | 466 | -.446 | -.608--.248 | <.0001 | 20.722 | <.001 | 80.697 |
| Cornell Scale for Depression in Dementia\* | 5 | 811 | -.200 | -.361--.027 | .0235 | 19.089 | .001 | 79.046 |
| Neuropsychiatric symptoms/BPSD | 16 | 2484 | -.321 | -.377--.263 | <.0001 | 34.096 | .003 | 26.007 |
| Neuropsychiatric Inventory | 12 | 1609 | -.333 | -.404--.257 | <.0001 | 27.782 | .003 | 60.406 |
| Neuropsychiatric measures excluding Neuropsychiatric Inventory | 5 | 1080 | -.297 | -.372--.219 | <.0001 | 6.800 | .147 | 41.175 |
| Presence of co-morbid conditions\* | 6 | 873 | -.121 | -.186--.054 | .0004 | 3.383 | .641 | 0 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 21f: Factors associated with proxy ratings of quality of life for the person with dementia made by family carers only using dementia-specific quality of life measures – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 7 | 825 | .064 | -.066-.192 | .3364 | 20.696 | .002 | 71.008 |
| Higher scores on cognitive screening measures | 9 | 1069 | .005 | -.069-.080 | .8879 | 11.186 | .191 | 28.483 |
| Mini-Mental State Examination\* | 9 | 1069 | .005 | -.069-.080 | .8879 | 11.186 | .191 | 28.483 |
| Better functional ability | 8 | 1108 | .121 | -.009-.247 | .0685 | 32.214 | <.001 | 78.270 |
| Basic activities of daily living | 5 | 701 | .074 | -.032-.178 | .1721 | 7.379 | .117 | 45.792 |
| Depression\* | 7 | 761 | -.362 | -.494--.215 | <.0001 | 26.611 | <.001 | 77.453 |
| Geriatric Depression Scale (all versions)\* | 5 | 466 | -.446 | -.608--.248 | <.0001 | 20.722 | <.001 | 80.697 |
| Neuropsychiatric symptoms/BPSD | 9 | 1191 | -.366 | -.441--.285 | <.0001 | 17.687 | .024 | 54.770 |
| Neuropsychiatric Inventory | 8 | 997 | -.376 | -.463--.282 | <.0001 | 17.110 | .017 | 59.088 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 21g: Factors associated with proxy ratings of quality of life for the person with dementia made by health care professionals only using dementia-specific quality of life measures – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 5 | 989 | -.095 | -.290-.107 | .3569 | 34.171 | <.001 | 88.294 |
| Female gender | 5 | 1015 | .037 | -.025-.099 | .2417 | 1.664 | .797 | 0 |
| Taking medication\* | 5 | 886 | -.120 | -.207--.030 | .0088 | 6.916 | .140 | 42.161 |
| Better functional ability | 6 | 862 | .082 | .008-.156 | .0300 | 5.544 | .353 | 16.522 |
| Basic activities of daily living\* | 6 | 862 | .082 | .008-.156 | .0300 | 5.544 | .353 | 16.522 |
| Depression\* | 5 | 583 | -.347 | -.417--.272 | <.0001 | 3.665 | .453 | 0 |
| Neuropsychiatric symptoms/BPSD | 5 | 1005 | -.295 | -.382--.203 | <.0001 | 8.874 | .064 | 54.926 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 21h: Factors associated with proxy ratings of quality of life for people with Alzheimer’s disease made using dementia-specific quality of life measures – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Higher scores on cognitive screening measures | 6 | 669 | .041 | -.036-.118 | .3003 | 4.481 | .482 | 0 |
| Mini-Mental State Examination\* | 6 | 669 | .041 | -.036-.118 | .3003 | 4.481 | .482 | 0 |
| Better functional ability | 5 | 745 | .224 | .052-.382 | .0110 | 22.280 | <.001 | 82.047 |
| Neuropsychiatric symptoms/BPSD | 8 | 974 | -.361 | -.464--.249 | <.0001 | 22.197 | .002 | 68.465 |
| Neuropsychiatric Inventory | 7 | 934 | -.341 | -.448--.225 | <.0001 | 19.313 | .004 | 68.932 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 21i: Factors associated with proxy ratings of quality of life for people with Alzheimer’s disease – factors pertaining to the family carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Higher scores on cognitive screening measures\* | 6 | 669 | .041 | -.036-.118 | .3003 | 4.481 | .482 | 0 |
| Mini-Mental State Examination\* | 6 | 669 | .041 | -.036-.118 | .3003 | 4.481 | .482 | 0 |
| Better functional ability\* | 5 | 745 | .224 | .052-.382 | .0110 | 22.280 | <.001 | 82.047 |
| Neuropsychiatric symptoms/BPSD\* | 8 | 974 | -.361 | -.464--.249 | <.0001 | 22.197 | .002 | 68.465 |
| Neuropsychiatric Inventory\* | 7 | 934 | -.341 | -.448--.225 | <.0001 | 19.313 | .004 | 68.932 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 21j: Factors associated with proxy ratings of quality of life for the person with dementia, excluding studies that focused specifically on people diagnosed with Alzheimer’s disease – factors pertaining to the person with dementia factors**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 11 | 1893 | -.007 | -.133-.120 | .9182 | 71.381 | <.001 | 85.991 |
| Female gender | 9 | 1637 | .029 | -.020-.078 | .2455 | 1.889 | .984 | 0 |
| More advanced dementia | 6 | 1266 | -.306 | -.438--.161 | <.0001 | 34.496 | <.001 | 85.506 |
| Higher scores on cognitive screening measures | 10 | 1310 | .127 | .005-.245 | .0412 | 41.275 | <.001 | 78.195 |
| Mini-Mental State Examination | 7 | 889 | .062 | -.098-.218 | .4491 | 30.517 | <.001 | 80.339 |
| Taking medication | 6 | 1080 | -.098 | -.179--.017 | .0181 | 8.829 | .116 | 43.367 |
| Better functional ability | 10 | 1556 | .110 | .010-.207 | .0318 | 30.559 | <.001 | 70.549 |
| Basic activities of daily living\* | 10 | 1556 | .110 | .010-.207 | .0318 | 30.559 | <.001 | 70.549 |
| Basic activities of daily living measures excluding Barthel Index & Katz Index of Independence in Activities of Daily Living | 7 | 1009 | .144 | .021-.263 | .0220 | 19.591 | .003 | 69.373 |
| Depression | 9 | 1277 | -.323 | -.428--.209 | <.0001 | 32.990 | <.001 | 75.750 |
| Neuropsychiatric symptoms/BPSD | 9 | 1586 | -.290 | -.354--.223 | <.0001 | 14.887 | .061 | 46.262 |
| Neuropsychiatric Inventory | 5 | 711 | -.284 | -.385--.177 | <.0001 | 8.768 | .067 | 54.378 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory | 5 | 1080 | -.297 | -.372--.219 | <.0001 | 6.800 | .147 | 41.175 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 21k: Factors associated with proxy ratings of quality of life for the person with dementia, excluding studies that focused specifically on people diagnosed with Alzheimer’s disease made by health care professionals only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 5 | 989 | -.095 | -.290-.107 | .3569 | 34.171 | <.001 | 88.294 |
| Female gender | 5 | 1015 | .037 | -.025-.099 | .2417 | 1.664 | .797 | 0 |
| Taking medication | 5 | 886 | -.120 | -.207--.030 | .0088 | 6.916 | .140 | 42.161 |
| Better functional ability | 6 | 862 | .082 | .008-.156 | .0300 | 5.544 | .353 | 16.522 |
| Basic activities of daily living\* | 6 | 862 | .082 | .008-.156 | .0300 | 5.544 | .353 | 16.522 |
| Depression | 5 | 583 | -.347 | -.417--.272 | <.0001 | 3.665 | .453 | 0 |
| Neuropsychiatric symptoms/BPSD | 5 | 1005 | -.295 | -.382--.203 | <.0001 | 8.874 | .064 | 54.926 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 21l: Factors associated with proxy ratings of quality of life for people with dementia living in the community – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 7 | 710 | .068 | -.073-.207 | .3436 | 20.293 | .002 | 70.433 |
| Female gender | 5 | 428 | .061 | -.035-.156 | .2148 | 1.637 | .802 | 0 |
| Higher scores on cognitive screening measures | 8 | 712 | .006 | -.093-.105 | .9103 | 11.279 | .127 | 37.940 |
| Mini-Mental State Examination\* | 8 | 712 | .006 | -.093-.105 | .9103 | 11.279 | .127 | 37.940 |
| Better functional ability | 5 | 574 | .163 | -.063-.373 | .1570 | 28.959 | <.001 | 86.187 |
| Depression | 7 | 625 | -.376 | -.489--.251 | <.0001 | 16.538 | .011 | 63.720 |
| Geriatric Depression Scale (all versions) | 5 | 466 | -.446 | -.608--.248 | <.0001 | 20.722 | <.001 | 80.697 |
| Neuropsychiatric symptoms/BPSD | 7 | 609 | -.419 | -.519--.308 | <.0001 | 13.330 | .038 | 54.990 |
| Neuropsychiatric Inventory | 5 | 375 | -.429 | -.550--.291 | <.0001 | 8.769 | .067 | 54.384 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 21m: Factors associated with proxy ratings of quality of life for people with dementia living in the community made by family carers only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age\* | 7 | 710 | .068 | -.073-.207 | .3436 | 20.293 | .002 | 70.433 |
| Female gender\* | 5 | 428 | .061 | -.035-.156 | .2148 | 1.637 | .802 | 0 |
| Higher scores on cognitive screening measures\* | 8 | 712 | .006 | -.093-.105 | .9103 | 11.279 | .127 | 37.940 |
| Mini-Mental State Examination\* | 8 | 712 | .006 | -.093-.105 | .9103 | 11.279 | .127 | 37.940 |
| Better functional ability\* | 5 | 574 | .163 | -.063-.373 | .1570 | 28.959 | <.001 | 86.187 |
| Depression | 6 | 548 | -.406 | -.521--.277 | <.0001 | 13.161 | .022 | 62.010 |
| Geriatric Depression Scale (all versions)\* | 5 | 466 | -.446 | -.608--.248 | <.0001 | 20.722 | <.001 | 80.697 |
| Neuropsychiatric symptoms/BPSD\* | 7 | 609 | -.419 | -.519--.308 | <.0001 | 13.330 | .038 | 54.990 |
| Neuropsychiatric Inventory\* | 5 | 375 | -.429 | -.550--.291 | <.0001 | 8.769 | .067 | 54.384 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 21n: Factors associated with proxy ratings of quality of life for people with dementia living in residential care settings – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 1418 | -.093 | -.227-.045 | .1875 | 36.520 | <.001 | 83.571 |
| Female gender | 7 | 1444 | .032 | -.020-.084 | .2246 | 1.759 | .941 | 0 |
| More advanced dementia\* | 6 | 1266 | -.306 | -.438--.161 | <.0001 | 34.496 | <.001 | 85.506 |
| Taking medication | 5 | 886 | -.120 | -.207--.030 | .0088 | 6.916 | .140 | 42.161 |
| Higher scores on cognitive screening measures | 6 | 834 | .260 | .176-.341 | <.0001 | 7.532 | .184 | 33.617 |
| Better functional ability | 7 | 1177 | .161 | .037-.281 | .0115 | 23.078 | .001 | 74.001 |
| Basic activities of daily living\* | 7 | 1177 | .161 | .037-.281 | .0115 | 23.078 | .001 | 74.001 |
| Basic activities of daily living measures excluding Barthel Index & Katz Index of Independence in Activities of Daily Living | 5 | 790 | .182 | .043-.314 | .0107 | 13.498 | .009 | 70.367 |
| Depression | 6 | 891 | -.267 | -.400--.124 | .0003 | 19.642 | .001 | 74.544 |
| Neuropsychiatric symptoms/BPSD | 7 | 1293 | -.271 | -.350--.188 | <.0001 | 13.079 | .042 | 54.126 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 21o: Factors associated with proxy ratings of quality of life for people with dementia living in residential care settings made by health care professionals only – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 5 | 989 | -.095 | -.290-.107 | .3569 | 34.171 | <.001 | 88.294 |
| Female gender | 5 | 1015 | .037 | -.025-.099 | .2417 | 1.664 | .797 | 0 |
| Taking medication\* | 5 | 886 | -.120 | -.207--.030 | .0088 | 6.916 | .140 | 42.161 |
| Depression | 5 | 583 | -.347 | -.417--.272 | <.0001 | 3.665 | .453 | 0 |
| Neuropsychiatric symptoms/BPSD | 5 | 1005 | -.295 | -.382--.203 | <.0001 | 8.874 | .064 | 54.926 |

Note: those asterisked are unchanged from previous analyses.

**Supplementary Table 22a: Factors associated with the difference between self-ratings and informant ratings made by family carers only of the quality of life of the person with dementia – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 9 | 1543 | -.046 | -.069-.046 | .0716 | .632 | 1.000 | 0 |
| Female gender | 9 | 1606 | .075 | .026-.124 | .0028 | 5.137 | .743 | 0 |
| Higher level of education\* | 7 | 1212 | .027 | -.056-.110 | .5198 | 10.832 | .094 | 44.606 |
| Higher scores on cognitive screening measures | 18 | 2415 | .126 | .069-.183 | <.0001 | 30.397 | .024 | 44.074 |
| Mini-Mental State Examination | 16 | 2186 | .124 | .060-.186 | .0001 | 28.605 | .018 | 47.561 |
| Better functional ability | 14 | 1944 | .211 | .130-.290 | <.0001 | 37.453 | <.001 | 65.290 |
| Basic activities of daily living | 8 | 1206 | .261 | .133-.381 | <.0001 | 27.266 | <.001 | 74.327 |
| Instrumental activities of daily living\* | 7 | 1019 | .099 | .037-.160 | .0018 | 1.227 | .976 | 0 |
| Lawton’s Instrumental Activities of Daily Living\* | 7 | 1019 | .099 | .037-.160 | .0018 | 1.227 | .976 | 0 |
| Depression | 8 | 709 | -.325 | -.470--.163 | .0001 | 32.779 | <.001 | 78.645 |
| Geriatric Depression Scale (all versions) | 6 | 422 | -.422 | -.599--.206 | .0003 | 26.203 | <.001 | 80.918 |
| Neuropsychiatric symptoms/BPSD | 12 | 1614 | -.227 | -.296--.156 | <.0001 | 20.396 | .040 | 46.067 |
| Neuropsychiatric Inventory | 11 | 1494 | -.221 | -.295--.145 | <.0001 | 19.188 | .038 | 47.883 |
| Being married\* | 6 | 668 | .075 | -.002-.151 | .0559 | 2.727 | .742 | 0 |
| Living alone | 7 | 1399 | -.061 | -.114--.009 | .0223 | 5.883 | .436 | 0 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 22b: Factors associated with the difference between self-ratings and informant ratings made by family carers only of the quality of life of the person with dementia – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age\* | 7 | 1397 | -.038 | -.090-.015 | .1629 | 3.621 | .728 | 0 |
| Female gender\* | 8 | 1538 | .072 | .022-.122 | .0050 | 6.524 | .480 | 0 |
| Burden or stress | 9 | 1672 | -.229 | -.296--.160 | <.0001 | 15.501 | .050 | 48.392 |
| Zarit Burden Interview | 7 | 1262 | -.258 | -.342--.171 | <.0001 | 14.043 | .029 | 57.273 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 22c: Factors associated with the difference between self-ratings and informant ratings of the quality of life of the person with dementia made using the Quality of Life-Alzheimer’s Disease (QoL-AD) – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 7 | 1144 | -.037 | -.095-.022 | .2172 | 1.239 | .975 | 0 |
| Female gender | 5 | 987 | .063 | .000-.125 | .0498 | 3.222 | .521 | 0 |
| Higher level of education\* | 6 | 1068 | .016 | -.079-.110 | .7457 | 10.078 | .073 | 50.389 |
| Higher scores on cognitive screening measures | 14 | 1695 | .086 | .036-.135 | .0007 | 13.477 | .412 | 3.540 |
| Mini-Mental State Examination | 13 | 1576 | .091 | .035-.145 | .0014 | 13.463 | .336 | 10.866 |
| Better functional ability | 12 | 1429 | .254 | .153-.350 | <.0001 | 34.572 | <.001 | 68.182 |
| Basic activities of daily living | 5 | 731 | .263 | .101-.411 | .0017 | 10.803 | .029 | 62.972 |
| Instrumental activities of daily living\* | 5 | 818 | .105 | .036-.173 | .0028 | .760 | .944 | 0 |
| Lawton’s Instrumental Activities of Daily Living\* | 5 | 818 | .105 | .036-.173 | .0028 | .760 | .944 | 0 |
| Depression | 6 | 511 | -.402 | -.584--.182 | .0006 | 31.243 | <.001 | 83.996 |
| Neuropsychiatric symptoms/BPSD | 11 | 1475 | -.234 | -.309--.155 | <.0001 | 20.272 | .027 | 50.670 |
| Neuropsychiatric Inventory | 10 | 1355 | -.227 | -.309--.142 | <.0001 | 19.115 | .024 | 52.917 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 22d: Factors associated with the difference between self-ratings and informant ratings of the quality of life of the person with dementia made using the Quality of Life-Alzheimer’s Disease (QoL-AD) – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Female gender\* | 6 | 1128 | .080 | .012-.147 | .0217 | 6.093 | .297 | 17.940 |
| Older age\* | 5 | 987 | .018 | -.045-.081 | .5771 | 3.457 | .484 | 0 |
| Burden or stress | 7 | 1262 | -.258 | -.342--.171 | <.0001 | 14.043 | .029 | 57.273 |
| Zarit Burden Interview | 8 | 1353 | -.248 | -.319--.174 | <.0001 | 12.557 | .084 | 44.253 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 22e: Factors associated with the difference between self-ratings and informant ratings of the quality of life of the person with dementia made using dementia-specific quality of life measures – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 8 | 1235 | -.046 | -.102-.011 | .1122 | 1.043 | .994 | 0 |
| Female gender | 6 | 1078 | .058 | -.002-.118 | .0584 | 2.758 | .737 | 0 |
| Higher level of education | 5 | 1068 | .018 | -.078-.113 | .7203 | 10.263 | .068 | 51.280 |
| Higher scores on cognitive screening measures | 17 | 1867 | .085 | .039-.131 | .0003 | 13.756 | .617 | 0 |
| Mini-Mental State Examination | 16 | 1748 | .086 | .039-.133 | .0004 | 13.740 | .545 | 0 |
| Better functional ability | 13 | 1520 | .239 | .144-.330 | <.0001 | 35.835 | <.001 | 66.513 |
| Basic activities of daily living | 6 | 822 | .218 | .082-.346 | .0019 | 12.141 | .033 | 58.819 |
| Instrumental activities of daily living | 6 | 909 | .106 | .041-.170 | .0015 | .767 | .979 | 0 |
| Lawton’s Instrumental Activities of Daily Living\* | 6 | 909 | .106 | .041-.170 | .0015 | .767 | .979 | 0 |
| Depression | 9 | 683 | -.293 | -.443--.127 | .0007 | 35.850 | <.001 | 77.685 |
| Geriatric Depression Scale (all versions) | 7 | 396 | -.374 | -.572--.135 | .0027 | 33.819 | <.001 | 82.259 |
| Neuropsychiatric symptoms/BPSD | 13 | 1556 | -.232 | -.303--.158 | <.0001 | 22.021 | .037 | 45.507 |
| Neuropsychiatric Inventory | 12 | 1436 | -.226 | -.302--.147 | <.0001 | 20.896 | .034 | 47.357 |
| Being married\* | 6 | 668 | .075 | -.002-.151 | .0559 | 2.727 | .742 | 0 |
| Living alone | 5 | 1014 | -.032 | -.094-.030 | .3118 | .078 | .999 | 0 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 22f: Factors associated with the difference between self-ratings and informant ratings of the quality of life of the person with dementia made using dementia-specific quality of life measures – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 1078 | -.038 | -.098-.022 | .2160 | 3.621 | .605 | 0 |
| Female gender | 7 | 1219 | .066 | .008-.124 | .0269 | 6.255 | .395 | 4.077 |
| Burden or stress | 10 | 1434 | -.259 | -.341--.174 | <.0001 | 21.812 | .009 | 58.738 |
| Zarit Burden Interview\* | 10 | 1434 | -.259 | -.341--.174 | <.0001 | 21.812 | .009 | 58.738 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 22g: Factors associated with the difference between self-ratings and informant ratings of the quality of life of the person with dementia made using health-related quality of life measures – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Higher scores on cognitive screening measures | 5 | 1192 | .208 | .077-.332 | .0020 | 17.420 | .002 | 77.038 |

**Supplementary Table 22h: Factors associated with the difference between self-ratings and informant ratings of the quality of life of people with Alzheimer’s disease – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 5 | 903 | -.040 | -.105-.026 | .2324 | .150 | .997 | 0 |
| Higher level of education | 5 | 903 | .060 | -.006-.125 | .0734 | .798 | .939 | 0 |
| Higher scores on cognitive screening measures | 13 | 1496 | .086 | .042-.144 | .0004 | 8.458 | .748 | 0 |
| Mini-Mental State Examination | 12 | 1386 | .082 | .029-.135 | .0026 | 6.163 | .862 | 0 |
| Better functional ability | 8 | 1150 | .161 | .067-.253 | .0008 | 14.404 | .044 | 51.401 |
| Instrumental activities of daily living | 6 | 928 | .097 | .032-.161 | .0033 | 1.203 | .945 | 0 |
| Lawton’s Instrumental Activities of Daily Living\* | 6 | 928 | .097 | .032-.161 | .0033 | 1.203 | .945 | 0 |
| Depression | 7 | 508 | -.326 | -.483--.149 | .0004 | 23.464 | .001 | 74.429 |
| Geriatric Depression Scale (all versions) | 6 | 386 | -.375 | -.552--.166 | .0007 | 21.049 | .001 | 76.246 |
| Neuropsychiatric symptoms/BPSD | 10 | 1241 | -.243 | -.335--.147 | <.0001 | 21.567 | .010 | 58.270 |
| Neuropsychiatric Inventory | 9 | 1121 | -.238 | -.340--.131 | <.0001 | 20.327 | .009 | 60.644 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 22i: Factors associated with the difference between self-ratings and informant ratings of the quality of life of people with Alzheimer’s disease – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Female gender | 5 | 963 | .078 | -.006-.162 | .0703 | 5.897 | .207 | 32.166 |
| Burden or stress | 7 | 1059 | -.287 | -.402--.164 | <.0001 | 20.777 | .002 | 71.122 |
| Zarit Burden Interview\* | 7 | 1059 | -.287 | -.402--.164 | <.0001 | 20.777 | .002 | 71.122 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 22j: Factors associated with the difference between self-ratings and informant ratings of the quality of life of people with dementia, excluding studies that focused specifically on people diagnosed with Alzheimer’s disease – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 1346 | -.043 | -.096-.011 | .1191 | 2.099 | .910 | 0 |
| Female gender | 7 | 1415 | .085 | .033-.137 | .0015 | 2.083 | .912 | 0 |
| Higher scores on cognitive screening measures | 10 | 1707 | .159 | .071-.244 | .0004 | 25.360 | .003 | 64.512 |
| Mini-Mental State Examination | 9 | 1588 | .170 | .073-.263 | .0006 | 24.883 | .002 | 67.850 |
| Better functional ability | 9 | 930 | .283 | .172-.387 | <.0001 | 21.198 | .007 | 62.260 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 22k: Factors associated with the difference between self-ratings and informant ratings of the quality of life of people with dementia living in the community – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 1275 | -.044 | -.099-.011 | .1204 | .366 | .996 | 0 |
| Female gender | 6 | 1275 | .051 | -.004-.106 | .0676 | 1.145 | .950 | 0 |
| Higher scores on cognitive screening measures | 11 | 1722 | .114 | .034-.192 | .0053 | 23.729 | .008 | 57.858 |
| Mini-Mental State Examination | 9 | 1493 | .106 | .013-.198 | .0259 | 21.590 | .006 | 62.946 |
| Better functional ability | 6 | 1305 | .146 | .085-.206 | <.0001 | 5.928 | .313 | 15.650 |
| Depression | 5 | 447 | -.167 | -.323--.003 | .0459 | 10.887 | .028 | 63.260 |
| Neuropsychiatric symptoms/BPSD | 6 | 986 | -.211 | -.270--.150 | <.0001 | 3.932 | .559 | 0 |
| Neuropsychiatric Inventory | 5 | 866 | -.198 | -.262--.133 | <.0001 | 2.711 | .607 | 0 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 22l: Factors associated with the difference between self-ratings and informant ratings of the quality of life of people with dementia living in the community – factors pertaining to the carer Factors associated with the difference between self- and informant-rated quality of life of person with dementia quality of life: community living only studies: carer factors**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 1275 | -.041 | -.096-.014 | .1466 | 3.460 | .629 | 0 |
| Female gender | 6 | 1275 | .053 | -.003-.107 | .0623 | 1.405 | .924 | 0 |
| Burden or stress | 8 | 1355 | -.205 | -.289--.118 | <.0001 | 15.132 | .034 | 53.739 |
| Zarit Burden Interview | 7 | 1036 | -.227 | -.327--.122 | <.0001 | 13.748 | .033 | 56.358 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 23a: Baseline factors associated with self-ratings of quality of life for the person with dementia made by the person with dementia at follow-up in longitudinal studies – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| More advanced dementia | 5 | 383 | -.078 | -.179-.025 | .1376 | .521 | .971 | 0 |
| Clinical Dementia Rating\* | 5 | 383 | -.078 | -.179-.025 | .1376 | .521 | .971 | 0 |
| Higher scores on cognitive screening measures | 6 | 572 | .050 | -.034-.132 | .2431 | 1.683 | .891 | 0 |
| Mini-Mental State Examination | 6 | 572 | .051 | -.032-.134 | .2266 | 1.617 | .899 | 0 |
| Better functional ability | 5 | 371 | .053 | -.069-.173 | .3941 | 5.239 | .264 | 23.643 |
| Neuropsychiatric symptoms/BPSD | 6 | 572 | -.111 | -.198--.022 | .0147 | 5.547 | .353 | 9.869 |
| Quality of life rating at baseline | 9 | 1040 | .243 | -.000-.459 | .0503 | 113.798 | <.001 | 92.970 |
| Quality of Life-Alzheimer’s Disease rating at baseline | 7 | 859 | .211 | -.099-.484 | .1806 | 107.747 | <.001 | 94.431 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 23b: Baseline factors associated with informant ratings of quality of life for the person with dementia made by the family carer at follow-up in longitudinal studies – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Quality of life rating at baseline | 6 | 949 | .157 | -.159-.444 | .3296 | 106.253 | <.001 | 95.294 |
| Quality of Life-Alzheimer’s Disease rating at baseline | 5 | 812 | .097 | -.307-.472 | .6458 | 118.082 | <.001 | 96.613 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 23c: Baseline factors associated with informant ratings of quality of life for the person with dementia made by health care professionals at follow-up in longitudinal studies – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Quality of life rating at baseline | 5 | 429 | .405 | .249-.541 | <.0001 | 10.235 | .037 | 60.918 |

**Supplementary Table 23d: Baseline factors associated with ratings of quality of life for the person with dementia made using the Quality of Life-Alzheimer’s Disease (QoL-AD) at follow-up in longitudinal studies – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 6 | 497 | -.079 | -.170-.013 | .0912 | 2.901 | .715 | 0 |
| Female gender | 5 | 480 | .112 | .016-.206 | .0221 | 4.152 | .386 | 3.659 |
| More advanced dementia\* | 6 | 561 | -.062 | -.147-.024 | .1600 | .879 | .972 | 0 |
| Clinical Dementia Rating\* | 5 | 439 | -.078 | -.175-.021 | .1227 | .459 | .977 | 0 |
| Higher scores on cognitive screening measures | 6 | 628 | .064 | -.017-.144 | .1228 | 2.891 | .717 | 0 |
| Mini-Mental State Examination | 6 | 628 | .065 | -.016-.146 | .1132 | 2.798 | .731 | 0 |
| Better functional ability\* | 5 | 371 | .115 | .012-.216 | .0287 | 2.867 | .580 | 0 |
| Neuropsychiatric symptoms/BPSD | 6 | 572 | -.112 | -.193--.029 | .0082 | 3.792 | .580 | 0 |
| Quality of life rating at baseline\* | 10 | 1352 | .233 | .022-.425 | .0309 | 125.859 | <.001 | 92.849 |
| Quality of Life-Alzheimer’s Disease rating at baseline\* | 10 | 1352 | .233 | .022-.425 | .0309 | 125.859 | <.001 | 92.849 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 23e: Baseline factors associated with ratings of quality of life for the person with dementia made using dementia-specific quality of life measures at follow-up in longitudinal studies – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age\* | 7 | 544 | -.079 | -.166-.009 | .0771 | 2.901 | .821 | 0 |
| Female gender\* | 6 | 527 | .112 | .023-.199 | .0138 | 4.176 | .524 | 0 |
| More advanced dementia\* | 6 | 561 | -.062 | -.147-.024 | .1600 | .879 | .972 | 0 |
| Clinical Dementia Rating\* | 5 | 439 | -.078 | -.175-.021 | .1227 | .459 | .977 | 0 |
| Higher scores on cognitive screening measures | 8 | 770 | .138 | .024-.248 | .0180 | 15.596 | .029 | 55.116 |
| Mini-Mental State Examination | 7 | 675 | .121 | -.003-.242 | .0554 | 13.562 | .035 | 55.758 |
| Better functional ability\* | 5 | 371 | .115 | .012-.216 | .0287 | 2.867 | .580 | 0 |
| Depression\* | 5 | 447 | -.144 | -.255--.029 | .0144 | 5.052 | .282 | 20.826 |
| Neuropsychiatric symptoms/BPSD\* | 7 | 619 | -.120 | -.199--.041 | .0031 | 4.361 | .628 | 0 |
| Quality of life rating at baseline | 14 | 1672 | .296 | .140-.437 | .0003 | 129.614 | <.001 | 89.970 |
| Quality of Life-Alzheimer’s Disease rating at baseline\* | 10 | 1352 | .233 | .022-.425 | .0309 | 125.859 | <.001 | 92.849 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 23f: Baseline factors associated with self-ratings of quality of life for the person with dementia made using dementia-specific quality of life measures at follow-up in longitudinal studies – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| More advanced dementia\* | 6 | 561 | -.062 | -.147-.024 | .1600 | .879 | .972 | 0 |
| Clinical Dementia Rating\* | 5 | 439 | -.078 | -.175-.021 | .1227 | .459 | .977 | 0 |
| Higher scores on cognitive screening measures | 6 | 572 | .050 | -.034-.132 | .2431 | 1.683 | .891 | 0 |
| Mini-Mental State Examination | 6 | 572 | .051 | -.032-.134 | .2266 | 1.167 | .899 | 0 |
| Better functional ability\* | 5 | 371 | .053 | -.069-.173 | .3941 | 5.239 | .264 | 23.643 |
| Neuropsychiatric symptoms/BPSD\* | 6 | 572 | -.111 | -.198--.022 | .0147 | 5.547 | .353 | 9.869 |
| Quality of life rating at baseline | 8 | 929 | .239 | -.034-.478 | .0849 | 107.995 | <.001 | 93.518 |
| Quality of Life-Alzheimer’s Disease rating at baseline\* | 7 | 859 | .211 | -.099-.484 | .1806 | 107.747 | <.001 | 94.431 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 23g: Baseline factors associated with informant ratings of quality of life for the person with dementia made by family carers using dementia-specific quality of life measures at follow-up in longitudinal studies – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Quality of life rating at baseline | 6 | 951 | .194 | -.151-.497 | .2691 | 128.606 | <.001 | 96.112 |
| Quality of Life-Alzheimer’s Disease rating at baseline\* | 5 | 812 | .097 | -.307-.472 | .6458 | 118.082 | <.001 | 96.613 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 23h: Baseline factors associated with ratings of quality of life for people with dementia, excluding studies that focused specifically on people diagnosed with Alzheimer’s disease at follow-up in longitudinal studies – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Female gender\* | 6 | 527 | .112 | .023-.199 | .0138 | 4.176 | .524 | 0 |
| More advanced dementia\* | 6 | 561 | -.062 | -.147-.024 | .1600 | .879 | .972 | 0 |
| Clinical Dementia Rating\* | 5 | 439 | -.078 | -.175-.021 | .1227 | .459 | .977 | 0 |
| Higher scores on cognitive screening measures | 7 | 694 | .147 | .008-.282 | .0390 | 17.798 | .007 | 66.289 |
| Mini-Mental State Examination | 7 | 694 | .148 | .009-.282 | .0367 | 17.580 | .007 | 65.870 |
| Depression\* | 5 | 447 | -.144 | -.255--.029 | .0144 | 5.052 | .282 | 20.826 |
| Neuropsychiatric symptoms/BPSD | 5 | 401 | -.115 | -.212--.015 | .0238 | 2.023 | .732 | 0 |
| Quality of life rating at baseline | 12 | 1455 | .314 | .202-.418 | <.0001 | 47.617 | <.001 | 76.899 |
| Quality of Life-Alzheimer’s Disease rating at baseline | 8 | 1128 | .307 | .142-.455 | .0004 | 48.904 | <.001 | 85.686 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 23i: Baseline factors associated with self-ratings of quality of life for people with dementia, excluding studies that focused specifically on people diagnosed with Alzheimer’s disease at follow-up in longitudinal studies – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Quality of life rating at baseline | 7 | 849 | .168 | -.148-.453 | .2977 | 109.614 | <.001 | 94.526 |
| Quality of Life-Alzheimer’s Disease rating at baseline | 6 | 737 | .165 | -.210-.498 | .3895 | 106.404 | <.001 | 95.301 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data.

**Supplementary Table 23j: Baseline factors associated with ratings of quality of life for people with dementia living in residential care settings at follow-up in longitudinal studies – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Quality of life rating at baseline | 6 | 965 | .286 | .103-.450 | .0025 | 35.782 | <.001 | 86.026 |

**Supplementary Table 24a: Moderating effect of age on the association between self-ratings of quality of life and factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Point estimate** | **Standard error** | **95% CI** | **Z** | **p** |
| Depression | 67 | -.00325 | .00532 | -.01368 to .00719 | -.60974 | .54203 |

**Supplementary Table 24b: Moderating effect of MMSE score on the association between self-ratings of quality of life and factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Point estimate** | **Standard error** | **95% CI** | **Z** | **p** |
| Depression | 57 | -.00306 | .00583 | -.01448 to .00836 | -.52495 | .59962 |

**Supplementary Table 25a: Moderating effect of age on the association between informant ratings of quality of life and factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Point estimate** | **Standard error** | **95% CI** | **Z** | **p** |
| Functional ability | 87 | -.00491 | .00574 | -.01616 to .00634 | -.85482 | .39265 |
| Neuropsychiatric symptoms/BPSD | 76 | -.01372 | .00591 | -.02530 to -.00213 | -2.32040 | .02032 |
| Global Deterioration indices | 14 | -.01558 | .01869 | -.05222 to .02106 | -.83361 | .40450 |
| Depression | 67 | -.00325 | .00532 | -.01368 to .00719 | -.60974 | .54203 |

**Supplementary Table 25b: Moderating effect of age on the association between informant ratings of quality of life and factors pertaining to the carer**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Point estimate** | **Standard error** | **95% CI** | **Z** | **p** |
| Burden/stress | 25 | -.01874 | .01312 | -.04446 to -.00698 | -1.42792 | .15332 |
| Distress (Neuropsychiatric Inventory) | 10 | .00074 | .01080 | -.02043 to .02191 | .06820 | .94563 |

**Supplementary Table 25c: Moderating effect of MMSE score on the association between informant ratings of quality of life and factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Point estimate** | **Standard error** | **95% CI** | **Z** | **p** |
| Functional ability | 67 | -.00631 | .00477 | -.01565 to .00304 | -1.32300 | .18583 |
| Neuropsychiatric symptoms/BPSD | 61 | -.00084 | .00597 | -.01253 to .01085 | -.14098 | .88789 |
| Global Deterioration indices\* | 6 |  |  |  |  |  |
| Depression | 57 | -.00306 | .00583 | -.01448 to .00836 | -.52495 | .59962 |

Note: those asterisked are where moderator analysis was not conducted as there were data available for less than 10 studies

**Supplementary Table 25d: Moderating effect of MMSE score on the association between informant ratings of quality of life and factors pertaining to the carer**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Point estimate** | **Standard error** | **95% CI** | **Z** | **p** |
| Burden/stress | 18 | .00319 | .01440 | -.02502 to .03141 | .22185 | .82443 |
| Distress (Neuropsychiatric Inventory)\* | 8 |  |  |  |  |  |

Note: those asterisked are where moderator analysis was not conducted as there were data available for less than 10 studies

**Supplementary Table 26a: Sensitivity analyses removing the inserted correlation of zero for non-significant p values. Factors associated with self-ratings of quality of life by the person with dementia: factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 52 | 7671 | -.024 | .005--.053 | .1042 | 74.548 | .017 | 31.588 |
| Female gender | 39 | 5709 | .009 | -.022-.039 | .5813 | 49.031 | .108 | 22.498 |
| White ethnicity | 10 | 1562 | .199 | .137-.259 | <.0001 | 13.734 | .132 | 34.471 |
| Higher income | 7 | 1002 | .166 | -.008-.331 | .0620 | 45.738 | <.001 | 86.882 |
| Higher level of education | 40 | 4841 | .068 | .030-.106 | .0005 | 63.786 | .007 | 38.858 |
| Underweight | 7 | 1052 | -.004 | .125--.133 | .9542 | 25.777 | <.001 | 76.724 |
| Alzheimer’s (vs. other dementia subtypes) | 9 | 1552 | .148 | -.030-.316 | .1028 | 96.047 | <.001 | 91.671 |
| Longer disease duration | 9 | 1470 | -.008 | .066--.083 | .8246 | 13.668 | .091 | 41.469 |
| More advanced dementia | 24 | 3541 | -.098 | -.048--.148 | .0001 | 48.246 | .002 | 52.328 |
| Global Deterioration Scale\* | 6 | 886 | -.103 | -.177--.029 | .0067 | 5.897 | .316 | 15.207 |
| Clinical Dementia Rating | 15 | 2177 | -.091 | -.016--.165 | .0180 | 40.310 | <.001 | 65.270 |
| Higher scores on cognitive screening measures | 88 | 13102 | .096 | .065-.127 | <.0001 | 229.036 | <.001 | 62.015 |
| Mini-Mental State Examination | 80 | 11698 | .090 | .057-.123 | <.0001 | 211.413 | <.001 | 62.632 |
| Alzheimer's Disease Assessment Scale-Cognitive Subscale\* | 5 | 3095 | .066 | .030-.100 | .0003 | 3.239 | .519 | 0 |
| Taking medication | 19 | 4606 | -.142 | -.192--.092 | <.0001 | 42.001 | .001 | 57.143 |
| Acetylcholinesterase inhibitors | 5 | 968 | -.135 | -.207--.061 | .0004 | 4.714 | .318 | 15.138 |
| Polypharmacy | 8 | 1396 | -.151 | -.203--.099 | <.0001 | 1.392 | .986 | 0 |
| Psychotropic drugs | 9 | 2519 | -.159 | -.251--.064 | .0011 | 27.124 | .001 | 70.506 |
| Longer duration of care home stay | 7 | 665 | -.102 | -.026--.178 | .0091 | 5.420 | .491 | 0 |
| Better functional ability | 76 | 12784 | .182 | .148-.216 | <.0001 | 252.425 | <.001 | 70.288 |
| Alzheimer's Disease Co-operative Study-Activities of Daily Living Inventory | 3 | 581 | .152 | -.069-.235 | .2773 | 22.156 | <.001 | 81.946 |
| Disability Assessment for Dementia | 3 | 581 | .152 | -.132-.414 | .2936 | 20.451 | <.001 | 90.221 |
| Basic activities of daily living | 48 | 8431 | .228 | .183-.272 | <.0001 | 173.193 | <.001 | 72.863 |
| Barthel Index | 16 | 2365 | .210 | .105-.311 | .0001 | 95.399 | <.001 | 84.277 |
| Katz Index of Independence in Activities of Daily Living | 11 | 1338 | .225 | .127-.319 | <.0001 | 26.257 | .003 | 61.915 |
| Physical Self-Maintenance Scale\* | 6 | 703 | .216 | .132-.297 | <.0001 | 6.403 | .269 | 21.917 |
| Basic activities of daily living measures excluding Barthel Index, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale | 18 | 4353 | .233 | .165-.298 | <.0001 | 58.459 | <.001 | 70.920 |
| Instrumental activities of daily living\* | 25 | 3330 | .148 | .087-.208 | <.0001 | 65.771 | <.001 | 63.510 |
| Functional Activities Questionnaire\* | 5 | 398 | .176 | .077-.271 | .0005 | 2.319 | .678 | 0 |
| Lawton’s Instrumental Activities of Daily Living\* | 13 | 1660 | .115 | .059-.170 | <.0001 | 14.161 | .291 | 15.259 |
| Instrumental activities of daily living measures excluding Lawton’s Instrumental Activities of Daily Living & Functional Activities Questionnaire\* | 8 | 1372 | .208 | .059-.349 | .0066 | 50.192 | <.001 | 86.054 |
| Presence of unmet needs\* | 5 | 838 | -.204 | -.305--.100 | .0002 | 9.273 | .055 | 56.866 |
| More awareness\* | 10 | 1285 | .145 | .090-.198 | <.0001 | 7.769 | .558 | 0 |
| Better self-rated memory functioning | 8 | 1320 | .035 | -.019-.089 | .2084 | 6.239 | .512 | 0 |
| Depression | 79 | 11394 | -.321 | -.280--.361 | <.0001 | 386.517 | <.001 | 79.820 |
| Cornell Scale for Depression in Dementia\* | 27 | 5537 | -.245 | -.300--.189 | <.0001 | 102.956 | <.001 | 74.746 |
| Geriatric Depression Scale (all versions) | 27 | 2787 | -.455 | -.359--.541 | <.0001 | 218.578 | <.001 | 88.105 |
| Geriatric Depression Scale-15 | 15 | 1605 | -.524 | -.392--.635 | <.0001 | 150.171 | <.001 | 90.677 |
| Geriatric Depression Scale-30\* | 11 | 1079 | -.320 | -.397--.240 | <.0001 | 15.873 | .103 | 36.999 |
| Neuropsychiatric Inventory-Depression\* | 12 | 1855 | -.262 | -.363--.154 | <.0001 | 55.863 | <.001 | 80.309 |
| Depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression\* | 28 | 2802 | -.332 | -.401--.259 | <.0001 | 109.001 | <.001 | 75.229 |
| Anxiety | 20 | 2479 | -.255 | -.174--.333 | <.0001 | 76.351 | <.001 | 75.115 |
| Neuropsychiatric Inventory-Anxiety | 8 | 970 | -.094 | -.031--.157 | .0037 | 6.022 | .537 | 0 |
| Rating of Anxiety in Dementia\* | 6 | 925 | -.328 | -.462--.180 | <.0001 | 21.077 | .001 | 76.278 |
| Anxiety measures excluding Rating of Anxiety in Dementia & Neuropsychiatric Inventory-Anxiety\* | 8 | 872 | -.351 | -.482--.204 | <.0001 | 35.812 | <.001 | 80.453 |
| Neuropsychiatric symptoms/BPSD | 53 | 9200 | -.119 | -.097--.141 | <.0001 | 55.255 | .353 | 5.892 |
| Neuropsychiatric Inventory | 39 | 7681 | -.118 | -.092--.144 | <.0001 | 42.768 | .274 | 11.149 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory | 16 | 1605 | -.131 | -.082--.180 | <.0001 | 12.231 | .661 | 0 |
| Pain\* | 10 | 2720 | -.157 | -.236--.077 | .0001 | 24.305 | .004 | 62.971 |
| Better self-rated health | 11 | 1702 | .269 | .167-.366 | <.0001 | 44.359 | <.001 | 77.457 |
| Presence of co-morbid conditions | 29 | 3573 | -.228 | -.173--.282 | <.0001 | 73.744 | <.001 | 62.031 |
| Better quality of relationship with carer\* | 6 | 802 | .384 | .148-.579 | .0019 | 62.659 | <.001 | 92.020 |
| Cared for by spouse (vs. other carer type) | 7 | 1629 | .137 | .072-.201 | <.0001 | 9.840 | .132 | 39.025 |
| Being married | 19 | 3216 | .099 | .065-.134 | <.0001 | 14.866 | .671 | 0 |
| Living alone | 7 | 1449 | -.160 | -.012--.301 | .0342 | 45.751 | <.001 | 86.885 |
| Greater social engagement\* | 11 | 1035 | .314 | .121-.483 | .0017 | 94.157 | <.001 | 89.379 |
| Presence of religious beliefs/spirituality\* | 8 | 641 | .352 | .120-.547 | .0035 | 60.621 | <.001 | 88.453 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 26b: Sensitivity analyses removing the inserted correlation of zero for non-significant p values. Factors associated with self-ratings of quality of life by the person with dementia: factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 9 | 1662 | -.067 | -.002--.133 | .0441 | 11.922 | .155 | 32.899 |
| Female gender | 10 | 1562 | .021 | -.049-.090 | .5631 | 15.283 | .083 | 41.113 |
| Higher level of education | 10 | 1621 | .097 | .036-.158 | .0020 | 12.622 | .180 | 28.697 |
| Depression | 9 | 1008 | -.148 | -.021--.270 | .0227 | 31.182 | <.001 | 74.344 |
| Center for Epidemiologic Studies Depression Scale\* | 5 | 564 | -.118 | -.244-.011 | .0738 | 9.181 | .057 | 56.432 |
| Distress at NPS symptoms\* | 9 | 1089 | -.140 | -.202--.078 | .0001 | 8.536 | .383 | 6.284 |
| Burden or stress | 19 | 2713 | -.153 | -.091--.214 | <.0001 | 41.462 | .001 | 56.587 |
| Zarit Burden Interview | 14 | 1691 | -.141 | -.055--.226 | .0015 | 35.267 | .001 | 63.138 |
| Burden or stress measures excluding Zarit Burden Interview\* | 5 | 1032 | -.166 | -.225--.105 | <.0001 | 3.010 | .556 | 0 |
| Poorer mental health (GHQ)\* | 5 | 702 | -.156 | -.275--.034 | .0126 | 6.753 | .150 | 40.767 |
| Carer quality of life (self-rated) | 6 | 667 | .277 | .114-.424 | .0010 | 21.397 | .001 | 76.632 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 27a: Sensitivity analyses removing the inserted correlation of zero for non-significant p values. Factors associated with informant ratings of quality of life: factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 51 | 10314 | -.030 | .002--.063 | .0626 | 119.267 | <.001 | 58.077 |
| Female gender | 51 | 10743 | .030 | -.001-.061 | .0616 | 119.932 | <.001 | 57.476 |
| White ethnicity\* | 7 | 1486 | .101 | .042-.159 | .0008 | 7.612 | .268 | 21.180 |
| Higher level of education | 27 | 4964 | .045 | .016-.074 | .0024 | 27.401 | .389 | 5.112 |
| Underweight | 4 | 1229 | -.120 | -.196--.042 | .0025 | 5.634 | .131 | 46.756 |
| Alzheimer’s (vs. other dementia subtypes) | 7 | 2214 | .069 | -.031-.167 | .1774 | 26.825 | <.001 | 77.633 |
| Longer disease duration | 10 | 1530 | -.076 | -.026--.126 | .0032 | 7.018 | .635 | 0 |
| More advanced dementia | 39 | 7949 | -.307 | -.228--.381 | <.0001 | 518.263 | <.001 | 92.668 |
| Clinical Dementia Rating | 24 | 5735 | -.278 | -.172--.378 | <.0001 | 394.685 | <.001 | 94.173 |
| Global Deterioration Scale | 6 | 887 | -.303 | -.218--.384 | <.0001 | 9.145 | .103 | 45.328 |
| Advanced dementia measures excluding Clinical Dementia Rating & Global Deterioration Scale\* | 9 | 1327 | -.388 | -.535--.216 | <.0001 | 86.493 | <.001 | 90.751 |
| Higher scores on cognitive screening measures | 81 | 14207 | .193 | .157-.230 | <.0001 | 358.994 | <.001 | 77.716 |
| Dementia Rating Scale | 4 | 527 | .351 | .173-.507 | .0002 | 14.162 | .003 | 78.817 |
| Mini-Mental State Examination | 72 | 12533 | .182 | .143-.221 | <.0001 | 315.903 | <.001 | 77.525 |
| Cognitive screening measures excluding Dementia Rating Scale & Mini-Mental State Examination | 12 | 4547 | .216 | .128-.300 | <.0001 | 75.165 | <.001 | 85.366 |
| Taking medication | 19 | 5401 | .101 | .058-.143 | <.0001 | 36.547 | .006 | 50.748 |
| Acetylcholinesterase inhibitors | 6 | 895 | .161 | .096-.225 | <.0001 | 4.749 | .447 | 0 |
| Polypharmacy\* | 9 | 1834 | -.060 | -.105--.014 | .0112 | 6.754 | .563 | 0 |
| Psychotropic drugs | 11 | 3649 | .128 | .057-.198 | .0004 | 35.279 | <.001 | 71.655 |
| Antipsychotic | 5 | 1244 | .191 | .085-.293 | .0005 | 11.304 | .023 | 64.615 |
| Antidepressants | 5 | 1060 | .125 | .005-.241 | .0414 | 10.512 | .033 | 61.949 |
| Anxiolytics | 4 | 960 | .105 | -.067-.271 | .2317 | 13.673 | .003 | 78.060 |
| Longer duration of care home stay | 11 | 2178 | -.114 | -.054--.173 | .0002 | 16.974 | .075 | 41.085 |
| Degree to which residential care is person-centred | 6 | 1815 | .167 | .063-.266 | .0016 | 13.219 | .021 | 62.176 |
| Community dwelling (vs. residential care)\* | 5 | 1011 | .123 | .062-.184 | .0001 | 3.398 | .494 | 0 |
| Special dementia unit (vs. other residential facility)\* | 5 | 2366 | .114 | .069-.158 | <.0001 | 4.753 | .314 | 15.838 |
| Better functional ability\* | 87 | 18707 | .337 | .292-.380 | <.0001 | 893.737 | <.001 | 90.377 |
| Alzheimer's Disease Co-operative Study-Activities of Daily Living Inventory\* | 6 | 1264 | .346 | .223-.458 | <.0001 | 25.967 | <.001 | 80.745 |
| Bristol Activities of Daily Living Scale\* | 5 | 859 | .450 | .393-.504 | <.0001 | 4.094 | .393 | 2.296 |
| Disability Assessment for Dementia\* | 6 | 3206 | .249 | .110-.378 | .0005 | 45.745 | <.001 | 89.070 |
| Basic activities of daily living\* | 61 | 13149 | .371 | .317-.423 | <.0001 | 695.854 | <.001 | 91.378 |
| Barthel Index\* | 19 | 3429 | .484 | .372-.583 | <.0001 | 268.501 | <.001 | 93.296 |
| Dependence Scale\* | 7 | 3523 | .328 | .154-.483 | .0003 | 123.388 | <.001 | 95.137 |
| Katz Index of Independence in Activities of Daily Living\* | 16 | 2991 | .300 | .247-.354 | <.0001 | 31.816 | .007 | 52.854 |
| Physical Self-Maintenance Scale\* | 9 | 1494 | .333 | .265-.398 | <.0001 | 13.285 | .102 | 39.780 |
| Basic activities of daily living measures excluding Barthel Index, Dependence Scale, Katz Index of Independence in Activities of Daily Living & Physical Self-Maintenance Scale\* | 11 | 1859 | .300 | .208-.386 | <.0001 | 40.364 | <.001 | 75.225 |
| Instrumental activities of daily living\* | 24 | 3234 | .351 | .270-.428 | <.0001 | 134.793 | <.001 | 82.937 |
| Lawton’s Instrumental Activities of Daily Living\* | 15 | 2306 | .303 | .210-.390 | <.0001 | 72.120 | <.001 | 80.588 |
| Instrumental activities of daily living measures excluding Lawton’s Instrumental Activities of Daily Living\* | 10 | 1039 | .458 | .382-.528 | <.0001 | 16.148 | .064 | 44.267 |
| More awareness\* | 5 | 557 | .275 | .037-.484 | .0241 | 31.084 | <.001 | 87.132 |
| Better self-rated memory functioning\* | 8 | 1185 | .213 | .054-.363 | .0092 | 47.334 | <.001 | 85.211 |
| Depression | 68 | 12382 | -.307 | -.262--.351 | <.0001 | 456.872 | <.001 | 85.335 |
| Cornell Scale for Depression in Dementia\* | 28 | 6671 | -.339 | -.396--.280 | <.0001 | 171.626 | <.001 | 84.268 |
| Geriatric Depression Scale (all versions) | 18 | 1919 | -.268 | -.180--.352 | <.0001 | 62.428 | <.001 | 72.769 |
| Geriatric Depression Scale-30\* | 10 | 1082 | -.289 | -.414--.154 | <.0001 | 40.764 | <.001 | 77.922 |
| Geriatric Depression Scale-15 | 7 | 803 | -.229 | -.104--.347 | .0004 | 18.424 | .005 | 67.434 |
| Neuropsychiatric Inventory-Depression\* | 12 | 2223 | -.263 | -.396--.118 | .0004 | 117.702 | <.001 | 90.654 |
| Other depression measures excluding Geriatric Depression Scale, Cornell Scale for Depression in Dementia & Neuropsychiatric Inventory-Depression\* | 19 | 2503 | -.309 | -.392--.221 | <.0001 | 93.689 | <.001 | 80.787 |
| Anxiety\* | 18 | 3143 | -.148 | -.189--.107 | <.0001 | 20.328 | .258 | 16.371 |
| Neuropsychiatric Inventory-Anxiety\* | 12 | 2128 | -.151 | -.209--.092 | <.0001 | 16.069 | .139 | 31.545 |
| Anxiety measures excluding Neuropsychiatric Inventory-Anxiety\* | 7 | 1201 | -.163 | -.235--.089 | <.0001 | 8.765 | .187 | 31.546 |
| Neuropsychiatric symptoms/BPSD | 74 | 14595 | -.339 | -.295--.381 | <.0001 | 564.243 | <.001 | 87.062 |
| Cohen-Mansfield Agitation Inventory\* | 9 | 1332 | -.150 | -.213--.085 | <.0001 | 10.839 | .211 | 26.191 |
| Neuropsychiatric Inventory | 48 | 10355 | -.352 | -.296--.406 | <.0001 | 427.307 | <.001 | 89.001 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory & Cohen-Mansfield Agitation Inventory\* | 23 | 3685 | -.353 | -.417--.286 | <.0001 | 107.094 | <.001 | 79.457 |
| Pain\* | 13 | 4048 | -.203 | -.307--.095 | .0003 | 124.860 | <.001 | 90.389 |
| Better self-rated health\* | 8 | 1826 | .198 | .131-.263 | <.0001 | 12.123 | .097 | 42.260 |
| Presence of co-morbid conditions | 26 | 5188 | -.104 | -.064--.143 | <.0001 | 45.393 | .008 | 44.925 |
| Cared for by spouse (vs. other carer type) | 9 | 1613 | .137 | .081-.193 | <.0001 | 9.920 | .271 | 19.351 |
| Being married | 17 | 3552 | .105 | .060-.149 | <.0001 | 26.545 | .047 | 39.724 |
| Living alone | 11 | 1709 | -.170 | -.123--.216 | <.0001 | 6.506 | .771 | 0 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 27b: Sensitivity analyses removing the inserted correlation of zero for non-significant p values. Factors associated with informant ratings of quality of life: factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 13 | 2239 | -.043 | .022--.108 | .1933 | 23.940 | .021 | 49.874 |
| Female gender | 12 | 2364 | .055 | -.005-.116 | .0743 | 20.183 | .043 | 45.497 |
| Higher level of education\* | 12 | 2313 | .084 | .035-.132 | .0007 | 13.597 | .256 | 19.098 |
| More time spent caring (residential care only)\* | 6 | 772 | -.159 | -.253--.061 | .0016 | 9.538 | .089 | 47.578 |
| More time spent caring (community only) | 4 | 520 | -.179 | -.016--.332 | .0317 | 9.410 | .024 | 68.119 |
| Depression\* | 14 | 2694 | -.255 | -.338--.169 | <.0001 | 64.440 | <.001 | 79.826 |
| Center for Epidemiologic Studies Depression Scale\* | 6 | 905 | -.299 | -.458--.122 | .0012 | 32.272 | <.001 | 84.507 |
| Geriatric Depression Scale (all versions)\* | 5 | 591 | -.362 | -.496--.211 | <.0001 | 14.617 | .006 | 72.634 |
| Depression measures excluding Geriatric Depression Scale & Center for Epidemiologic Studies Depression Scale\* | 6 | 1449 | -.202 | -.313--.085 | .0008 | 22.218 | <.001 | 77.496 |
| Burden or stress\* | 25 | 4460 | -.324 | -.398--.247 | <.0001 | 180.102 | <.001 | 86.674 |
| Zarit Burden Interview\* | 18 | 3284 | -.345 | -.435--.248 | <.0001 | 148.814 | <.001 | 88.576 |
| Burden or stress measures excluding Zarit Burden Interview\* | 8 | 1247 | -.276 | -.391--.152 | <.0001 | 32.129 | <.001 | 78.213 |
| Distress at NPS symptoms\* | 10 | 1665 | -.320 | -.379--.258 | <.0001 | 15.219 | .085 | 40.863 |
| Poorer mental health (GHQ)\* | 6 | 715 | -.242 | -.311--.170 | <.0001 | 3.990 | .551 | 0 |
| Carer quality of life (self-rated)\* | 8 | 1509 | .314 | .212-.410 | <.0001 | 28.246 | <.001 | 75.218 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 28a: Sensitivity analyses removing the inserted correlation of zero for non-significant p values. Factors associated with proxy ratings of quality of life: factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 13 | 1934 | -.017 | .099--.132 | .7735 | 70.895 | <.001 | 83.073 |
| Female gender | 10 | 1378 | -.004 | -.058-.049 | .8731 | 6.380 | .701 | 0 |
| More advanced dementia\* | 8 | 1421 | -.302 | -.413--.183 | <.0001 | 35.674 | <.001 | 80.378 |
| Higher scores on cognitive screening measures | 15 | 1788 | .116 | .023-.207 | .0147 | 48.959 | <.001 | 71.405 |
| Mini-Mental State Examination | 12 | 1367 | .072 | -.033-.175 | .1784 | 35.776 | <.001 | 69.253 |
| Taking medication | 6 | 966 | -.142 | -.067--.215 | .0002 | 6.745 | .240 | 25.866 |
| Better functional ability | 13 | 1975 | .186 | .089-.279 | .0002 | 52.252 | <.001 | 77.035 |
| Basic activities of daily living | 11 | 1699 | .167 | .067-.264 | .0012 | 38.486 | <.001 | 74.017 |
| Basic activities of daily living measures excluding Barthel Index & Katz Index of Independence in Activities of Daily Living | 8 | 1135 | .228 | .126-.325 | <.0001 | 18.565 | .010 | 62.269 |
| Depression\* | 13 | 1651 | -.317 | -.409--.219 | <.0001 | 47.495 | <.001 | 74.734 |
| Cornell Scale for Depression in Dementia\* | 5 | 811 | -.200 | -.361--.027 | .0235 | 19.089 | .001 | 79.046 |
| Geriatric Depression Scale\* | 5 | 466 | -.446 | -.608--.248 | <.0001 | 20.722 | <.001 | 80.697 |
| Neuropsychiatric symptoms/BPSD\* | 17 | 2559 | -.316 | -.373--.257 | <.0001 | 37.956 | .002 | 57.845 |
| Neuropsychiatric Inventory\* | 12 | 1645 | -.315 | -.387--.238 | <.0001 | 28.633 | .003 | 61.582 |
| Neuropsychiatric symptom measures excluding Neuropsychiatric Inventory\* | 6 | 1120 | -.315 | -.396--.228 | <.0001 | 10.134 | .072 | 50.659 |
| Presence of co-morbid conditions\* | 6 | 873 | -.121 | -.186--.054 | .0004 | 3.383 | .641 | 0 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 28b: Sensitivity analyses removing the inserted correlation of zero for non-significant p values. Factors associated with proxy ratings of quality of life: factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 5 | 412 | -.017 | -.160-.126 | .8173 | 7.963 | .093 | 49.768 |

**Supplementary Table 29a: Sensitivity analyses removing the inserted correlation of zero for non-significant p values. Factors associated with the difference between self-ratings and informant-ratings of the quality of life of the person with dementia – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age\* | 12 | 2249 | -.042 | -.083--.000 | .0497 | 2.254 | .997 | 0 |
| Female gender\* | 11 | 2237 | .007 | -.052-.066 | .8093 | 16.622 | .083 | 39.840 |
| Higher level of education\* | 7 | 1212 | .027 | -.056-.110 | .5198 | 10.832 | .094 | 44.606 |
| Higher scores on cognitive screening measures\* | 23 | 3203 | .128 | .079-.175 | <.0001 | 35.229 | .037 | 37.552 |
| Mini-Mental State Examination\* | 21 | 2974 | .126 | .074-.177 | <.0001 | 33.508 | .030 | 40.312 |
| Better functional ability\* | 17 | 2080 | .221 | .147-.292 | <.0001 | 40.001 | .001 | 60.011 |
| Basic activities of daily living\* | 8 | 1207 | .204 | .115-.291 | <.0001 | 12.960 | .073 | 45.988 |
| Instrumental activities of daily living\* | 7 | 1019 | .099 | .037-.160 | .0018 | 1.227 | .976 | 0 |
| Lawton’s Instrumental Activities of Daily Living\* | 7 | 1019 | .099 | .037-.160 | .0018 | 1.227 | .976 | 0 |
| Depression\* | 11 | 1354 | -.277 | -.397--.148 | <.0001 | 46.807 | <.001 | 78.635 |
| Geriatric Depression Scale (all versions)\* | 9 | 1067 | -.337 | -.486--.168 | .0002 | 47.848 | <.001 | 83.281 |
| Neuropsychiatric symptoms/BPSD\* | 14 | 1700 | -.224 | -.289--.157 | <.0001 | 22.251 | .052 | 41.576 |
| Neuropsychiatric Inventory\* | 13 | 1580 | -.218 | -.287--.147 | <.0001 | 21.047 | .050 | 42.984 |
| Presence of co-morbid conditions\* | 5 | 467 | -.131 | -.311-.058 | .1739 | 15.201 | .004 | 73.686 |
| Being married\* | 6 | 668 | .075 | -.002-.151 | .0559 | 2.727 | .742 | 0 |
| Living alone\* | 7 | 1402 | -.061 | -.113--.008 | .0234 | 5.335 | .502 | 0 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 29b: Sensitivity analyses removing the inserted correlation of zero for non-significant p values. Factors associated with the difference between self-ratings and informant-ratings of the quality of life of the person with dementia – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age\* | 7 | 1397 | -.038 | -.090-.015 | .1629 | 3.621 | .728 | 0 |
| Female gender\* | 8 | 1538 | .034 | -.036-.104 | .3398 | 11.970 | .102 | 41.519 |
| Burden or stress\* | 11 | 1753 | -.242 | -.317--.163 | <.0001 | 25.123 | .005 | 60.196 |
| Zarit Burden Interview\* | 10 | 1434 | -.259 | -.341--.174 | <.0001 | 21.812 | .009 | 58.738 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 30: Sensitivity analyses removing the inserted correlation of zero for non-significant p values. Baseline factors associated with ratings of quality of life for the person with dementia at follow-up in longitudinal studies – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Older age | 5 | 390 | -.096 | .005--.195 | .0616 | 2.913 | .573 | 0 |
| Female gender | 6 | 457 | -.157 | -.316-.012 | .0682 | 13.744 | .017 | 63.621 |
| More advanced dementia | 5 | 529 | -.066 | -.154-.023 | .1480 | .760 | .944 | 0 |
| Clinical Dementia Rating | 4 | 407 | -.084 | -.184-.019 | .1088 | .270 | .966 | 0 |
| Higher scores on cognitive screening measures | 8 | 853 | .171 | .056-.281 | .0037 | 18.486 | .010 | 62.134 |
| Mini-Mental State Examination | 8 | 853 | .172 | .058-.281 | .0033 | 18.222 | .011 | 61.586 |
| Better functional ability | 4 | 339 | .126 | .018-.230 | .0225 | 2.443 | .486 | 0 |
| Depression\* | 5 | 447 | -.144 | -.255--.029 | .0144 | 5.052 | .282 | 20.826 |
| Neuropsychiatric symptoms/BPSD | 6 | 587 | -.127 | -.045--.206 | .0024 | 3.914 | .564 | 0 |
| Quality of life rating at baseline | 15 | 1782 | .265 | .112-.406 | .0008 | 141.101 | <.001 | 90.078 |
| Quality of Life-Alzheimer’s Disease rating at baseline | 10 | 1352 | .210 | -.021-.420 | .0743 | 149.171 | <.001 | 93.967 |

Note: where enough data existed individual measures were analysed separately. This analysis is included indented under the relevant factor label. The overall factor includes this and other relevant data. Those asterisked are unchanged from previous analyses.

**Supplementary Table 31: Effect sizes after poor quality articles were removed from the analysis for self-ratings of quality of life by the person with dementia – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Depression | 78 | 11200 | .315 | .275-.355 | <.0001 | 362.847 | <.001 | 78.779 |
| Anxiety | 20 | 2956 | .211 | .135-.285 | <.0001 | 76.021 | <.001 | 75.007 |
| Functional ability | 78 | 12848 | .172 | .138-.206 | <.0001 | 262.571 | <.001 | 70.675 |
| Neuropsychiatric symptoms/BPSD | 55 | 9250 | .108 | .084-.132 | <.0001 | 63.012 | .188 | 14.302 |
| Dementia diagnostic category | 8 | 1233 | .097 | .029-.165 | .0053 | 9.846 | <.001 | 28.903 |
| Cognitive screening measures | 92 | 13447 | .081 | .053-.108 | <.0001 | 193.861 | <.001 | 53.059 |
| Self-rated memory functioning | 7 | 1141 | .038 | -.023-.098 | .2204 | 6.225 | .398 | 3.619 |
| Age | 55 | 7900 | .026 | .004-.048 | .0215 | 48.970 | .668 | 0 |
| Disease duration | 11 | 1739 | .011 | -.049-.071 | .7169 | 13.827 | .181 | 27.676 |

**Supplementary Table 32a: Effect sizes after poor quality articles were removed from the analysis for informant ratings of quality of life for the person with dementia – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Functional ability | 86 | 17118 | .348 | .303-.391 | <.0001 | 839.025 | <.001 | 89.869 |
| Global Deterioration indices | 13 | 2073 | .322 | .189-.443 | <.0001 | 121.704 | <.001 | 90.140 |
| Depression | 66 | 12199 | .302 | .256-.347 | <.0001 | 456.610 | <.001 | 85.765 |
| Pain | 12 | 3654 | .208 | .088-.323 | .0008 | 123.733 | <.001 | 91.110 |
| Cognitive screening measures | 85 | 14518 | .176 | .141-.211 | <.0001 | 346.654 | <.001 | 75.768 |
| Length of care home stay | 11 | 2221 | .103 | .041-.163 | .0011 | 18.471 | .048 | 45.860 |
| Co-morbidity | 25 | 4895 | .090 | .051-.128 | <.0001 | 39.714 | .023 | 39.568 |
| Gender | 47 | 9932 | .067 | .044-.090 | <.0001 | 56.471 | .139 | 18.542 |
| Medication | 20 | 5609 | .058 | .030-.085 | <.0001 | 19.736 | .411 | 3.729 |
| Diet | 4 | 1361 | .047 | -.055-.148 | .3672 | 10.368 | .016 | 71.066 |
| Age | 58 | 11926 | .025 | -.003-.052 | .0837 | 118.082 | <.001 | 51.728 |

**Supplementary Table 32b: Effect sizes after poor quality articles were removed from the analysis for informant ratings of quality of life for the person with dementia – factors pertaining to the carer**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Burden/stress | 25 | 4465 | .328 | .250-.401 | <.0001 | 179.696 | <.001 | 86.644 |
| Depression | 14 | 2698 | .261 | .174-.344 | <.0001 | 65.084 | <.001 | 80.026 |

**Supplementary Table 33: Effect sizes after poor quality articles were removed from the analysis for proxy ratings of quality of life for the person with dementia – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Cognitive screening measures | 15 | 1845 | .085 | .000-.169 | .0497 | 41.897 | <.001 | 66.584 |

**Supplementary Table 34: Effect sizes after poor quality articles were removed from the analysis for baseline factors associated with ratings of quality of life at follow-up in longitudinal studies – factors pertaining to the person with dementia**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Factor** | **Number of studies** | **Number of participants** | **r** | **95% CI** | **p** | **Cochran’s Q** | **p value (Cochran’s Q)** | ***I2*** |
| Baseline quality of life | 15 | 1801 | .328 | .200-.445 | <.0001 | 106.472 | <.001 | 86.851 |
| Cognitive screening measures | 8 | 853 | .171 | .056-.281 | .0037 | 18.486 | .010 | 62.134 |
| Neuropsychiatric symptoms/BPSD | 6 | 587 | .127 | .045-.206 | .0024 | 3.914 | .562 | 0 |
| Functional ability | 4 | 339 | .126 | .018-.230 | .0225 | 2.443 | .486 | 0 |
| Gender | 5 | 495 | .102 | .010-.192 | .0299 | 3.397 | .494 | 0 |
| Clinical Dementia Rating | 4 | 446 | .085 | -.009-.177 | .0768 | .345 | .651 | 0 |
| Age | 6 | 516 | .076 | -.014-.165 | .0958 | 3.634 | .603 | 0 |

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