**A comprehensive model of factors associated with quality of life, satisfaction with life and well-being for family carers of people living with mild-to-moderate dementia: findings from the IDEAL study**

**Supplementary information**

**Analytical methods**

The analysis was based on version 2.0 of the IDEAL dataset.

The analysis first investigated the relationships between individual measures and living well outcomes using linear regression modelling and adjusting for age, sex, dementia subtypes and type of caregiving relationship. This was used to quantify the strength and direction of individual associations. Within each of the seven domains reflecting carers’ perceptions of their personal resources and experiences (Supplementary Table 1), all variables were fitted in one multivariate regression model adjusting for age, sex, subtypes and type of carers. Based on the adjusted results, three selection criteria were applied to identify the variables most clearly related to life satisfaction (Satisfaction with Life Scale; SwLS), wellbeing (World Health Organization-Five Well-Being Index; WHO-5) and quality of life (World Health Organization Quality of Life-BREF; WHOQOL-BREF) and to simplify the model as much as possible:

(a) Statistical significance: Wald test was used to examine whether the associations between living well outcomes and a specific measurement achieved statistical significance.

(b) Meaningful difference: The effect sizes were considered to be meaningful when unstandardised regression coefficients achieved SwLS>1.5 or WHO-5>5.0. Since there is no cut-off for the WHOQOL-BREF factor score, this criterion only applied to the other two living well measures. These cut-offs were determined to address the need for clinical relevance and based on the literature.

(c) Binary/ordinal variables: If there was a dose-response relationship, the measure was used as an ordinal variable. Categorical variables were regrouped into binary variables if appropriate.

After the selection process using multivariate modelling, structural equation modelling (SEM) was employed to generate a latent factor for the selected variables within each domain and build a structural model examining the associations between individual latent factors and the living well latent with SwLS fixed at 1. The variances of individual latent factors were fixed at 1. Two domains had only one variable each: for Managing everyday life with dementia this was the Neuropsychiatric Inventory Questionnaire distress scale and for Relationship it was the Positive Affect Index assessing current relationship quality. The results of SEM for the other five domains are reported in Supplementary Table 2. A full model was fitted to include the five latent factors and two individual variables, and was adjusted for age, sex, dementia subtypes and type of caregiving relationship. To account for correlations between latent factors and stabilise estimates in the full model, loneliness was found to also be important in the experiencing caregiving domain. To enable the model to reflect a positive perspective on ‘living well’ the scales of the three living well measures were reversed. The results of the full model are reported in Supplementary Table 3. Multiple imputation was used to address missing data in selected variables and living well outcomes. The percentage of missing data was between 7% and 20% across all domains. Age, sex, dementia subtypes and type of caregiving relationship were also included in the imputation model. Since imputation of ten datasets is usually sufficient to address potential variability of coefficient estimates,1 ten imputed datasets were generated and combined using Rubin’s rule.2 All analyses were conducted using Stata 14.2.

Supplementary Table 1. Variables under each domain considered for inclusion in the structural equation model

|  |  |
| --- | --- |
| Variables | Scale/source and reference |
| SOCIAL CAPITALS, ASSETS AND RESOURCES |
| Frequency of social contact | Office for National Statistics Social Capital Scale3 |
| Social network | Lubben Social Network Scale4 |
| Social resources | Resource Generator-UK5 |
| Social participation | Office for National Statistics Social Capital Scale3 |
| Civic participation | Office for National Statistics Social Capital Scale3 |
| Neighbourhood trust | Office for National Statistics Social Capital Scale3 |
| Neighbourhood willingness to help | Office for National Statistics Social Capital Scale3 |
| Education | Highest level of education achieved |
| Cultural activity | Questions from Cultural Capital and Social Exclusion Survey6 |
| SOCIAL LOCATION |
| Socio-economic status | Socio-economic status based on occupation7 |
| Social comparison | Single item |
| Perceived status in society | MacArthur Scale of Subjective Social Status (social ladder)8 |
| Perceived status in community  | MacArthur Scale of Subjective Social Status (community ladder)8 |
| PSYCHOLOGICAL CHARACTERISTICS AND HEALTH |
| Personality  | Mini-IPIP9 |
| Religion | Single item10 |
| Spirituality | Single item |
| Optimism | Life Orientation Test-Revised11 |
| Self-esteem | Rosenberg Self-Esteem Scale12; single item13 |
| Self-efficacy | Generalized Self-Efficacy Scale14 |
| Loneliness | De Jong Gierveld Loneliness Scale15; single item |
| Depression  | Center for Epidemiologic Studies Depression Scale-Revised16 |
| Subjective age | Single item |
| Life events | Modified 10-item Social Readjustment Rating Scale17 |
| PHYSICAL FITNESS AND HEALTH |
| Physical activity | General Practice Physical Activity Questionnaire18 |
| Falls | Number of falls in past year19 |
| Eyesight | Single item19 |
| Hearing | Single item19 |
| Alcohol consumption | Currently does/does not consume alcohol |
| Smoking | Current smoker/former smoker/never smoked |
| Self-rated health | Single item20 |
| Health conditions  | Charlson Co-morbidity Index21, 22 |
| MANGING EVERYDAY LIFE WITH DEMENTIA |
| Hours of care | Single item |
| Distress at neuropsychiatric symptoms | Neuropsychiatric Inventory Questionnaire23 |
| RELATIONSHIP WITH PERSON WITH DEMENTIA |
| Current relationship quality | Positive Affect Index24 |
| Past relationship quality | Positive Affect Index24 |
| EXPERIENCING CAREGIVING |
| Positive aspects of caregiving | Positive aspects of caregiving25 |
| Role captivity | Role captivity26 |
| Caregiving competence  | Caregiving competence27 |
| Management of situation – firm | Management of situation26 |
| Management of situation – things | Management of situation26 |
| Management of situation – busy | Management of situation26 |
| Management of situation – learn | Management of situation26 |
| Management of meaning – experiences | Management of meaning26 |
| Management of meaning – comparisons | Management of meaning26 |
| Management of meaning – larger sense  | Management of meaning26 |
| Social restriction  | Modified Social Restriction Scale28 |
| Stress | Relative Stress Scale29 |
| Coping  | Single item30 |

**Supplementary Table 2.** Results of structural equation modelling for the five latent factors

**(a) Social capitals, assets and resources (CAR)**

|  |  |  |
| --- | --- | --- |
|  | Model 1 | Model 2 |
| **Measurement: living well** |  |  |
| SwLS | 1 | 1 |
| WHO-5 | 3.32 (3.07, 3.57) | 3.32 (3.07, 3.58) |
| WHOQOL-BREF | 0.41 (0.38, 0.44) | 0.39 (0.36, 0.42) |
|  |  |  |
| **Measurement: Capitals, assets and resources** |
| Frequency of social contact |  |  |
|  Ordinal variable | 0.53 (0.42 0.65) | 0.66 (0.56, 0.76) |
| Civic participation |  |  |
|  High vs low (ref.) | 0.06 (0.02, 0.09) | 0.05 (0.01, 0.09) |
| Social resources |  |  |
|  Continuous variable | -3.50 (-4.18, -2.81) | -2.84 (-3.34, -2.34) |
|  |  |  |
| **Structural**  |  |  |
| CAR -> Living well | 1.68 (1.24, 2.12) | 2.16 (1.65, 2.67) |

Model 1: unadjusted; Model 2: adjusted for age, sex, subtypes and type of carers

 **(b) Social location (SLC)**

|  |  |  |
| --- | --- | --- |
|  | Model 1 | Model 2 |
| **Measurement: living well** |  |  |
| SwLS | 1 | 1 |
| WHO-5 | 3.33 (3.09, 3.57) | 3.34 (3.10, 3.58) |
| WHOQOL-BREF | 0.41 (0.38, 0.44) | 0.40 (0.37, 0.43) |
|  |  |  |
| **Measurement: Social locations** |
| Social comparison |  |  |
|  Ordinal variable | 0.40 (0.31, 0.48) | 0.43 (0.29, 0.57) |
| Societal ladder |  |  |
|  Ordinal variable | 0.64 (0.58, 0.70) | 0.63 (0.54, 0.72) |
| Community ladder |  |  |
|  Ordinal variable | 0.54 (0.49, 0.59) | 0.53 (0.46, 0.60) |
|  |  |  |
| **Structural**  |  |  |
| SLC -> Living well | 2.19 (1.71, 2.68) | 2.24 (1.55, 2.93) |

Model 1: unadjusted; Model 2: adjusted for age, sex, subtypes and type of carers

 **(c) Psychological characteristics & health (PSY)**

|  |  |  |
| --- | --- | --- |
|  | Model 1 | Model 2 |
| **Measurement: living well** |  |  |
| SwLS | 1 | 1 |
| WHO-5 | 3.32 (3.08, 3.56) | 3.33 (3.09, 3.57) |
| WHOQOL-BREF | 0.39 (0.36, 0.42) | 0.39 (0.36, 0.42) |
|  |  |  |
| **Measurement: Psychological characteristics & health** |
| Personality- Neuroticism |  |  |
|  Continuous variable | 2.24 (2.06, 2.42) | 2.25 (2.08, 2.44) |
| Optimism |  |  |
|  Continuous variable | -2.45 (-2.67, -2.22) | -2.43 (-2.66, -2.20) |
| Depression |  |  |
|  Yes vs No (ref.) | 0.19 (0.17, 0.22) | 0.19 (0.17, 0.22) |
| Subjective age |  |  |
|  Ordinal variable | -0.27 (-0.31, -0.23) | -0.27 (-0.31, -0.23) |
| Self-esteem (Rosenberg) |  |  |
|  Ordinal variable | -0.73 (-0.78, -0.69) | -0.72 (-0.78, -0.68) |
| Loneliness |  |  |
|  Ordinal variable | 0.37 (0.33, 0.40) | 0.36 (0.32, 0.40) |
|  |  |  |
| **Structural**  |  |  |
| PSY -> Living well | -4.41 (-4.75, -4.07) | -4.45 (-4.80, -4.10) |

Model 1: unadjusted; Model 2: adjusted for age, sex, subtypes and type of carers

**(d) Physical fitness & health (PHY)**

|  |  |  |
| --- | --- | --- |
|  | Model 1 | Model 2 |
| **Measurement: living well** |  |  |
| SwLS | 1 | 1 |
| WHO-5 | 3.34 (3.11, 3.58) | 3.37 (3.13, 3.60) |
| WHOQOL-BREF | 0.47 (0.43, 0.51) | 0.45 (0.41, 0.48) |
|  |  |  |
| **Measurement: Physical fitness & health** |
| Eyesight |  |  |
|  Ordinal variable | 0.38 (0.33, 0.44) | 0.39 (0.33, 0.44) |
| Self-rated health |  |  |
|  Ordinal variable | 0.71 (0.64, 0.78) | 0.70 (0.63, 0.76) |
| Smoking |  |  |
|  Ordinal variable | 0.09 (0.05, 0.13) | 0.09 (0.05, 0.13) |
|  |  |  |
| **Structural**  |  |  |
| PHY -> Living well | -3.07 (-3.45, -2.69) | -3.19 (-3.58, -2.81) |

Model 1: unadjusted; Model 2: adjusted for age, sex, subtypes and type of carers

 **(e) Experiencing caregiving (EC)**

|  |  |  |
| --- | --- | --- |
|  | Model 1 | Model 2 |
| **Measurement: living well** |  |  |
| SwLS | 1 | 1 |
| WHO-5 | 3.28 (3.03, 3.53) | 3.28 (3.03, 3.53) |
| WHOQOL-BREF | 0.37 (0.35, 0.40) | 0.37 (0.34, 0.40) |
|  |  |  |
| **Measurement: Experiencing caregiving** |
| Stress |  |  |
|  Ordinal variable | 0.76 (0.72, 0.79) | 0.75 (0.71, 0.78) |
| Role captivity |  |  |
|  Ordinal variable | 0.54 (0.50, 0.58) | 0.55 (0.51, 0.59) |
| Social restriction |  |  |
|  Ordinal variable (ref.) | 0.27 (0.22, 0.32) | 0.28 (0.23, 0.33) |
|  |  |  |
| **Structural**  |  |  |
| EC -> Living well | -3.42 (-3.77, -3.06) | -3.39 (-3.75, -3.03) |

Model 1: unadjusted; Model 2: adjusted for age, sex, subtypes and type of carers

**Supplementary Table 3.** Results of structural equation modelling including all five latent factors, neuropsychiatric inventory distress scale (NPI) and current relationship quality (CR)

|  |  |  |
| --- | --- | --- |
|  | Unadjusted | Adjusted |
| Measurement model (LW) |  |  |
| SwLS | 1 (fixed) | 1 (fixed) |
| WHO-5 | 3.43 (3.19, 3.66) | 3.42 (3.19, 3.66) |
| WHOQOL-BREF | 0.40 (0.38, 0.43) | 0.40 (0.38, 0.43) |
| Structural association |  |  |
| PSY | 2.54 (2.15, 2.93) | 2.53 (2.08, 2.97) |
| PHY | 1.37 (1.06, 1.68) | 1.48 (1.04, 1.91) |
| EC | 1.32 (0.97, 1.66) | 1.34 (0.99, 1.70) |
| CAR | 0.58 (0.34, 0.83) | 0.68 (0.35, 1.00) |
| SLC | 0.08 (-0.17, 0.34) | 0.28 (-0.33, 0.89) |
| NPI | 0.08 (-0.13, 0.28) | 0.06 (-0.15, 0.28) |
| CR | -0.21 (-0.40, -0.03) | -0.22 (-0.41, -0.03) |
| Correlation/Covariance |  |  |
| (PSY, PHY) | 0.54 (0.45, 0.62) | 0.54 (0.46, 0.62) |
| (PSY, EC) | 0.55 (0.50, 0.61) | 0.56 (0.50, 0.61) |
| (PSY, CAR) | 0.27 (0.18, 0.36) | 0.26 (0.17, 0.35) |
| (PSY, SLC) | -0.48 (-0.57, -0.38) | -0.59 (-0.84, -0.34) |
| (PSY, NPI) | 0.36 (0.29, 0.43) | 0.36 (0.29, 0.43) |
| (PSY, CR) | -0.36 (-0.43, -0.30) | -0.36 (-0.43, -0.30) |
| (PHY, EC) | 0.26 (0.17, 0.34) | 0.26 (0.18, 0.34) |
| (PHY, CAR) | 0.28 (0.18, 0.38) | 0.28 (0.18, 0.39) |
| (PHY, SLC) | -0.42 (-0.52, -0.31) | -0.53 (-0.77, -0.28) |
| (PHY, NPI) | 0.17 (0.09, 0.24) | 0.17 (0.09, 0.25) |
| (PHY, CR) | -0.10 (-0.19, -0.02) | -0.11 (-0.19, -0.02) |
| (EC, CAR) | 0.07 (-0.03, 0.18) | 0.05 (-0.05, 0.16) |
| (EC, SLC) | -0.20 (-0.30, -0.11) | -0.31 (-0.57, -0.05) |
| (EC, NPI) | 0.64 (0.58, 0.69) | 0.64 (0.58, 0.69) |
| (EC, CR) | -0.56 (-0.62, -0.50) | -0.56 (-0.62, -0.50) |
| (CAR, SLC) | -0.35 (-0.45, -0.26) | -0.33 (-0.46, -0.20) |
| (CAR, NPI) | -0.04 (-0.13, 0.05) | -0.05 (-0.13, 0.04) |
| (CAR, CR) | -0.02 (-0.10, 0.07) | 0.00 (-0.09, 0.08) |
| (SLC, NPI) | -0.15 (-0.23, -0.06) | -0.23 (-0.43, -0.03) |
| (SLC, CR) | 0.17 (0.09, 0.24) | 0.22 (0.09, 0.35) |
| (NPI, CR) | -0.40 (-0.46, -0.34) | -0.40 (-0.46, -0.34) |

Adjusted for age, sex, subtypes and type of carers

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