A comprehensive model of factors associated with subjective perceptions of living well with dementia: findings from the IDEAL study

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Abstract

Introduction: We aimed to better understand what predicts the capability to 'live well' with dementia through identifying the relative contribution of life domains associated with the subjective experience of living well.

Method: We analysed data from 1547 individuals with mild-to-moderate dementia in the IDEAL cohort. We generated a 'living well' latent factor from measures of quality of life, satisfaction with life and well-being. We used multivariate modelling to identify variables related to living well measures and structural equation modelling to derive latent variables for five life domains and to examine the associations of these domains with living well.

Results: All five domains were individually associated with living well. When modelled together, the psychological characteristics and psychological health domain was the only independent predictor of living well (effect size 3.55; 95% CI: 2.93, 4.17), and effect sizes were smaller for physical fitness and physical health (1.23, 95% CI: -.10, 2.58), social capitals, assets and resources (0.67; 95% CI: -.04, 1.38), managing everyday life with dementia (0.33; 95% CI: -0.06, 0.71), and social location (0.08; 95% CI: -2.10, 2.26).

Discussion: Psychological resources, and the social, environmental and physical factors that underpin positive psychological states, are potentially important targets for interventions and initiatives that aim to improve the experience of living with dementia.

Keywords

A comprehensive model of factors associated with the subjective experience of 'living well' with dementia: findings from the IDEAL study

Introduction

To live well with chronic illness and disability means experiencing 'the best achievable state of health that encompasses all dimensions of physical, mental and social well-being', reflected in 'a self-perceived level of comfort, function and contentment with life' (pg. 32).[1] The concept of living well is now frequently mentioned in policy documents and reports relating to dementia,[2, 3] and is used to convey the message that it is, or should be, possible to experience a subjective sense of 'comfort, function and contentment with life' while living with the condition. This reflects a move from a focus on symptoms and 'deficits' to a broader focus acknowledging personhood and the rights of people with dementia, enabling optimal functioning, and supporting participation and inclusion.

In the research context, the subjective experience of living well is typically equated with experiencing a good quality of life (QoL).[4] QoL is a wide-ranging construct defined as representing 'an individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' and affected by a person's 'physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship… to the environment' (pg. 153).[5] Theoretical models of QoL in dementia similarly emphasise the influence of a wide range of psychological, social, environmental and cultural factors.[6] Other potential indices of a sense of 'comfort, function and contentment with life' are measures of satisfaction with life and subjective well-being. Satisfaction with life entails a global evaluation of one's current life while subjective well-being reflects the experience of an appropriate balance of positive and negative emotions.[7] Well-being can be considered as a state of equilibrium or balance which is affected by life events or challenges.[8] These aspects have been less widely studied in relation to dementia.

A recent systematic review[9] indicates that numerous individual variables demonstrate small associations with self-rated QoL when assessed at the same time, while only a very few variables emerge as moderately associated. These are primarily social or psychological in nature; in this review, depression was moderately associated with poorer QoL (effect size -

0.31), while being more socially engaged (0.31), having a positive relationship with one's carer (0.38), and holding religious beliefs (0.35) were moderately associated with better QoL. Models combining several individual variables, mainly basic demographic features, symptoms, and co-morbidity, account for only a small proportion of the variance in QoL scores.[10-12] The available evidence therefore provides limited guidance about influences on QoL or possible directions for improving the experience of living with dementia.

This suggests the need first for a broader perspective on 'living well' with dementia that is commensurate with key definitions and theoretical models, and second for a more comprehensive approach to modelling the factors associated with capability to 'live well' with dementia. The Improving the experience of Dementia and Enhancing Active Life (IDEAL) cohort study[13] has been set up in part to address this need, using a theoretically derived conceptual framework as a basis for examining multiple influences on living well with dementia. In this framework, the potential for living well is influenced by, and reflects the balance between, the unique set of resources that each person brings to the situation and the particular challenges faced. Resources are the person's accumulated experiences and abilities together with current social capitals, assets and resources in the socio-environmental, psychological, economic and physical domains.[14, 15] Challenges are the personal, social, physical and practical impact of the disability resulting from the development and progression of dementia.[16] Here we use data from the IDEAL initial interviews to model the way in which the social, psychological and physical resources that the person is able to deploy, and the specific challenges encountered during the development and progression of dementia, are associated with perceptions of capability to 'live well' with the condition among people with mild-to-moderate dementia living in community settings.

Methods

Design

IDEAL is a longitudinal cohort study involving people with dementia and, where available, their primary carers, recruited through 29 National Health Service (NHS) sites throughout England, Scotland and Wales. Information is collected through face-to-face interviews conducted in participants' own homes by trained interviewers. The study is overseen by an involvement group of people with dementia and carers, known as the ALWAYs (Action on Living Well: Asking You) group, that assisted with the design and contributes to understanding of the results. The present analysis is based on cross-sectional data from the first wave of data collection and utilises version 2.0 of the dataset. The IDEAL study was approved by the Wales Research Ethics Committee 5 (reference 13/WA/0405) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014 – 11684). IDEAL is registered with the UK Clinical Research Network (UKCRN), number 16593.

Participants

Participants were recruited through NHS memory services and other specialist clinics, and via the online UK Join Dementia Research portal https://www.joindementiaresearch.nihr.ac.uk/, between July 2014 and August 2016. Inclusion criteria required participants to have a clinical diagnosis of dementia (any sub-type), to be in the mild-to-moderate stages as indicated by a Mini-Mental State Examination (MMSE)[17] score of 15 or over, and to be living in the community at the time of enrolment, excluding individuals with terminal illness, inability to provide informed consent, and any known potential for home visits to pose a significant risk to researchers. In total 3,105 people with dementia were approached about participation, of whom 363 were ineligible and 1,106 declined. Of the 1,636 who consented, 8 subsequently proved ineligible and 81 withdrew. This resulted in a sample of 1,547 participants with dementia (a response rate of 57% among eligible people with dementia). The majority of participants (1283, 82.9%) had a family member or other informal carer who agreed to participate in the study, and 1045 (67.6%) lived with the participating carer.

Measures of capability to 'live well'

Living well was defined as comprising subjective perceptions of quality of life, satisfaction with life and well-being reported by participants with dementia. Quality of life was assessed

using the 13-item Quality of Life in Alzheimer's Disease scale (QoL-AD)[18, 19] with responses to each item given on a four-point scale (1-4) and the scores added to provide a total score out of 52; higher scores indicate more positive ratings of QoL. Satisfaction with life was assessed using the 5-item Satisfaction with Life Scale (SwLS).[20] Items are rated on a 7-point scale (1-7) and responses are summed to give a total score out of 35, with higher scores indicating greater satisfaction. Well-being was assessed using the World Health Organization-Five Well-Being Index (WHO-5).[21] Responses are scored on a 6-point scale (0-5), summed to give a total out of 25, and multiplied by 4 to give a score out of 100, with higher scores indicating greater well-being.

Measures of resources and challenges potentially associated with 'living well'

In our framework, derived from definitions of 'living well' and theoretical models of QoL in dementia, resources include the domains of psychological characteristics and psychological health (e.g. personality, optimism, loneliness, depression), physical fitness and physical health (e.g. exercise, diet, eyesight), social capitals, assets and resources (e.g. education, income, cultural capital, social networks), and social location (perceptions of one's place in society, e.g. social class, social status). Challenges include the symptoms of dementia and their effects, and the impact of these on ability to manage everyday life with dementia (e.g. cognition, functional ability). See Supplementary Table 1 for details of the variables considered in each domain and how these were measured. All data were based on self-report.

Statistical methods

The analysis was undertaken in a staged approach. Potential variables within each domain were examined in relation to both statistical significance and clinical relevance. Statistical significance was investigated with the Wald test, and the effect size for an unstandardised regression coefficient needed to be >1.5 for QoL-AD or SwLS, and >5 for WHO-5 to be considered clinically relevant.[22-24] Initial analysis was undertaken within each domain against the multivariate outcome (QoL-AD, SwLS and WHO-5). Factors that were found to be influential in a univariable investigation were included within a multivariable, multivariate investigation. Recoding of variables (from continuous to ordinal groups, or from groups to binary variables) was undertaken to simplify the model, but effect sizes were retained. Multiple imputation by chained equations was conducted to allow for the missing response data. For the complete model the latent factors representing the five domains were regressed on the living well latent factor, adjusting for age, sex and dementia subtype. The model is

parameterised to reflect positive associations indicating enhanced living well outcomes. A coefficient estimate was assumed to be significant if its 95% confidence interval did not include 0. See the Supplementary section on statistical methods for expanded details.

Results

Participant characteristics

Characteristics of the 1547 participants and scores on the three living well measures are summarised in Table 1. The overall mean scores and standard deviations were 36.8 (5.9) for QoL-AD, 26.1 (6.1) for SwLS and 60.9 (20.6) for WHO-5. There were no differences according to sex, but mean ratings were lower for younger people and those with Parkinson's disease dementia and dementia with Lewy bodies.

(((Table 1 near here))

Variables included in the analysis

The variables selected for each domain through univariable multivariate modelling are summarised in Table 2. Full details of the stages of modelling are given in the supplementary information.

(((Table 2 near here)))

Relationships among the latent variables

The relationship between each of the domains and the living well latent is presented in Figure 1, and further detail is provided in Supplementary Table 3, including correlations between domains. Individual associations with living well were 4.86 (95% CI: 4.54, 5.18) for the psychological characteristics and psychological health domain, -4.66 (95% CI: -5.72, -3.60) for social location, 4.21 (95% CI: 3.84, 4.58) for physical fitness and physical health, 2.83 (95% CI: 2.23, 3.44) for social capitals, assets and resources, and 1.98 (95% CI: 1.61, 2.35) for managing everyday life with dementia. Following multiple imputation analysis and with adjustment, the model shows that the psychological characteristics and psychological health domain was most strongly associated with living well (3.55; 95% CI: 2.93, 4.17). Effect sizes for the other domains ranged from 1.23 to 0.08 (physical fitness and physical health: 1.23, 95% CI: -0.01, 2.58; social capitals, assets and resources: 0.67; 95% CI: -0.04, 1.38;

managing everyday life with dementia: 0.33; 95% CI: -0.06, 0.71; social location: 0.08; 95% CI: -2.10, 2.26). These factors did not have independent associations with living well when included alongside the psychological characteristics and psychological health domain. Examination of correlations between the latent factors for the five domains shows particularly strong associations between the psychological and physical domains and social location (>0.7).

Impact of changes for scores on living well measures

These effects from the standardised analysis were converted back to show the associated change in scores on the outcome variables. For each unit increase in the latent score for each domain, we present the associated changes in scores on the living well measures. These results, seen in Table 3, show that a one unit increase in psychological characteristics and psychological health was associated with an increase of 3.55 (95% CI: 2.93, 4.17) points on QoL-AD, 2.94 (95% CI: 2.40, 3.49) points on SwLS and 11.14 (95% CI: 9.14, 13.15) points on WHO-5. A one unit increase in the physical fitness and physical health latent factor was associated with an approximately 1 point increase in QoL-AD and SwLS and a 3.9 point increase in WHO-5. For the other three latent factors, a one unit increase was related to a ≤1 point increase on QoL-AD and SwLS and a ≤2 point increase on WHO-5.

(((Figure 1 near here)))

(((Table 3 near here)))

Discussion

Using data from 1547 people living with mild-to-moderate dementia participating in the IDEAL study, we have presented a comprehensive model of factors associated with perceived ability to live well with the condition, conceptualised as balancing resources and challenges. IDEAL is one of very few large studies to explore subjective perceptions of ability to live well with dementia among people in the mild-to-moderate stages of the condition living in the community, both with or without the support of a carer. It is unique in combining the constructs of QoL, satisfaction with life and well-being to provide a

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comprehensive measure of living well, in the wide range of personal, psychological, physical, social and environmental factors examined, and in drawing a study population from numerous socially and environmentally diverse areas in Great Britain. The model presented here demonstrates that, when domains are considered individually, the domain of psychological characteristics and psychological health is most strongly associated with concurrent perceptions of living well, followed by social locations and physical fitness and physical health; relatively smaller effect sizes were observed for the domains of social capitals, assets and resources and managing everyday life with dementia. When domains are considered together, the psychological domain is dominant in the model. When consulted about the model, the ALWAYs involvement group members thought it was reasonably easy to understand, seemed logical, and provided support for their sense of the important aspects contributing to their ability to live well with the condition.

The psychological characteristics and psychological health domain emerged as particularly important. The dominance of psychological characteristics and psychological health may in part relate to the nature of the constructs being measured, as the self-ratings of psychological features are most similar to the subjective perception of living well when measured at the same time. However, the correlations between domains and living well measures are accounted for in the model and none had perfect correlations; furthermore, this study considered a wide range of factors in the psychological domain such as personality traits, optimism, self-esteem, and attitudes toward own ageing, in addition to depression. Evidence from a number of studies indicates that poor psychological health, represented by higher scores on measures of depressive symptoms, is associated with lower ratings of QoL.[9, 12, 25] Although psychological characteristics have traditionally been accorded limited emphasis in studies of QoL in people with dementia, recent work has begun to consider a wider range of psychological variables, including personality traits.[12]

The strengths of our approach lie in the presentation of a detailed model that demonstrates the relative associations of five latent factors, reflecting distinct domains, with subjective perceptions of ability to live well with dementia, based on a large sample of people with mild-to-moderate dementia. The modelling included a detailed investigation of and adjustment for missing data via multiple imputation. Missing data were observed within both the measured variables and the outcomes; while low levels of missing data (<3%) were observed for the SwLS and WHO-5, the percentage of missing data for QoL-AD was higher

at 9.4%. The modelling process included maximal information, allowing for continuous, ordinal and binary variables.

There are several limitations to consider. Our investigation estimates the impacts of variables relating to living well at the same time-point, and hence causal direction cannot be inferred. Although all variables were potentially important, some degree of selection was required in developing the model. Despite the large sample size, some factors did not show statistical significance in the first stage of modelling, or showed significance but were thought less clinically relevant, and the factors remaining within the latent structure were those that showed domain-specific relationships. Hence some small effect sizes may have been dismissed within the final modelling stage. Some variables assessed in IDEAL were not suitable for inclusion in the structural equation modelling as they did not have linear relationships with living well measures. Some variables were excluded because they were only available for those individuals with a participating carer, for example ratings of the quality of relationship with the carer. Others were available only through single questions embedded in other measures and hence less amenable to inclusion; one example in the physical health domain is pain. These variables remain to be explored in future work. Our model is based on self-ratings made by the participants with dementia. While concerns are sometimes raised about the impact of a potential lack of awareness on self-ratings of constructs such as QoL, previous research has shown that variations in awareness are of minor relevance in this regard.[12] The validity of self-ratings reflecting the subjective perceptions of people living with mild-to-moderate dementia is now widely accepted.

The findings of this study suggest that living well with dementia might be enhanced through improving psychological and physical health as well as addressing other social factors. While the greatest gain in living well ratings is likely to be achieved through positive increases in factors within the psychological domain, all five domains, and all individual factors within the five domains, were individually associated with perceived capability to live well with dementia. Although some factors are unlikely to be amenable to intervention, there are several modifiable factors in each domain. For example, while the variables included in the psychological characteristics and psychological health domain encompass some traits, such as dispositional optimism and the personality trait of neuroticism, which may not be direct targets for intervention, other variables such as depression and loneliness may offer more potential for change. Improving physical health where possible, and enabling people to

manage disability more effectively, could also improve capability to live well. Social factors that impact on experience in the psychological domain may also provide immediate options for intervention; for example, community efforts to address isolation, enhance neighbourhood trust and increase social engagement could help to address depression and loneliness. Our findings also support the potential for developing an integrated approach to evaluating outcomes that reflects the experiences and needs of people with dementia through creating a new scale measuring 'living well' with dementia. In supporting people to 'live well' with dementia, our findings reflect the need to take account, not only of disease-related factors, but also of the multiple personal and social factors impacting on psychological health and well-being, as outlined in the recent operationalisation of the construct of social health in relation to dementia.[26] A comprehensive approach to enabling people with dementia, and family carers, to balance resources and challenges must acknowledge this complexity and address multiple factors in an integrated manner.

In conclusion, this study provides new evidence about factors associated with the subjective experience of living well with dementia in the mild-to-moderate stages and about potential targets for immediate intervention. We have adopted a broad perspective on living well and demonstrated that, while in a combined analysis the domain of psychological characteristics and psychological health is most strongly associated with living well, the domains of physical fitness and health, social capitals, assets and resources, managing everyday life with dementia and social location all contribute to the overall evaluation of living well when considered individually. Increased understanding of the contribution of these wide-ranging psychological and social factors will help to yield new approaches to enhancing the ability to live well with dementia.

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Conflicts of interest

The authors report no conflicts of interest

Author contributions

IDEAL investigators LC, IRJ, CRV, SMN, AM, CQ, JAP, JVH, RWJ, MK, MDK, FEM, RGM, JR, and JT contributed to all aspects of the IDEAL project including design, supporting the conduct of field work and data acquisition. LC developed the original idea for this study and designed the approach in collaboration with the IDEAL team; FEM operationalized the study aims, acquired the data and supervised the data analysis. YTW conducted the analysis and is guarantor of the analysis. LC and FEM wrote the first draft from a technical report of the analysis prepared by YTW. All authors reviewed and commented on the draft and approved the final version.

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Figure 1. Complete model using imputed data and adjusting for age, sex and dementia sub-type (n = 1547)
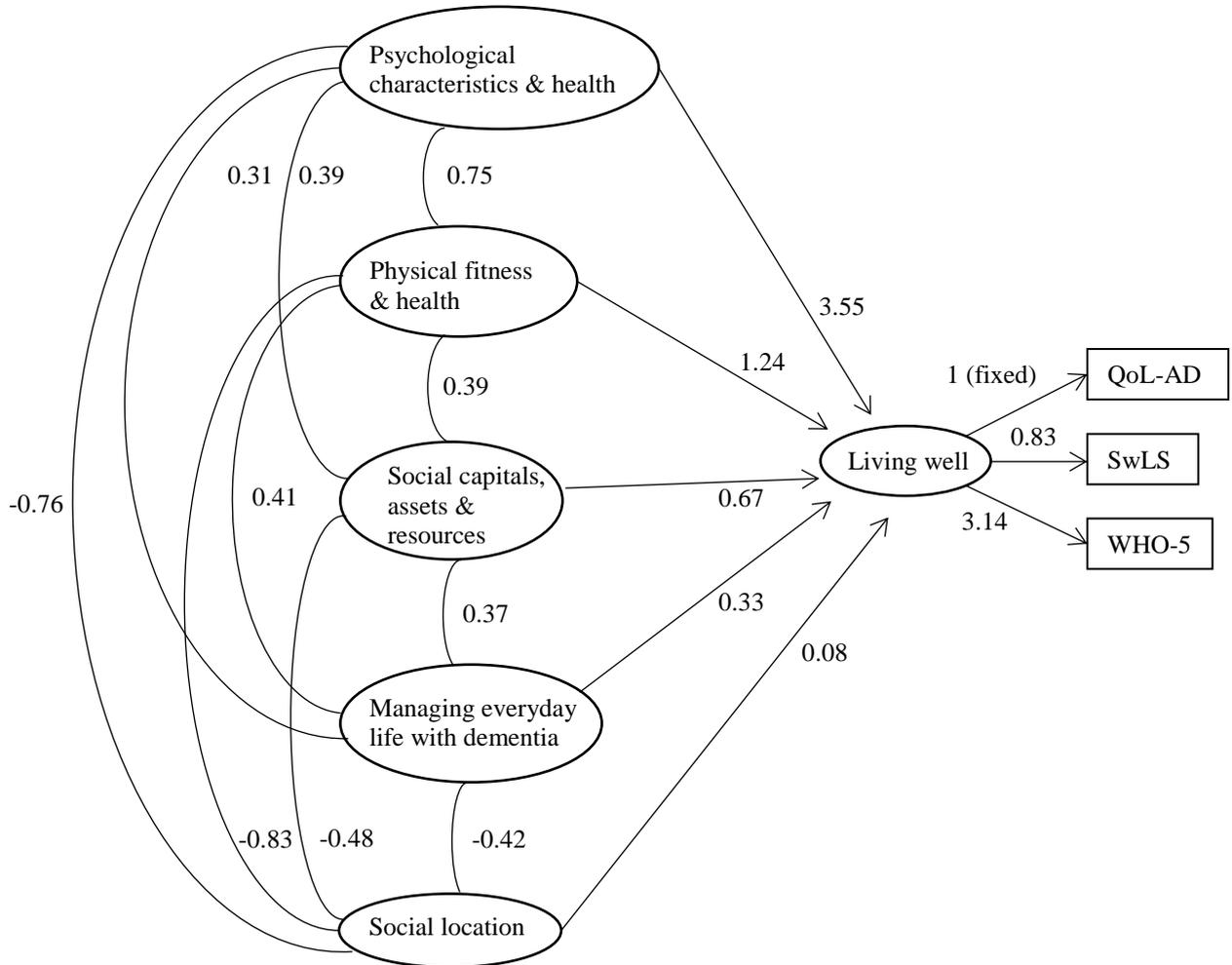
Note: QoL-AD: Quality of Life in Alzheimer's Disease scale; SwLS: Satisfaction with Life Scale; WHO-5: World Health Organization-Five Well-Being Index. Direction of scoring: lower scores for Living Well reflect better ability to live well, lower scores for Psychological characteristics and psychological health, Physical fitness and physical health, Social capitals, assets and resources, and Managing everyday life with dementia reflect better experiences or functioning in those domains, and higher scores for social location reflect higher ratings of perceived social status.

Table 1. Scores on measures of living well by age, sex and dementia sub-type (mean, SD)

Characteristic	N (%)	QoL-AD	SwLS	WHO-5
Age				
80+	603 (39.0)	37.2 (5.5)	26.7 (5.8)	63.3 (18.9)
75-79	370 (23.9)	37.1 (5.9)	26.6 (5.8)	61.1 (20.2)
70-74	260 (16.8)	36.8 (5.8)	25.7 (5.9)	59.5 (20.7)
65-69	178 (11.5)	36.2 (6.6)	25.5 (6.4)	57.5 (21.8)
<65	136 (8.8)	35.0 (6.6)	23.1 (7.1)	57.5 (24.8)
Sex				
Men	872 (56.4)	36.7 (6.0)	26.1 (6.0)	61.5 (20.2)
Women	675 (43.6)	36.9 (5.8)	26.0 (6.2)	60.2 (21.0)
Dementia sub-types				
AD	858 (55.5)	37.7 (5.5)	26.8 (5.7)	63.8 (19.6)
VaD	171 (11.1)	35.2 (6.6)	24.8 (6.7)	56.1 (21.7)
Mixed AD & VaD	326 (21.1)	36.2 (5.8)	25.9 (6.1)	59.4 (20.6)
FTD	54 (3.5)	38.6 (5.5)	25.7 (5.9)	62.9 (20.6)
PDD	44 (2.8)	33.0 (5.6)	22.2 (6.7)	48.1 (20.2)
DLB	53 (3.4)	32.8 (6.3)	22.5 (6.2)	49.5 (18.5)
Other	41 (2.7)	34.9 (7.8)	26.1 (7.2)	59.1 (24.8)

Note: SD: standard deviation; AD: Alzheimer's disease; VaD: vascular dementia; FTD: fronto-temporal dementia; PDD: Parkinson's disease dementia; DLB: dementia with Lewy bodies; QoL-AD: Quality of Life in Alzheimer's Disease scale; SwLS: Satisfaction with Life Scale; WHO-5: World Health Organization-Five Well-Being Index.

Table 2. Variables included in the five latent factors and direction of effect

Latent factor	Variables included	Direction of association with better [+] or poorer [-] scores on living well measures
Psychological characteristics and psychological health	Optimism	Greater optimism [+]
	Self-esteem	Higher self-esteem [+]
	Attitude toward own ageing	More positive attitude [+]
	Subjective age	Lower subjective age [+]
	Personality	Higher neuroticism [-]
	Loneliness	More loneliness [-]
	Depression	More depressive symptoms [-]
Physical fitness and physical health	Sleep	Poor sleep [-]
	Eyesight	Poor eyesight [-]
	Hearing	Poor hearing [-]
	Appetite	Poor appetite [-]
	Change in olfaction	Change in olfaction [-]
	Smoking	Smoking [-]
	Subjective health	Poor subjective health [-]
Social capitals, assets and resources	Cultural capital	Greater cultural capital [+]
	Social networks	Isolation [-]
	Neighbourhood reciprocity and local trust	Lower neighbourhood reciprocity and trust [-]
Managing everyday life with dementia	Disability	Greater disability [-]
	Dependence	Greater dependence [-]
Social location	Social comparison	More positive ranking [+]
	Status in community	Higher ranking [+]

Table 3. Changes in scores on measures of living well per unit increase in each latent factor, adjusted for age, sex and dementia sub-type and all latent factors, with multiple imputation; domains are ranked according to size of predicted change

Latent factor	Living well measure	Predicted change in score per unit increase in latent factor - Coefficient (95% CI)
Psychological characteristics and psychological health	QoL-AD	3.55 (2.93, 4.17)
	SwLS	2.94 (2.40, 3.49)
	WHO-5	11.14 (9.14, 13.15)
Physical fitness and physical health	QoL-AD	1.24 (-0.10, 2.58)
	SwLS	1.03 (-0.08, 2.13)
	WHO-5	3.89 (-0.30, 8.09)
Social capitals, assets and resources	QoL-AD	0.67 (-0.04, 1.38)
	SwLS	0.55 (-0.03, 1.14)
	WHO-5	2.10 (-0.13, 4.33)
Managing everyday life with dementia	QoL-AD	0.33 (-0.06, 0.71)
	SwLS	0.27 (-0.05, 0.59)
	WHO-5	1.02 (-0.19, 2.23)
Social location	QoL-AD	0.08 (-2.10, 2.26)
	SwLS	0.07 (-1.74, 1.88)
	WHO-5	0.26 (-6.58, 7.11)

Note: CI: confidence interval; QoL-AD: Quality of Life in Alzheimer's Disease scale; SwLS: Satisfaction with Life Scale; WHO-5: World Health Organization-Five Well-Being Index.

Supplementary information

Statistical methods

The analysis first investigated the relationships between individual measures and living well outcomes using linear regression modelling and adjusting for age, sex and dementia subtypes. This was used to ensure directions and strengths of individual associations. Based on the five domains in the conceptual model (Supplementary Table 1), all variables identified within the same domain were fitted in one multivariate regression model adjusting for age, sex and subtypes. Based on the adjusted results, three selection criteria were applied to identify the important variables related to living well (Quality of Life in Alzheimer's Disease scale (QoL-AD),[1, 2] Satisfaction with Life Scale (SwLS),[3] World Health Organization-Five Well-Being Index (WHO-5)[4]) 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 in the multivariate model.

b) Meaningful difference: The effect sizes were considered to be meaningful when unstandardised regression coefficients achieved QoL-AD>1.5 or SwLS>1.5 or WHO-5>5.0. These cut-offs were determined to balance the need for clinical relevance and based on the literature.[5-7]

c) Binary/ordinal variables: If there was a dose-response relationship, an ordinal model was used for the variable. Categorical variables were regrouped into binary variables if appropriate (given similar effect sizes at different levels).

After the selection process using multivariate modelling, structural equation modelling (SEM) was employed to generate a latent factor for selected variables within each domain

and build a structural model examining the associations between individual latent factors and the living well latent with QoL-AD fixed at 1. The variances of individual latent factors were fixed at 1. The results of SEM for the five individual constructs are reported in Supplementary Table 2. A full model was fitted to include all five latent factors and adjusted for age, sex and dementia subtypes. To account for correlations between latent factors and stabilise estimates in the full model, two variables from the PSY domain, attitude toward own ageing and depression, were found to also be important in the MEL 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. Quasi-maximum likelihood estimation methods were used to estimate coefficients and appropriate confidence intervals for categorical/ordinal variables.

Multiple imputation (MI) was used to address missing data in selected variables and living well outcomes. A formal MI should impute all individual items within a scale.[8] However, due to the combination of the complex model and the proportion of missing data, the formal MI approach could not be applied to the full model in a single attempt. To identify a reasonable method balancing efficiency and accuracy, MI was first conducted within each latent factor and missing variables were imputed by i) categories, ii) total scores and iii) individual items, using the method of multiple imputation by chained equations, and for continuous variables predictive mean matching. Age, sex and dementia subtypes were also included in the imputation model. If the SEM results were similar across different imputed datasets, the most efficient method (categories>total scores>individual items) was used for the full model. Estimates from 10 imputed datasets were combined using Rubin's rules.[8] Based on the results of imputed full model, changes in QoL-AD, SwLS and WHO-5 scores were estimated for per unit increase in the five latent factors. All analyses were conducted using Stata 14.0.[9]

Supplementary Table 1. Variables considered for inclusion under each domain

Factor	Measure
Psychological Characteristics and Psychological Health (PSY)	
Personality	Mini-IPIP[10]
Religious belief	Single item[11]
Spirituality	Single item
Optimism	Life Orientation Test-Revised[12]
Self-esteem	Rosenberg Self-Esteem Scale[13]; single item[14]
Self-acceptance	Ryff Scales of Psychological Well-Being[15] self-acceptance subscale[16]
Self-efficacy	Generalized Self-Efficacy Scale[17]
Continuity of sense of self	Single item
Loneliness	De Jong Gierveld Loneliness Scale[18]; single item
Depression	Geriatric Depression Scale-10[19]
Stressful life events	Social Readjustment Rating Scale[20] abbreviated 10-item version
Attitudes towards own ageing	Philadelphia Geriatric Center Morale Scale[21]
Subjective age	Single item
Experience of stigma	Stigma Impact Scale[22, 23] abbreviated 4-item version
Physical Fitness and Health (PHY)	
Physical activity	General Practice Physical Activity Questionnaire[24]
Smoking	Current smoker/former smoker/never smoked
Alcohol consumption	Currently does/does not consume alcohol
Appetite	Short Nutritional Assessment Questionnaire[25]
Eyesight	Single item[16]
Hearing	Single item[16]
Change in gustation	Single item[26]
Change in olfaction	Single item[26]
Sleep quality	Single item
Falls	Number of falls in past year[16]
Co-morbid conditions	Charlson Co-morbidity Index[27, 28]
Self-rated health	Single item[29]
Social capitals, assets and resources (CAR)	

Education	Highest level of education achieved
Income	Income adjusted for household size[30]
Social capital	Resource Generator-UK[31]
Cultural capital	Cultural Capital and Social Exclusion Survey[32]
Social network	Lubben Social Network Scale[33]
Personal relations	Office for National Statistics Social Capital Scale[34]
Reciprocity and local trust	Office for National Statistics Social Capital Scale[34]
Social participation	Office for National Statistics Social Capital Scale[34]
Civic participation	Office for National Statistics Social Capital Scale[34]

Managing Everyday Life with Dementia (MEL)

Cognition	Addenbrooke's Cognitive Examination-III[35]
Functional ability	Functional Assessment Questionnaire amended 11-item version[36, 37]
Dependence	Dependence Scale[38]

Social Location (SLC)

Social class	Socio-economic status based on occupation[39]
Social comparison	Single item
Social status	MacArthur Scale of Subjective Social Status (social ladder [40]
Community status	MacArthur Scale of Subjective Social Status (community ladder [40]

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

(a) Psychological characteristics and psychological health (PSY)

	Model 1	Model 2
Measurement: living well		
QoL-AD	1 (fixed)	1 (fixed)
SwLS	0.87 (0.81, 0.93)	0.87 (0.81, 0.93)
WHO-5	3.19 (2.98, 3.40)	3.18 (2.97, 3.39)
Measurement: psychological characteristics and health		
Personality neuroticism		
Continuous score	1.76 (1.56, 1.96)	1.78 (1.58, 1.98)
Optimism		
Continuous score	-2.01 (-2.23, -1.80)	-2.00 (-2.22, -1.79)
Self-esteem		
Ordinal variable	-0.41 (-0.46, -0.36)	-0.41 (-0.46, -0.36)
Attitude toward own ageing		
Continuous score	-1.08 (-1.15, -1.01)	-1.07 (-1.15, -1.00)
Depression		
Yes vs no (ref)	0.33 (0.31, 0.34)	0.33 (0.31, 0.34)
Subjective age		
Ordinal variable	-0.17 (-0.22, -0.13)	-0.17 (-0.22, -0.13)
Loneliness		
Yes vs no (ref)	0.10 (0.08, 0.13)	0.10 (0.08, 0.13)
Structural		
PSY -> Living well	4.86 (4.55, 5.17)	4.86 (4.54, 5.18)

Note: Latent variance of psychological characteristics and health fixed at 1; Model 1: unadjusted; Model 2: adjusted for age, sex and subtypes. QoL-AD: Quality of Life in Alzheimer's Disease scale; SwLS: Satisfaction with Life Scale; WHO-5: World Health Organization-Five Well-Being Index.

(b) Physical fitness and health (PHY)

	Model 1	Model 2
Measurement: living well		
QoL-AD	1 (fixed)	1 (fixed)
SwLS	0.81 (0.75, 0.87)	0.82 (0.76, 0.88)
WHO-5	3.18 (2.95, 3.42)	3.19 (2.96, 3.43)
Measurement: Physical fitness and health		
Poor sleep		
Ordinal variable	0.50 (0.43, 0.57)	0.51 (0.44, 0.58)
Poor eyesight		
Ordinal variable	0.50 (0.44, 0.56)	0.50 (0.44, 0.56)
Poor hearing		
Ordinal variable	0.36 (0.29, 0.43)	0.35 (0.28, 0.42)
Poor self-rated health		
Ordinal variable	0.69 (0.64, 0.75)	0.70 (0.64, 0.75)
Poor appetite		
Binary variable	0.15 (0.13, 0.18)	0.15 (0.13, 0.18)
Smoking		
Ordinal variable	0.12 (0.08, 0.15)	0.11 (0.07, 0.15)
Change in olfaction		
Yes vs No (ref.)	0.08 (0.06, 0.11)	0.09 (0.06, 0.11)
PHY -> Living well	-4.29 (-4.64, -3.94)	-4.21 (-4.58, -3.84)

Note: Latent variance of physical fitness and health fixed at 1; Model 1: unadjusted; Model 2: adjusted for age, sex and subtypes. QoL-AD: Quality of Life in Alzheimer's Disease scale; SwLS: Satisfaction with Life Scale; WHO-5: World Health Organization-Five Well-Being Index.

(c) Social capitals, assets and resources (CAR)

	Model 1	Model 2
Measurement: living well		
QoL-AD	1 (fixed)	1 (fixed)
SwLS	0.84 (0.78, 0.91)	0.85 (0.78, 0.92)
WHO-5	3.18 (2.93, 3.43)	3.17 (2.93, 3.41)
Measurement: Social capitals, assets and resources		
Social network		
Isolated vs not isolated (ref.)	-0.23 (-0.27, -0.18)	-0.22 (-0.26, -0.19)
Cultural capital		
Ordinal variable	0.49 (0.40, 0.58)	0.55 (0.46, 0.64)
Reciprocity and local trust		
Not likely vs likely* (ref.)	-0.15 (-0.18, -0.11)	-0.13 (-0.16, -0.09)
Structural		
CAR -> Living well	2.69 (2.12, 3.27)	2.83 (2.23, 3.44)

*Note: Latent variance of social capitals, assets and resources fixed at 1; Model 1: unadjusted; Model 2: adjusted for age, sex and subtypes *Likelihood of return of lost wallet. QoL-AD: Quality of Life in Alzheimer's Disease scale; SwLS: Satisfaction with Life Scale; WHO-5: World Health Organization-Five Well-Being Index.*

(d) Managing everyday life with dementia (MEL)

	Model 1	Model 2
Measurement: living well		
QoL-AD	1 (fixed)	1 (fixed)
SwLS	0.82 (0.75, 0.88)	0.83 (0.76, 0.89)
WHO-5	3.16 (2.90, 3.42)	3.18 (2.93, 3.44)
Measurement: Managing everyday life		
Functional ability		
Ordinal variable	0.92 (0.83, 1.00)	0.91 (0.82, 1.00)
Dependence		
Ordinal variable	0.89 (0.81, 0.96)	0.89 (0.81, 0.97)
MEL -> Living well	-2.23 (-2.60, -1.86)	-1.98 (-2.35, -1.61)

Note: Latent variance of managing everyday life with dementia fixed at 1; Model 1: unadjusted; Model 2: adjusted for age, sex and subtypes. QoL-AD: Quality of Life in Alzheimer's Disease scale; SwLS: Satisfaction with Life Scale; WHO-5: World Health Organization-Five Well-Being Index.

(e) Social Location (SLC)

	Model 1	Model 2
Measurement: living well		
QoL-AD	1 (fixed)	1 (fixed)
SwLS	0.84 (0.78, 0.91)	0.84 (0.78, 0.91)
WHO-5	3.16 (2.92, 3.41)	3.16 (2.92, 3.41)
Measurement: Social location		
Social comparison		
Ordinal variable	0.50 (0.42, 0.59)	0.54 (0.45, 0.63)
Community status		
Ordinal variable	0.31 (0.26, 0.36)	0.29 (0.24, 0.34)
Structural		
SLC -> Living well	4.29 (3.64, 4.94)	4.66 (3.60, 5.72)

Note: Latent variance of social location fixed at 1; Model 1: unadjusted; Model 2: adjusted for age, sex and subtypes. QoL-AD: Quality of Life in Alzheimer's Disease scale; SwLS: Satisfaction with Life Scale; WHO-5: World Health Organization-Five Well-Being Index.

Supplementary Table 3. Coefficients and confidence intervals for the complete model

	Unadjusted		Adjusted for age, sex and dementia sub-type	
	Coef.	(95% CI)	Coef.	(95% CI)
Measurement model - living well				
QoL-AD	1	(fixed)	1	(fixed)
SwLS	0.83	(0.78, 0.88)	0.83	(0.78, 0.88)
WHO-5	3.15	(2.97, 3.33)	3.14	(2.96, 3.32)
Structural associations				
PSY	3.49	(2.93, 4.05)	3.55	(2.93, 4.17)
SLC	-0.06	(-1.34, 1.21)	0.08	(-2.10, 2.26)
MEL	0.33	(-0.06, 0.73)	0.33	(-0.06, 0.71)
PHY	1.23	(0.36, 2.11)	1.23	(-0.10, 2.58)
CAR	0.58	(0.13, 1.03)	0.67	(-0.04, 1.38)
Correlations between latent factors				
PSY, SLC	-0.77	(-0.88, -0.66)	-0.76	(-0.87, -0.65)
PSY, MEL	0.32	(0.24, 0.41)	0.31	(0.23, 0.40)
PSY, PHY	0.75	(0.70, 0.80)	0.75	(0.70, 0.80)
PSY, CAR	0.41	(0.31, 0.52)	0.39	(0.29, 0.50)
SLC, MEL	-0.43	(-0.53, -0.33)	-0.42	(-0.52, -0.32)
SLC, PHY	-0.84	(-0.95, -0.73)	-0.83	(-0.94, -0.72)
SLC, CAR	-0.52	(-0.68, -0.36)	-0.48	(-0.64, -0.32)
MEL, PHY	0.41	(0.34, 0.47)	0.41	(0.35, 0.47)
MEL, CAR	0.38	(0.27, 0.48)	0.37	(0.27, 0.47)
PHY, CAR	0.40	(0.30, 0.50)	0.39	(0.29, 0.48)

Note: QoL-AD: Quality of Life in Alzheimer's Disease scale; SwLS: Satisfaction with Life Scale; WHO-5: World Health Organization-Five Well-Being Index; SLC: Social Location; CAR: Social capitals, assets and resources; PSY: Psychological Characteristics and Psychological Health; PHY: Physical Fitness and Health; MEL: Managing Everyday Life with Dementia

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