

Relationship between depressive symptoms and capability to live well in people with mild to moderate dementia and their carers: results from the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study

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None

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Data availability statement

The datasets generated and analysed during the current study are not publicly available due to the restrictions imposed in the original study but are available from the IDEAL study team on reasonable request.

Author contributions

YTW and FEM developed the original idea and designed the approach. YTW conducted the data analysis and FEM supervised the analysis. YTW, LC and FEM contributed to manuscript writing. YTW had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Abstract

Objectives

Depression is a common condition in dementia and has a substantial impact on quality of life and wellbeing. There is limited evidence on how depressive symptoms in the person with dementia impact on the carer, and vice versa. The aim of this study is to investigate dyadic relationships between depressive symptoms and capability to live well in both people with dementia and their carers and to examine whether people with dementia who do not have a carer are more vulnerable to the impact of depressive symptoms than those who have a carer.

Methods

Using a large cohort study of 1547 community-dwelling people with mild to moderate dementia and 1283 carers in Great Britain, a Bayesian analysis framework was developed to incorporate dyads (N=981), people with dementia whose carers did not participate (N=127), people with dementia who did not have a carer (N=137) and dyads with missing data (N=302) and estimate actor and partner relationships between depressive symptoms and capability to live well, which was expressed as a latent factor derived from measures of quality of life, life satisfaction and wellbeing.

Results

Depressive symptoms in people with dementia and carers had negative associations with capability to live well both for the individual and for the partner. Compared to those who had a carer, depressive symptoms had a greater impact on capability to live well in people with dementia who did not had a carer.

Conclusions

The impact of depression may extend beyond the person experiencing the symptoms. Future interventions for depressive symptoms should utilise this potential wider impact to understand and optimise treatment effects.

Keywords

Dementia; Depression; Quality of Life/Wellbeing; Epidemiology; Dyadic analysis

Introduction

‘Living well’ with dementia has become an important topic in health research and policy planning (UK government, 2009) and can be conceptualised as reflecting quality of life, life satisfaction and wellbeing (Martyr et al., 2018). Although a wide range of factors has been related to quality of life in people with dementia and carers (Farina et al., 2017; Martyr et al., 2018), few studies have investigated the interpersonal influence that conditions of either the person with dementia or the carer might have on the other. The person with dementia and the carer may be considered as a ‘dyad’ rather than two independent individuals. Indeed, some randomised controlled trials have included joint dyadic interventions to improve health and quality of life in both people with dementia and carers (Bielsten & Hellstrom, 2017). However, these studies did not compare the effects of individual and dyadic interventions or quantify potential interpersonal influences (Stahl et al., 2016). Evidence from observational studies can be used to indicate the potential impact of interventions beyond just the person treated and to identify factors that should be addressed for both the person with dementia and the carer.

One such factor that is likely to be relevant for people with dementia and carers is the extent of depressive symptoms that either or both may experience. Depression is a highly prevalent but treatable condition in people with dementia (Kitching, 2015), and is also seen at elevated

levels in carers of people with dementia, with a substantial impact on quality of life and wellbeing (Clare et al., 2019; Farina et al., 2017). For people with dementia, impairments in memory, language and functional abilities may have a negative impact on mood and increase carer burden (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). For carers, the stress of providing care can lead to depressive symptoms and poor health status and compromise the quality of caregiving (Gellert et al., 2017; Miller et al., 2019; Pinquart & Sorensen, 2007). Recent studies have reported the potential impact of depression and anxiety on quality of life in patient-carer dyads of those living with HIV/AIDS, cancer and chronic obstructive pulmonary disease (Bagheri, Taheri, & Motazedian, 2019; Ivziku, Clari, Piredda, De Marinis, & Matarese, 2019; Li, Lin, Xu, & Zhou, 2018) but few have focused on dyads of people with dementia and carers. Given the close relationship between people with dementia and their carers, depressive symptoms in one person may have a negative impact on quality of life and wellbeing not just for that individual but also for the other, and vice versa. Compared to those who have a carer, people with dementia who do not have a carer could be more vulnerable to the impact of depressive symptoms due to lack of emotional and social support from carers (Miranda-Castillo, Woods, & Orrell, 2010). Yet existing studies have not been able to incorporate these complicated situations in real life and estimate the relationships using a single analytical framework.

Interpersonal influences can be investigated using dyadic modelling methods (Ledermann & Kenny, 2017; Monin et al., 2018) but existing models can be limited when coping with real life situations such as the need for complete information from both members of the dyad.

Where people with dementia take part in a study, their carers may decline to participate in the research, or may provide only partial information. In these situations, general approaches such as maximum likelihood estimation or multiple imputation can be used to handle these missing data and estimate what would be found if the complete data could have been collected under different assumptions. Some people with dementia, particularly those in the early stages, might not have or need a carer. In these situations, the absence of carer data needs to be treated differently to missing data, as the data are ‘not applicable’ (i.e. the data never existed), rather than missing (i.e. the data existed but are incomplete). A novel analytical framework is needed to investigate the interpersonal influences within dyads appropriately while flexibly incorporating ways of managing these different reasons for the absence of data. Here we focus on the issue of depressive symptoms and their relationship with capability to live well with dementia, in order to properly investigate the impact of depressive symptoms on the dyads, and for those people with dementia who do not have a carer.

Using a large cohort study of community-dwelling people with mild to moderate dementia and carers in Great Britain, the aim of this study is to investigate dyadic relationships between

depressive symptoms and capability to live well in people with dementia and carers and to examine whether the impact of depressive symptoms is stronger in people with dementia who did not have a carer than in those who had a carer. A Bayesian dyadic framework was developed to incorporate complete person with dementia–carer dyads, people with dementia whose carers declined to participate and people with dementia who did not have a carer and to estimate how depressive symptoms might impact on capability to live well in the person with the symptoms (actor effect) and the other member of the dyad (partner effect).

Methods

Study population

The Improving the experience of Dementia and Enhancing Active Life (IDEAL) study is a longitudinal cohort study of 1547 community-dwelling people with mild to moderate dementia and 1283 carers across England, Scotland and Wales (Clare et al., 2014). The study was set up to investigate social, psychological and economic factors that enhance the capacity to live well with dementia. Baseline recruitment started from June 2014 to August 2016 through a network of 29 National Health Service sites and was carried out by trained clinical research network staff. The recruitment was designed to establish a cohort of people with mild to moderate dementia at baseline so that a sample ranging from mild to severe dementia could be observed at follow up waves (Clare et al., 2014). All participants were required to have a

clinical diagnosis of dementia and a Mini-Mental State Examination (MMSE) score of 15 or above on entry to the study. Although there are no established MMSE cut-offs for defining dementia severity (National Institute for Health and Care Excellence, 2011), a score of 15 or above could exclude those with severe dementia, who might have difficulty in completing the extensive questionnaires used in the study (>400 questions covering multiple topics).

Potential participants were identified from Memory Services, specialist clinics and databases listing people with dementia who are interested in taking part in research and were contacted by phone or letter or spoken in person during clinic appointments to establish their interest in participating in the IDEAL study. For those who expressed interest, a home visit was arranged to provide further information on the study and obtain written informed consent where appropriate. People with dementia who were not able to provide informed consent were excluded from recruitment. Primary carers, who provided practical or emotional unpaid support for the participants with dementia, were also invited to take part where possible. For those who agreed to take part, researchers visited participants to conduct structured interviews and asked carers to complete self-reported questionnaires separately. Informed consent was obtained from all individuals. The IDEAL study was approved by the Wales 5 Research Ethics Committee (reference 13/WA/0405) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014-11684). The study is registered with the UK Clinical Research Network, registration number 16593.

Measurements

The measures of ‘capability to live well’ for people with mild to moderate dementia and carers have been presented in previous IDEAL work (Clare et al., 2019a; 2019b; Wu et al., 2018) and incorporate three key aspects: quality of life, life satisfaction and wellbeing. For both people with dementia and carers, life satisfaction was measured by the Satisfaction with Life Scale (SwLS) (Diener, Emmons, Larsen, & Griffin, 1985) and wellbeing was measured by the World Health Organisation Five Well-being Index (WHO5) (Bech, 2004). Quality of life for people with dementia was measured by the Quality of Life in Alzheimer’s Disease (QoL-AD) while carers were assessed using the World Health Organisation Quality of Life-Brief (WHOQOL-BREF) (Skevington et al., 2004; Wu et al., 2018). More detailed information on these measures and their score ranges is provided in Table S1, Supplementary Materials.

Two different measures were used to assess depressive symptoms in people with dementia and carers. The 10-item Geriatric Depression Scale (GDS 10) (Sheikh & Yesavage, 1986) was used with people with dementia while the 20-item Center for Epidemiological Studies Depression (CES-D) (Radloff, 1977) was administered to carers. The range of possible GDS 10 scores was between 0 and 10 whereas the range for CES-D was between 0 and 60. In this

paper, we consider the entire spectrum of depressive symptom scores. To make the two measures more comparable and aid understanding of the models, the scores were divided into tertiles (low, middle and high) based on distributions of the study population. Cut-off points for the two measures are provided in Supplementary Materials (Table S2). There was missing data on depressive symptoms for 169 (11%) people with dementia and 82 (6.4%) carers.

Information on the age and sex of people with dementia was collected in the interviews. The age of participants was divided into five groups: <65, 65–69, 70–74, 75–79 and >80.

Interviewers also recorded the availability of carers: whether people with dementia had an informal carer and whether the carer agreed to take part or not.

Analytical strategy

Before undertaking dyadic modelling, multivariate regression and frequentist approaches were used to investigate the associations between levels of depressive symptoms and the three living well measures in people with dementia and carers. The complete case analysis included 981 dyads of people with dementia and carers, while 566 had either missing data or not applicable information (Figure 1). The 127 carers who declined to take part can be investigated with multiple imputation or other methods for missing data, whereas individuals without carers at all (N=137) are not ‘missing’ carer data in the conventional sense. Carer

information regarding the 137 people with dementia who did not have a carer should be treated as ‘not applicable’. Hence, the frequentist framework could only include the 1410 who had a carer for analysis and was not able to utilise all data from the 1547 participants. Since the Bayesian framework can be more flexible in incorporating different reasons for absence of data, either missing or not applicable, this analysis used a Bayesian model to investigate the dyadic relationships between depressive symptoms and capability to live well, including all 1547 people with dementia and 1283 carers.

Figure 2 shows the model structure for the dyadic analysis. Two latent factors including the three living well measures were generated for people with dementia (SwLS, WHO5 and QoL-AD) and carers (SwLS, WHO5 and WHOQOL factor score) with SwLS fixed at 1 (referent) in both latent factors. The correlation within dyads was estimated using a higher order latent factor (*Dyad*), following a normal distribution of mean=0 and variance= σ^2 . For those with a carer who either agreed or declined to take part (N=1413), a standard actor-partner independent model (APIM) for distinguishable members (Ledermann & Kenny, 2017) was fitted to estimate the actor ($P_GDS10-P_LW$, C_CESD-C_LW) and partner relationships ($P_GDS10-C_LW$, C_CESD-P_LW) between depressive symptoms and living well latent factors. Two types of model were carried out to incorporate those who did not have a carer: a ‘combined’ model which added these participants to the same actor relationship as those with

a carer ($P_GDS10-P_LW$); and a ‘separated’ model which indicated a different actor relationship ($P_GDS10-P_LW^*$). Age and sex of the people with dementia were adjusted in the analysis models.

Based on the assumption of missing-at-random (MAR), the missing data mechanism for living well measures was considered to be related only to aspects included in the modelling. A multivariate probit model was used to address missing data on depressive symptoms in people with dementia and carers (Molitor, Best, Jackson, & Richardson, 2009). The covariates were used to inform the missing data matrix. All full likelihood models were estimated based on non-informative or flat priors for all parameters. All models were fitted with 200000 burn-in samples with thinning of 10 in order to remove autocorrelation within the models. Model convergence was checked using Gelman-Rubin diagnostic (Brooks & Gelman, 1998). Median and 95% credible intervals of posterior density are reported for all parameters. This study was based on the IDEAL baseline data version 2.0. All analyses were performed using Stata 14.2 and Winbugs 1.4.3 (Spiegelhalter, Thomas, Best, & Lunn, 2007).

Results

Table 1 reports descriptive information about the study population. Among the 1547 people with mild to moderate dementia, over one-third were 80 years old or above and 56% were

men. Among the 1283 carers, 29% were aged 65 or below and 69% were women.

The mean scores for life satisfaction were 26.1 (standard deviation (SD)=6.1) in people with dementia and 23.8 (SD=6.5) in carers. For wellbeing, the mean scores were 60.9 (SD=20.6) in people with dementia and 55.3 (SD=19.8) in carers. Different measures for quality of life were used in people with dementia (QoL-AD: mean=36.8, SD=5.9) and carers (WHOQOL factor score: mean=0.0, SD=2.1). Mean scores for these living well measures all gradually decreased across low to high tertiles of depressive symptoms in both people with dementia and carers (Table S2, Supplementary Materials).

For people with dementia, the median depression score (GDS 10) was 2 with an interquartile range (IQR) between 1 and 4. For carers, the median score (CES-D) was 5 and IQR was between 2 and 10. Approximately 20% of people with mild to moderate dementia exceeded the cut-point of >4 on the GDS 10 recommended for referral to identify clinical depression, and 13% of carers exceeded the cut-point of >15 on CES-D indicated for referral to identify clinical depression.

The results of Bayesian dyadic modelling are reported in Table 2, including the associations between depressive symptoms and capability to live well, the loadings of three living well

measures and variance and covariance of two latent factors. Both combined and separated models suggested strong actor relationships and potential partner effects on capability to live well in the highest tertile of depressive symptoms. The separated model further showed a stronger association in those who did not have a carer. For people with dementia, the highest tertile of depressive symptoms was associated with lower capability to live well (-7.47; 95% CI: -8.06,-6.88) which also impacted on their carers (-1.49; 95% CI: -2.03,-0.98). For carers, the highest tertile of depressive symptoms was related to both their own capability to live well (-7.49; 95% CI: -8.14,-6.86) and that of the person with dementia (-0.85; 95% CI: -1.32,-0.38). Compared to those who had a carer, the effect sizes in participants who did not have a carer were stronger for those in the moderate (-4.99; 95% CI: -6.17,-3.83) and high tertile of depressive symptoms (-8.29; 95% CI: -9.45,-7.15).

Table 3 reports the results further adding the covariates, age and sex of the people with dementia. When adjusting for the covariates or using covariates to inform missing data, the estimates only had minimal changes.

Discussion

This study developed a Bayesian analysis framework to investigate the potential interpersonal influence of depressive symptoms on capability to live well in people with mild to moderate

dementia and their carers and addressed complex situations of missing and not applicable data. Both actor and partner relationships were apparent for those in the highest tertile of depressive symptoms. The partner effect of depressive symptoms in people with mild to moderate dementia was stronger than that seen for carers. Compared to those who had a carer, people with dementia who did not have a carer were found to be more vulnerable to depression and even a moderate level of depressive symptoms had a strong impact on their capability to live well.

Strengths and limitations

The IDEAL study included a large number of community-dwelling people with mild to moderate dementia and carers across Great Britain and used multiple measures to assess living well in both participants and their carers. The strength of large sample size allows investigation of complicated real life situations through a novel method of dyadic analysis.

Compared to frequentist approaches, this analytical framework was more flexible with regard to including participants who either had or did not have a carer and estimating all associations in one model. People who had a carer that declined to take part could be correctly included in dyadic modelling.

Different measures of depressive symptoms and quality of life were used in people with

dementia and carers. The categorisation of depression scores might reduce granularity of the measures and add complexity to the missing data model. However, this study focused on relative differences and hence the use of different measures should have limited impact on the results. This cross-sectional study could not indicate causal directions. Despite potential confounding effects of socioeconomic factors and comorbidities, previous IDEAL work has reported that depression and psychological health had the strongest associations with capability to live well relative to all other sociodemographic and physical health factors (Clare et al., 2018). Different types of relationship between the person with dementia and carer could potentially modify the dyadic associations, but additional stratification would reduce the power to investigate effects and the majority of the carers were spouses/partners (81%). The IDEAL study was designed to focus on people with mild to moderate dementia (median MMSE score=23.0) at baseline and used MMSE scores to determine eligibility given the complex requirements of the structured interview. Since the cohort did not include people across the full spectrum of dementia, the results here might not be generalised to those in the more advanced stages. The missing data mechanism was based on the MAR assumption. Although additional missing data models could be added to test plausible scenarios of missing not at random, the impact of missing data would need to be large to reduce the effects seen. Given that individuals with depression are less likely to take part in research than those without (Lamers et al., 2012), missing data would be more likely to increase the effects rather

than decrease them, and the results were changed little by including a more specific missing data model.

Interpretation of findings

Depressive symptoms might be considered to be a reverse measure for ‘living well’ and one might say that their negative relationships with quality of life and wellbeing are expected.

However, the additional partner effects found in this study may indicate that depressive symptoms are not equal to poor quality of life and wellbeing within individuals. Positive and negative aspects of mental health can be highly-related but distinct and complementary constructs (Winzer et al., 2014).

The results showed actor and partner relationships between depressive symptoms and capability to live well with dementia. This indicates that depressive symptoms in either person might have a negative impact on both members of the dyad. Similar to this, a recent observational study focusing on stroke survivors and their carers reported actor relationships between depression and quality of life in both members of the dyad and a potential partner effect of carer depression (Wan-Fei et al., 2017). These findings suggest that depression may play an important role in the management of chronic conditions and addressing depressive symptoms may improve quality of life and wellbeing in people living with a range of chronic

conditions and their carers, including dementia.

In addition to dyadic modelling, the results of the separated model highlight a stronger relationship between depressive symptoms and capability to live well in people with dementia who did not have a carer compared to those who had a carer. Although people who did not have a carer generally had better health and functional ability than those who did have a carer, they appeared to be more vulnerable to depressive symptoms. Previous research has suggested that people with dementia who live alone or do not have a carer are at increased risk for unmet social, psychological, environmental and medical needs (Miranda-Castillo, Woods & Orrell, 2010). These participants might have low resilience against depression due to a lack of emotional and social support.

Clinical implications and future research directions

This study demonstrates the potential interpersonal influence of depressive symptoms on capability to live well in dyads of people with dementia and carers. Existing studies have tested dyadic interventions on depression in later life (Bielsten & Hellstrom, 2017), though these focused on treating the dyads and seldom considered the impact of an intervention on both individual members of the dyad. Addressing depressive symptoms may impact not only on the person treated but also on the carer, or vice versa, and this wider definition of treatment

effects would assist with study design issues. More attention should be given to people who do not a carer as they may be more vulnerable to the impact of depressive symptoms and need additional social and psychological support.

In recent years, dyadic analysis methods have been widely used to investigate interpersonal influences in ageing research (Monin et al., 2018; Wong & Hsieh, 2017). In addition to the classical APIM, several dyadic models have been proposed to address specific research questions on interactions within close relationships (Ledermann & Kenny, 2017). Collecting additional data from carers, spouses or family members can be a fruitful approach to aid understanding of interpersonal factors and their associations with health outcomes in later life and develop potential interventions for people with chronic conditions and their carers.

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Tables

Table 1. Characteristics of the Study Population (N (%))

	People with dementia			Carers
	Carer available (N=1283)	Carer did not take part (N=127)	No carers (N=137)	(N=1283)
Age				
80+	482 (37.6)	54 (42.5)	67 (48.9)	216 (16.8)
75-79	306 (23.9)	37 (29.1)	27 (19.7)	223 (17.4)
70-74	232 (18.1)	15 (11.8)	13 0(9.5)	267 (20.8)
65-69	160 (12.4)	11 0(8.7)	7 0(5.1)	208 (16.2)
<65	103 0(8.0)	10 0(7.9)	23 (16.8)	369 (28.8)
Sex				
Men	755 (58.9)	61 (48.0)	56 (40.9)	402 (31.3)
Women	528 (41.1)	66 (52.0)	81 (59.1)	881 (68.7)
Depressive symptoms				
Low	430 (37.3)	47 (43.1)	41 (35.7)	496 (41.3)
Middle	393 (34.1)	28 (25.7)	35 (30.4)	338 (28.1)
High	331 (28.7)	34 (31.2)	39 (33.9)	367 (30.6)
Missing	129	18	22	82

Table 2. Results of Dyadic Relationships between Depressive Symptoms and Capability to

Live Well: Combined and Separated models (N=1547)

	Combined model: median (2.5%, 97.5%)		Separated model: median (2.5%, 97.5%)	
	P: Living well	C: Living well	P: Living well	C: Living well
<i>Dyadic association</i>				
P_GDS10: Low	(ref.)	(ref.)	(ref.)	(ref.)
P_GDS10: Middle	-2.58 (-3.03, -2.13)	-0.35 (-0.86, 0.16)	-2.35 (-2.81, -1.90)	-0.32 (-0.83, 0.20)
P_GDS10: High	-7.54 (-8.12, -6.97)	-1.51 (-2.05, -0.98)	-7.47 (-8.06, -6.88)	-1.49 (-2.03, -0.98)
C_CESD: Low	(ref.)	(ref.)	(ref.)	(ref.)
C_CESD: Middle	-0.25 (-0.72, 0.22)	-3.26 (-3.82, -2.72)	-0.50 (-0.99, -0.02)	-3.30 (-3.85, -2.76)
C_CESD: High	-0.60 (-1.05, -0.14)	-7.46 (-8.11, -6.82)	-0.85 (-1.32, -0.38)	-7.49 (-8.14, -6.86)
<i>People without carers</i>				
P_GDS10: Low			(ref.)	
P_GDS10: Middle			-4.99 (-6.17, -3.83)	
P_GDS10: High			-8.29 (-9.45, -7.15)	
<i>Loadings of Living Well latent factors</i>				
Life satisfaction	1 (fixed)	1 (fixed)	1 (fixed)	1 (fixed)
Wellbeing	3.79 (3.53, 4.07)	3.47 (3.22, 3.74)	3.75 (3.50, 4.03)	3.47 (3.22, 3.74)
Quality of life	1.19 (1.11, 1.28)	0.40 (0.38, 0.43)	1.18 (1.10, 1.27)	0.40 (0.38, 0.43)
<i>Variance/covariance</i>				
Var (e.P_LW/e.C_LW)	7.62 (6.34, 9.08)	9.37 (7.74, 11.18)	7.49 (6.20, 8.93)	9.33 (7.73, 11.13)
Cov(e.P_LW, e.C_LW)	1.39 (0.59, 2.20)		1.47 (0.64, 2.26)	

C_CESD: the 20-item Center for Epidemiological Studies Depression for carers; P_GDS10: the 10-item

Geriatric Depression Scale for people with dementia

Table 3. Results of Dyadic Relationships between Depressive Symptoms and Capability to

Live Well Adjusting for Age and Sex in People with Dementia

	Separated model- adjusted: median (2.5%, 97.5%)		Separated model- covariates informed missingness: median (2.5%, 97.5%)	
	P: Living well	C: Living well	P: Living well	C: Living well
<i>Dyadic association</i>				
P_GDS10: Low	(ref.)	(ref.)	(ref.)	(ref.)
P_GDS10: Middle	-2.41 (-2.87, -1.96)	-0.29 (-0.81, 0.22)	-2.34 (-2.80, -1.89)	-0.34 (-0.85, 0.17)
P_GDS10: High	-7.49 (-8.08, -6.92)	-1.51 (-2.05, -0.97)	-7.46 (-8.06, -6.89)	-1.51 (-2.05, -0.98)
C_CESD: Low	(ref.)	(ref.)	(ref.)	(ref.)
C_CESD: Middle	-0.46 (-0.95, 0.04)	-3.20 (-3.75, -2.66)	-0.50 (-0.98, -0.02)	-3.29 (-3.85, -2.75)
C_CESD: High	-0.82 (-1.31, -0.35)	-7.35 (-8.01, -6.72)	-0.85 (-1.32, -0.38)	-7.50 (-8.15, -6.85)
<i>People without carers</i>				
P_GDS10: Low	(ref.)		(ref.)	
P_GDS10: Middle	-5.03 (-6.21, -3.88)		-4.98 (-6.15, -3.83)	
P_GDS10: High	-8.31 (-9.49, -7.19)		-8.31 (-9.49, -7.17)	
<i>Loadings of Living Well latent factors</i>				
Life satisfaction	1 (fixed)	1 (fixed)	1 (fixed)	1 (fixed)
Wellbeing	3.72 (3.47, 4.00)	3.45 (3.21, 3.72)	3.75 (3.50, 4.03)	3.47 (3.22, 3.74)
Quality of life	1.17 (1.09, 1.25)	0.40 (0.37, 0.42)	1.18 (1.10, 1.27)	0.40 (0.38, 0.43)
<i>Variance/covariance</i>				
Var (e.P_LW/e.C_LW)	7.42 (6.16, 8.84)	9.19 (7.61, 11.01)	7.51 (6.23, 8.94)	9.31 (7.70, 11.13)
Cov(e.P_LW, e.C_LW)	1.51 (0.74, 2.32)		1.46 (0.65, 2.26)	

C_CESD: the 20-item Center for Epidemiological Studies Depression for carers; P_GDS10: the 10-item

Geriatric Depression Scale for people with dementia

Figure captions

Figure 1. Chart of the missing and not applicable patterns in the study population

Figure 2. The model structure of dyadic relationships between depressive symptoms and capability to live well in people with dementia (P) and carers (C)

Figure 1. Chart of the missing and not applicable patterns in the study population

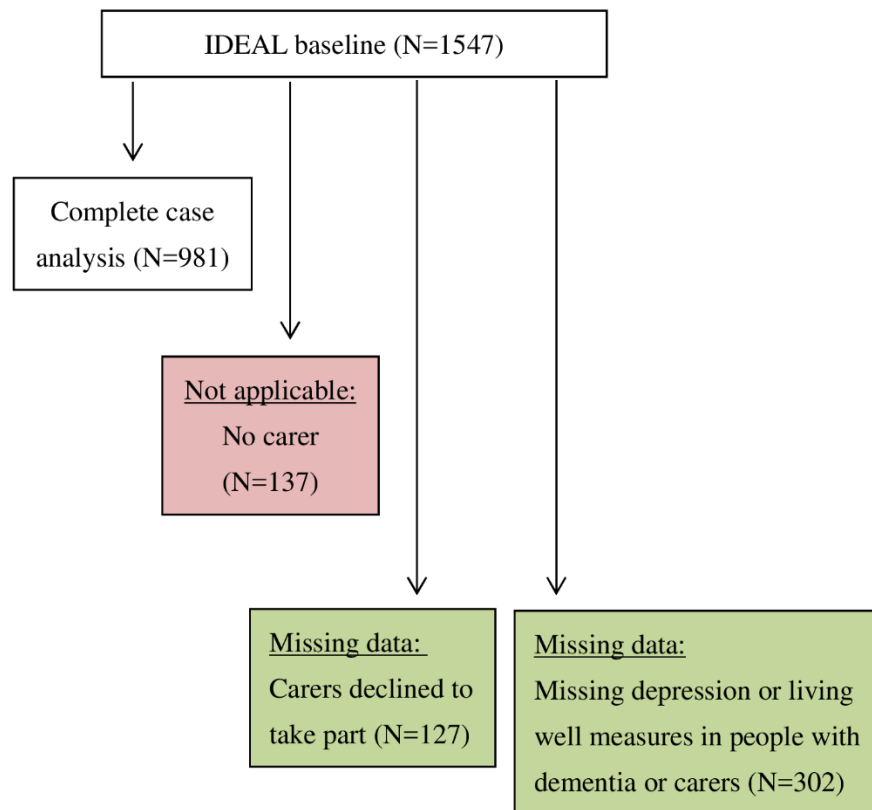
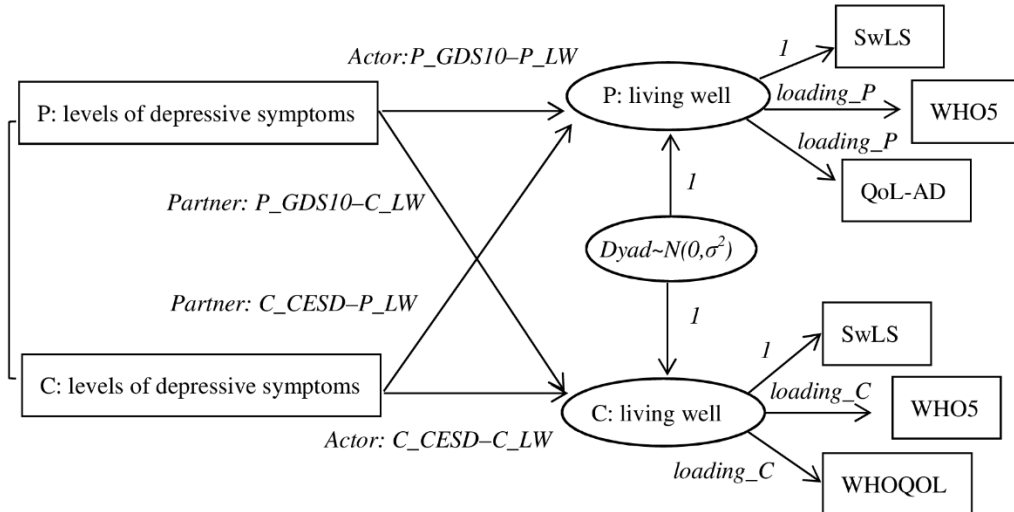
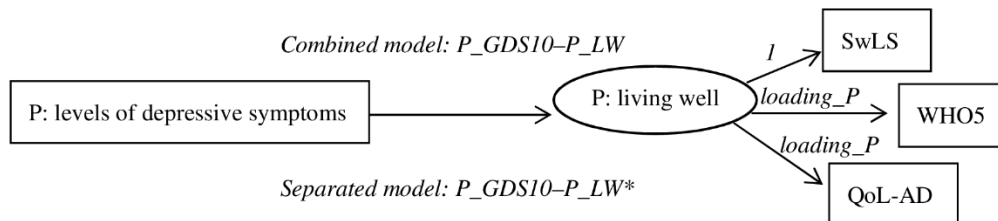


Figure 2. The model structure of dyadic relationships between depressive symptoms and capability to live well in people with dementia (P) and carers (C)

Dyads of people with dementia and carers (N=1410)



People with dementia who did not have a carer (N=137)



SwLS: Satisfaction with Life Scale; WHO5: World Health Organisation Five Well-being Index; QoL-AD: Quality of Life in Alzheimer's Disease; WHOQOL: Factor score for the World Health Organisation Quality of Life-Brief; LW: Living Well latent factor; GDS10: the 10-item Geriatric Depression Scale for people with dementia; CESD: the 20-item Center for Epidemiological Studies Depression for carers

Relationship between depressive symptoms and capability to live well in people with mild to moderate dementia and their carers: results from the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study

Supplementary Materials

Table S1. Measures of capability to live well in people with dementia and carers

	People with dementia	Carers
Life satisfaction	<i>Satisfaction with Life Scale (SwLS)</i> : a seven-item measure for global judgements of satisfaction with life; the score range is between 5 and 35. (Diener, Emmons, Larsen, & Griffin, 1985)	
Wellbeing	<i>World Health Organisation Five Well-being Index (WHO5)</i> : a short self-reported measure of current mental wellbeing including items on positive mood, vitality and general interests; a score range is between 0 and 100. (Bech, 2004)	
Quality of life	<i>Quality of Life in Alzheimer's Disease (QoL-AD)</i> : a dementia-specific measure incorporating multiple aspects of mood, health status, interpersonal relationships and financial situation; the measure includes 13 items with a score range between 13 and 52. (Logsdon, Gibbons, McCurry, & Teri, 2000)	<i>World Health Organisation Quality of Life-Brief (WHOQOL-BREF)</i> : a measure including two single indicators (overall quality of life and general health) and four domains (physical health, psychological health, social relationships and environment) (Skevington et al., 2004). An overall score was generated using a factor analysis including the six WHOQOL-BREF domains. Factor scores were estimated for those with complete data (mean=0.0; standard deviation=2.1) (Wu et al., 2018).

Table S2. Mean and standard deviation of three living well measures in people with dementia

(P) and carers (C)

<i>Dyads (N=981)</i>	Person with dementia			Carer		
P: depressive symptoms (GDS10)	SwLS	WHO5	QoL-AD	SwLS	WHO5	WHOQOL
Low (0-1)	29.2 (4.3)	73.6 (14.5)	40.7 (4.5)	24.8 (6.3)	59.7 (18.8)	0.4 (1.9)
Middle (2-3)	27.6 (4.7)	63.1 (15.9)	37.4 (4.4)	24.2 (6.2)	56.2 (18.5)	0.1 (2.0)
High (4-10)	22.2 (6.3)	45.0 (19.4)	31.4 (5.1)	22.4 (6.6)	51.2 (20.1)	-0.5 (2.2)
C: depressive symptoms (CESD)						
Low (0-3)	27.4 (5.5)	64.3 (19.3)	37.8 (5.7)	27.1 (4.9)	68.1 (14.2)	1.3 (1.5)
Middle (4-8)	26.6 (5.7)	62.1 (19.4)	37.0 (5.8)	23.6 (6.1)	55.7 (16.4)	0.1 (1.5)
High (9-58)	25.8 (6.2)	58.8 (21.2)	35.8 (6.1)	20.0 (6.4)	40.5 (16.3)	-1.7 (1.8)
<i>People without carers (N=107)</i>						
P: depressive symptoms (GDS10)	SwLS	WHO5	QoL-AD			
Low (0-1)	26.4 (6.4)	70.5 (14.6)	41.0 (4.3)			
Middle (2-3)	23.4 (5.0)	59.5 (14.1)	35.6 (4.0)			
High (4-10)	19.8 (5.7)	49.4 (19.2)	31.7 (5.6)			

SwLS: Satisfaction with Life Scale; WHO5: World Health Organisation Five Well-being Index; QoL-AD:

Quality of Life in Alzheimer's Disease; WHOQOL: Factor score for the World Health Organisation Quality of

Life-Brief; GDS10: the 10-item Geriatric Depression Scale for people with dementia; CESD: the 20-item Center

for Epidemiological Studies Depression for carers