

**Inequalities in living well with dementia – the impact of deprivation on wellbeing,
quality of life and life satisfaction: results from the Improving the experience of
Dementia and Enhancing Active Life study**

Running title: Deprivation and living well with dementia

Authors

Yu-Tzu Wu¹, Linda Clare¹, Ian Rees Jones², Anthony Martyr¹, Sharon M Nelis¹, Catherine Quinn¹, Christina R Victor³, Ruth A Lamont¹, Isla Rippon³, Fiona E Matthews⁴, On behalf of the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study

Affiliations

- ¹. REACH: The Centre for Research in Ageing and Cognitive Health, University of Exeter Medical School and College of Life and Environmental Sciences, St Luke's Campus, Exeter EX1 2LU, UK
- ². Wales Institute of Social and Economic Research, Data and Methods, Cardiff University, 38 Park Place, Cathays Park, Cardiff CF10 3BB, UK
- ³. Department of Clinical Sciences, College of Health and Life Sciences, Brunel University, London, Uxbridge UB8 3PH

⁴. Institute of Health and Society, Newcastle University, The Baddiley-Clark Building,
Richardson Road, Newcastle Upon Tyne, NE4 5PL, UK

Corresponding author

Yu-Tzu Wu

(Present address)

Health Service and Population Research Department, Institute of Psychiatry, Psychology and
Neuroscience, King's College London,

David Goldberg Centre, De Crespigny Park, Denmark Hill, London SE5 8AF

United Kingdom

Email: yu-tzu.wu@kcl.ac.uk

Telephone: 020 78480619

Word count

3165

Acknowledgements

We thank the local principal investigators and staff at our NHS sites, the IDEAL study participants and their families, the members of the ALWAYSs group and the Project Advisory Group.

Funding

The IDEAL study is funded by the Economic and Social Research Council (UK) and the National Institute for Health Research (UK) through grant ES/L001853/2 'Improving the experience of dementia and enhancing active life: living well with dementia' (Investigators: L. Clare, I.R. Jones, C.Victor, J.V. Hindle, R.W.Jones, M.Knapp, M.Kopelman, R.Litherland, A.Martyr, F.E. Matthews, R.G.Morris, S.M.Nelis, J.Pickett, C.Quinn, J.Rusted, J.Thom). We are grateful to the three UK research networks, the NIHR Clinical Research Network in England, the Scottish Dementia Network (SDN) and Health and Care Research Wales, for supporting the study.

Conflict of interest

None

Abstract

Objectives

Area level factors, such as deprivation and urban/rural settings, have been associated with variation in local resources and services and health inequality in later life. The aim of this study is to investigate the potential impact of deprivation and urban/rural areas on capability to live well with dementia and to examine whether availability of informal carers modified the associations.

Methods

The analysis was based on a large cohort study of 1547 community-dwelling people with dementia across Great Britain. Quality of life, life satisfaction and wellbeing were measured as indices of 'living well'. Multivariate modelling was used to investigate differences in living well measures across deprivation quintiles and urban/rural areas adjusting for sociodemographic factors and number of comorbidities and stratifying by three groups: those living with a carer, those with a non co-resident carer and those without a carer.

Results

Negative dose-response relationships between deprivation and measures of quality of life

(-2.12; 95%CI: -3.52, -0.73), life satisfaction (-1.27; 95%CI: -2.70, 0.16) and wellbeing (-5.24; 95%CI: -10.11, -0.36) were found in participants living with a carer. The associations were less clear in those with a non co-resident carer and those without a carer but these two groups generally reported lower scores on living well indicators than participants living with a carer. There was no urban/rural difference.

Conclusions

The findings suggest inequalities in living well with dementia according to levels of deprivation. Additional resources are needed to improve post-diagnostic care in highly deprived areas and support those who have no informal carer.

Keywords

Dementia; Quality of life; Wellbeing; Deprivation; Inequality

Key points

- Deprivation has a potential negative impact on capability to live well with dementia.
- There are no urban/rural differences in the capability to live well with dementia.
- People with dementia without a carer have lower capability to live well than those living with a carer.

Introduction

The large number of people with dementia has been a challenge both nationally and internationally [1]. Enabling people to live well with this condition, and maintain the best possible health and wellbeing, has become a critical aim for health policy and research [2].

Current National Health Service (NHS) policy in England focuses on enhancing rates of dementia diagnosis and plans to improve post-diagnostic care and support through primary care systems [3]. Although several monitoring indicators have been set up to review dementia care across different regions in England [4], the outcomes of these NHS initiatives for enhancing the capability to 'live well' with the condition have not been assessed.

There is a substantial body of research focusing on quality of life and positive health outcomes in relation to living with dementia [5,6]. A large number of observational studies have used different types of quality of life measures and investigated their associations with a wide range of social, psychological and physical health factors [5]. However, existing studies have predominantly focused on individual level factors. There has been little exploration of the potential impact of area level factors on living well with dementia and their interactions with other individual characteristics.

Area level factors, such as deprivation and urban/rural settings, have been associated with

variation in local resources and services as well as health inequality [7,8]. Empirical evidence from population-based studies has suggested a negative relationship between deprivation, health and wellbeing in older adults [9,10]. Research based on medical records has also reported variations in access to diagnosis and medication [11,12] as well as in cognitive function, health-rated quality of life and mortality in people with dementia across deprivation levels and urban/rural areas [13,14]. These area level measures may provide insights into the wider contextual barriers and enablers to living well with dementia and may have important public health implications for dementia care.

Although area level factors might be associated with the capability to live well with dementia, these relationships might vary depending on some individual characteristics such as availability of an informal carer. Spouse and family carers usually take a primary role in providing care for people with dementia and support basic needs in daily life [2]. People with dementia who live alone or do not have a carer have been recognised as a vulnerable group that is at increased risk for unmet social, psychological, environmental and medical needs [15]. This group might have low resilience to deprivation due to lack of support from informal carers. Thus, availability of a carer might act as a buffer to the negative impact of deprivation and may have a potential modifying effect on the associations between area level factors and living well indicators.

The aim of this study is to investigate the potential impact of area level factors on capability to live well with dementia and their interactions with individual characteristics using a large cohort study of people with dementia across Great Britain. The analysis investigated two specific questions: (1) How do area level factors, deprivation and urban/rural areas, influence capability to live well with dementia? (2) Does availability of an informal carer modify the impact of deprivation and urban/rural areas on capability to live well with dementia?

Materials and Methods

Study population

The Improving the experience of Dementia and Enhancing Active Life (IDEAL) study is a longitudinal cohort study of community-dwelling people with dementia and their carers [16].

The project aims to investigate the social, psychological and economic factors that support people in living well with dementia. The baseline study population included 1547 people with dementia and 1283 carers recruited through a network of 29 NHS sites across England, Scotland and Wales between July 2014 and August 2016. All participants had a clinical diagnosis of dementia and a Mini-Mental State Examination (MMSE) score of 15 or above on entry to the study. Primary carers of the participants were also recruited where possible. For those who consented to take part, researchers visited participants and completed structured

interviews. Written informed consent was secured for all participants. The IDEAL study was approved by the Wales Research Ethics Committee (reference: 13/WA/0405) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014 – 11684) and registered with the UK Clinical Research Network (registration number 16593).

Individual level measures

The IDEAL interviews included three indicators of subjective perceptions of living well: quality of life, life satisfaction and wellbeing. Quality of life was measured by the Quality of Life in Alzheimer's Disease (QoL-AD) Scale (score range 13-52) [17]. Life satisfaction was based on the Satisfaction with Life Scale (SwLS; score range 7-35) [18] and wellbeing was measured using the World Health Organization Five Well-being Index (WHO-5; score range 0-100) [19]. Individual socioeconomic status was measured using highest level of educational qualification and social class based on the main occupation in working life. Number of chronic conditions was used as an index of physical health and generated based on items from the Charlson Comorbidity Index [20]. Postcodes of people with dementia and carers were cross-referenced to determine whether they were co-resident. The participants were divided into three types: participants living with a carer, participants who had a non co-resident carer and those with no carer. In some cases, participants had a carer but the carer declined to take part (N=127). The residential status of this group was categorised as missing data and

addressed using multiple imputation.

Area level measures

Two area level measures, deprivation index and rural/urban categories, were linked to participants using both postcode information and national statistics. Since England, Scotland and Wales have different versions of deprivation indices and rural/urban classification systems, various data sources were used to determine deprivation and rural/urban status in the IDEAL study population. The deprivation index summarised different domains of characteristics related to poverty and socioeconomic disadvantage including income, employment, education and training, health and disability, barriers to housing and services, the living environment and crime. The latest deprivation index was obtained from the government websites of the three nations of Great Britain: English Index of Multiple Deprivation 2015 [21], Welsh Index of Multiple Deprivation 2014 [22], and Scottish Index of Multiple Deprivation 2016 [23]. To compare deprivation levels across the three countries, the index was divided into quintiles among all area units for each country. The first quintile (Q1) represents 20% of the most deprived areas in the country and the IDEAL participants in this quintile can be considered as living in highly deprived areas.

Urban/rural classification in the UK is mainly based on residential density and settlement size

[24,25]. The Scottish government adopts a different system of rural/urban classification (Scottish Government Urban Rural Classification 2013–2014) [24] from that used in England and Wales (2011 Census Rural Urban Classification) [25]. In England and Wales, physical settlements with a population of 10000 or more were defined as ‘urban’ and all smaller settlements were ‘rural’ [25]. Based on the density of settlements, urban areas were further divided into three types: major conurbation, minor conurbation, city and town, while rural areas included two types: town and fringe, village and dispersed. In Scotland, settlements of 3000 or more people were defined as urban areas. Rural areas, settlements with a population of less than 3000 people, were further divided into accessible (within a 30-minute drive to a settlement of 10000 or more) and remote rural (over a 30-minute drive) [24]. To examine urban/rural differences across countries, the detailed urban/rural categories were combined into a binary variable of urban and rural areas.

Statistical analysis

Multivariate modelling was used to investigate differences in living well indicators (quality of life, life satisfaction and wellbeing) across deprivation quintiles and urban/rural areas adjusting for individual level factors including age, sex, dementia subtypes, education and social class. Further adjustment for comorbidity was used to examine whether associations between living well and deprivation could be attributed to the burden of multiple chronic

conditions. The interaction terms between availability of informal carers (living with carer, non co-resident carer and no carer) and deprivation quintiles were included in regression models adjusting for individual level factors and country. Given the different measures for area level factors across the three countries, all models included country to account for any measurement variation. To account for missing data, multiple imputation was conducted including all variables in the modelling. Estimates from 20 imputed datasets were combined using Rubin's rules [26]. A Wald test was used to examine whether the associations between deprivation quintiles and living well measures achieved statistical significance. Since area level factors from different countries were combined, sensitivity analyses were conducted to examine potential variation across countries. To fully account for any country variation, interaction terms between area level factors and country were included in the models adjusting for individual level factors. This study was based on the IDEAL data version 2.0. All analyses were conducted using Stata 14.2.

Results

Descriptive information on the study population is reported in Table 1. Nearly 90% of the IDEAL participants lived in England (N=1387). The mean age was 76.4 (standard deviation=8.6) with a range between 43 and 98 years. The majority of participants had Alzheimer's disease (56%) and lived with 1-2 comorbidities (53%). Nearly 30% had no

formal educational qualifications and 35% had been employed in manual occupations. Over two-thirds of participants (N=1045) were living with their carer while 238 (16.7%) had a non co-resident carer and 137 (9.6%) had no carer.

Among the 1547 participants, 8.4% lived in the most deprived areas while nearly one-third were from the least deprived areas in the three countries (Table 2). Over two-thirds of participants lived in urban areas (N=1042). Mean scores for the three living well indicators gradually decreased from least to most deprived areas but were similar across urban /rural areas and the three countries.

Table 3 reports the unadjusted and adjusted associations between deprivation quintiles and living well indicators. Decreasing trends from least to most deprived quintiles were found in quality of life and life satisfaction but not wellbeing. Compared to the least deprived quintile, living in the most deprived areas was associated with a 2.5 point lower QoL-AD (-2.51; 95% CI: -3.66, -1.36) and a 2 point lower SwLS score (-1.94; 95% CI: -3.15, -0.73). After adjusting for sociodemographic factors and comorbidities, the differences reduced to 1.6 points on QoL-AD (-1.62; 95% CI: -2.76, -0.49) and 1.1 points on SwLS (-1.12; 95% CI: -2.32, 0.10).

Figure 1(A-C) show estimated scores for living well indicators across deprivation quintiles and stratified by three groups: participants living with a carer, participants who had a non co-resident carer and those without a carer. For those living with carers, decreasing trends from the least to most deprived quintiles were found in all three living well indicators. The adjusted differences between the least and most deprived quintiles were 2 points on QoL-AD (-2.12; 95% CI: -3.52, -0.73), 1.3 points on SwLS (-1.27; 95% CI: -2.70, 0.16) and 5 points on WHO-5 (-5.24; 95% CI: -10.11, -0.36). Participants who had a non co-resident carer or did not have a carer generally reported lower living well scores than those living with their carer although the confidence intervals were wide due to the small sample size.

There was no substantial difference in living well indicators across urban and rural areas.

More detailed information is provided in Supporting Information Table S1–S3.

Discussion

To the best of our knowledge, this is the first study investigating variation in living well indicators across deprivation levels and rural/urban settings using a large cohort of community-based people with dementia in Great Britain. The results show a negative relationship between deprivation quintiles and living well measures and availability of informal carers appeared to modify the associations. A clear dose-response relationship was

found in those living with a carer and the difference was approximate 10% between the least and most deprived quintiles. The decreasing trends were less clear in those with a non co-resident carer and those without a carer but these two groups generally reported lower scores on living well indicators compared to those living with a carer. Urban/rural differences in living well indicators were not found.

Strength and limitations

The IDEAL study recruited a large number of community-based people with dementia from different backgrounds, with varied socioeconomic status and health conditions. Building upon previous research which has tended to focus on quality of life alone, this study measured the concept of living well across three dimensions, providing a more comprehensive understanding of living well with dementia. Deprivation quintiles were defined based on comparison of deprivation scales at the country level.

Potential limitations of this study included the relatively large number of participants from least deprived areas. Although the nationwide distribution of people with dementia is unknown, the prevalence of dementia is suggested to be higher in more deprived areas [27].

People living the most deprived areas were likely to be under-represented but relative differences in living well indicators were clear across deprivation quintiles and were unlikely

to be over-estimated. As the study population only included participants with a MMSE score of 15 or above at baseline, the findings might not be generalisable to those with more severe dementia. Participants and carers might have the same postcodes but could live in different flats or nearby houses. This situation should have a minimal impact on the results as these carers should have the same deprivation level and urban/rural category as the people with dementia. The length of residence was not adjusted in the analysis as over 80% of participants had lived in the same address for more than 5 years. Measures of deprivation differed across countries. To compare deprivation level across countries and minimise the impact of country variation, this study created quintiles based on all area units for each country and adjusted for country in all analyses. The results of sensitivity analyses also show that the association between deprivation quintiles and living well indicators did not vary across countries (Supporting information Table S4). Despite different definitions of urban and rural areas in Scotland and in England and Wales, the sensitivity analysis suggests small variations between country and urban/rural settings (Supporting information Table S5). The detailed categories of urban/rural settings were combined into a binary variable and some nuanced variation might be lost. However, differences in mean scores of living well indicators were small across these detailed categories (Supporting Information Table S2). Due to limited sample sizes in some categories, there was insufficient statistical power to formally examine these differences.

Interpretation of findings

The results show decreasing scores on living well measures from the least to the most deprived quintiles. Although the differences seem to be modest after adjustment, the clear trends across deprivation quintiles correspond well to social gradients in health inequality [7,8] and the results of nationwide surveys of personal wellbeing, which suggest that personal wellbeing measures, including life satisfaction, feelings that life is worthwhile and happiness, decrease in more deprived areas [28]. Any marginal effects of deprivation may have a profound influence on the general population as well as the large number of people with dementia in the UK. The association between deprivation and living well indicators can be partially attributed to individual socioeconomic status and comorbidity but these individual factors only accounted for half of the difference between the most and least deprived quintiles. Some area level factors might contribute to the associations between deprivation and capability to live well with dementia.

Since the indices for area deprivation have been widely associated with inequalities in access to care and services [7], people with dementia living in deprived areas might have limited support from local health and social care systems. Recent analyses of UK primary care data suggested that people with dementia in least deprived areas were 25% more likely to be prescribed anti-dementia drugs such as cholinesterase inhibitors and memantine than the most

deprived [12] but did not find any variation in receipt of healthcare and psychotropic medication across deprivation levels [29]. On the other hand, Dementia Atlas, an interactive website developed to monitor indicators for primary, secondary and tertiary care in England, reveals disparity of care and different completion rates of the annual care review across areas [4]. Although evidence on inequalities in access to dementia care is not conclusive, the current study shows variation in quality of life, life satisfaction and wellbeing measures, which could be relevant to the quality and effectiveness of care. Qualitative research has also reported that some environmental or neighbourhood factors, such as access to green space, urban design and local support for people with dementia, might play an important role in quality of life and wellbeing [30].

The dose-response relationship between deprivation quintiles and living well indicators seems to be unclear in participants with a non co-resident carer or those without a carer. Despite wide confidence intervals, these participants tended to report lower scores on living well indicators than those living with carers across different deprivation levels. While some of these participants might be able to live independently and might not need a carer, they might still have unmet needs in terms of social and psychological support with greater risk of depression [31].

Clinical implications and future research directions

This study provides empirical evidence on inequalities in living well with dementia and indicates that those who live in deprived areas and do not have a carer may be at particular risk. The current living well indicators in the Dementia Atlas include the completion rate of the annual care review, number of volunteers for the Alzheimer's Society Dementia Friends scheme and availability of a dementia-friendly community [4]. Measures for quality of life and wellbeing could also be incorporated into the monitoring indicators in order to evaluate outcomes of existing services and inform future policy planning. Since variation in living well indicators might be related to limited health and social care in highly deprived areas [7], additional resources may be required to improve availability and accessibility of local services in deprived areas and address inequalities in living well with dementia. For health and social care professionals who provide post-diagnostic support and care review, it is important to identify high risk groups who have limited capability to cope with dementia. In addition to formal health and social care, facilitating the role of local community organisations or charities may be an effective way of providing support for these high risk groups.

The findings suggest a negative relationship between deprivation and capability to live well with dementia. Possible explanations need to be further explored, in particular the link between deprivation, dementia care provision and poor living well indicators and the interplay

between formal and informal care. Since qualitative studies have also suggested that neighbourhood factors are important in supporting the capability to live well with dementia [30], future research should utilise data from different sources, such as national statistics and geographic information systems, and generate area level measures for longitudinal cohorts. This will provide an opportunity to identify underlying mechanisms on how area level factors can support people to live well with dementia.

References

- 1 World Health Organization. Dementia: a public health priority. 2012. World Health Organization, 2012.
- 2 UK government, Department of Health. Prime Minister's challenge on dementia 2020. UK government, 2015.
- 3 National Health Services England. Dementia. Available from: <https://www.england.nhs.uk/mental-health/dementia/> [Accessed 13 Jan 2018]
- 4 UK government, Department of Health. Dementia Atlas: Putting a focus on dementia. UK government, 2016.
- 5 Martyr A, Nelis SM, Quinn C, Wu Y-T, Lamont RA, Henderson C et al. Living well with dementia: a systematic review and correlational meta-analysis of factors associated with quality of life, wellbeing and life satisfaction in people with dementia. *Psychol Med*, 2018. doi: 10.1017/S0033291718000405
- 6 Bowling A, Rowe G, Adams S, Sands P, Samsi K, Crane M et al. Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales. *Aging Ment Health* 2015;19(1):13-31.
- 7 Cromarty H. Adult social care funding (England). House of Commons Library, 2017.
- 8 Public Health England. Chapter 5: inequality in health. Health profile for England. Public Health England, 2017.

- 9 Gale CR, Dennison EM, Cooper C, Sayer AA. Neighbourhood environment and positive mental health in older people: The Hertfordshire Cohort Study. *Health Place* 2011;17(4): 867-874.
- 10 Julien D, Richard L, Gauvin L, Kestens Y. Neighborhood characteristics and depressive mood among older adults: an integrative review. *Int Psychogeriatr* 2012;24(8):1207-25.
- 11 Connolly A, Gaehl E, Martin H, Morris J, Purandare N. Underdiagnosis of dementia in primary care: Variations in the observed prevalence and comparisons to the expected prevalence. *Aging Ment Health* 2011;15(8): 978-984.
- 12 Cooper C, Lodwick R, Walters K, Raine R, Manthorpe J, Iliffe S, et al. Observational cohort study: deprivation and access to anti-dementia drugs in the UK. *Age Ageing* 2016;45(1):148–154.
- 13 Park M, Smith S, Neuburger J, Chrysanthaki T, Hendriks A, Black N. Sociodemographic characteristics, cognitive function, and health-related quality of life of patients referred to memory assessment services in England. *Alzheimer Dis Assoc Disord* 2017;31(2):159-167.
- 14 Sleeman K, Ho Y, Verne J, Gao W, Higginson I. Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001-2010. *BMC Neurol* 2014;14:59.
- 15 Miranda-Castillo C, Woods B, Orrell M. People with dementia living alone: what are

- their needs and what kind of support are they receiving? *Int Psychogeriatr*. 2010 Jun;22(4):607-17.
- 16 Clare L, Nelis SM, Quinn C, Martyr A, Henderson C, Hindle JV, et al. Improving the experience of dementia and enhancing active life-living well with dementia: study protocol for the IDEAL study. *Health Qual Life Outcomes* 2014;12:164.
 - 17 Logsdon RG, Gibbons LE, McCurry SM, Teri L. Quality of life in Alzheimer's disease: patient and caregiver reports. New York: Springer; 2000:17-30.
 - 18 Diener E, Emmons RA, Larsen RJ, Griffin S. The Satisfaction with Life Scale. *J Pers Assess* 1985;49:71-75.
 - 19 Bech P. Measuring the dimension of psychological general well-being by the WHO-5. *Qual Life Newslett*. 2004;32:15-6.
 - 20 Charlson ME, Charlson RE, Peterson JC, Marinopoulos SS, Briggs WM & Hollenberg JP. The Charlson Comorbidity Index is adapted to predict costs of chronic disease in primary care patients. *J Clin Epidemiol* 2008;61:1234-1240.
 - 21 UK government. Department for Communities and Local Government. English indices of deprivation 2015. UK government, 2015.
 - 22 Welsh government. Welsh index of multiple deprivation. Welsh government, 2014.
 - 23 Scottish government. The Scottish Index of Multiple Deprivation. Scottish government, 2016.

- 24 Scottish government. Scottish Government Urban Rural Classification 2013-2014.
Scottish government, 2014.
- 25 UK government, Department for Environment, Food & Rural Affairs. 2011 Census rural urban classification. UK government, 2013.
- 26 Rubin DB. Multiple imputation after 18+ years (with discussion). *J Am Stat Assoc* 1996;91:473.
- 27 Matthews FE, Arthur A, Barnes LE, Bond J, Jagger C, Robinson L, et al. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. *Lancet* 2013;382(9902):1405-12.
- 28 Oguz S. Exploring personal well-being and place. Office for National Statistics, 2014.
- 29 Cooper C, Lodwick R, Walters K, Raine R, Manthorpe J, Iliffe S, Petersen I. Inequalities in receipt of mental and physical healthcare in people with dementia in the UK. *Age Ageing* 2017;46(3):393-400.
- 30 Burton E & Mitchell L. Inclusive urban design: streets for life. Oxford: Architectural Press; 2006.
- 31 Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM. Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the MIND at home study. *J Am Geriatr Soc* 2013;61(12):2087-2095.

Tables

Table 1: Descriptive information about the IDEAL study population

		England (N=1387)	Wales (N=83)	Scotland (N=77)	Total (N=1547)
Age	80+	524 (37.8)	47 (56.6)	32 (41.6)	603 (39.0)
	75-79	345 (24.9)	12 (14.5)	13 (16.9)	370 (23.9)
	70-74	233 (16.8)	8 (9.6)	19 (24.7)	260 (16.8)
	65-69	163 (11.8)	9 (10.8)	6 (7.8)	178 (11.5)
	<65	122 (8.8)	7 (8.4)	7 (9.1)	136 (8.8)
Sex	Men	783 (56.4)	42 (50.6)	47 (61.0)	872 (56.4)
	Women	604 (43.6)	41 (49.4)	30 (39.0)	675 (43.6)
Dementia subtypes	Alzheimer's disease (AD)	780 (56.2)	42 (50.6)	36 (46.8)	858 (55.5)
	Vascular dementia (VaD)	143 (10.3)	12 (14.5)	16 (20.8)	171 (11.1)
	Mixed AD and VaD	288 (20.8)	21 (25.3)	17 (22.1)	326 (21.1)
	Frontotemporal dementia (FTD)	50 (3.6)	0 (0.0)	4 (5.2)	54 (3.5)
	Parkinson's dementia (PDD)	39 (2.8)	5 (6.0)	0 (0.0)	44 (2.8)
	Lewy body dementia (LBD)	47 (3.4)	3 (3.6)	3 (3.9)	53 (3.4)
	Unspecified	40 (2.9)	0 (0.0)	1 (1.3)	41 (2.7)
Education (missing=35)	No qualifications	369 (27.2)	36 (45.0)	18 (23.7)	423 (28.0)
	GCSE	246 (18.1)	10 (12.5)	13 (17.1)	269 (17.8)
	A-level	463 (34.1)	22 (27.5)	31 (40.8)	516 (34.1)
	College	278 (20.5)	12 (15.0)	14 (18.4)	304 (20.1)
Social class (missing=79)	I (High)	122 (9.3)	2 (2.5)	9 (12.5)	133 (9.1)
	II	466 (35.4)	32 (40.5)	23 (31.9)	521 (35.5)
	IIINM	274 (20.8)	12 (15.2)	14 (19.4)	300 (20.4)
	IIIM	271 (20.6)	19 (24.1)	19 (26.4)	309 (21.1)
	IV/V (Low)	184 (14.0)	14 (17.7)	7 (9.7)	205 (14.0)
Number of comorbidities (missing=116)	1-2	677 (52.8)	42 (54.6)	29 (39.7)	748 (52.2)
	3-4	438 (34.2)	26 (33.8)	29 (39.7)	493 (34.5)
	5+	166 (13.0)	9 (11.7)	15 (20.6)	190 (13.3)
Access to informal carers	Living with carer	944 (68.1)	49 (59.0)	52 (67.5)	1045 (67.6)
	Non co-resident carer	217 (15.7)	8 (9.6)	13 (16.9)	238 (15.4)
	Declined carer	110 (7.9)	15 (18.1)	2 (2.6)	127 (8.2)
	No carer	116 (8.4)	11 (13.3)	10 (13.0)	137 (8.9)

Table 2: Mean and standard deviation of living well indicators by deprivation quintiles and

urban/rural areas

	N (%)	QoL-AD (N=1402)	SwLS (N=1504)	WHO-5 (N=1521)
<u>Deprivation</u>				
Q5 (least)	469 (30.3)	37.6 (5.7)	26.7 (5.9)	63.0 (19.2)
Q4	382 (24.7)	37.0 (6.1)	26.1 (6.1)	61.3 (20.1)
Q3	328 (21.2)	36.8 (5.8)	25.9 (6.0)	61.0 (21.2)
Q2	238 (15.4)	35.6 (5.9)	25.6 (6.1)	56.9 (22.4)
Q1 (most)	130 (8.4)	35.1 (5.8)	24.8 (7.0)	59.7 (20.8)
<u>Urban/rural</u>				
Urban	1042 (67.4)	36.7 (6.0)	26.2 (6.0)	60.7 (20.6)
Rural	505 (32.6)	36.9 (5.7)	25.9 (6.3)	61.5 (20.5)
<u>Country</u>				
England	1387 (89.7)	36.8 (5.9)	26.0 (6.1)	60.9 (20.5)
Wales	83 (5.3)	36.2 (5.4)	25.8 (6.0)	62.6 (18.9)
Scotland	77 (5.0)	36.5 (6.4)	26.9 (6.9)	59.9 (23.1)

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 3: The association between deprivation quintiles and living well indicators in people with dementia (accounting for country and imputed for missing data, N=1547)

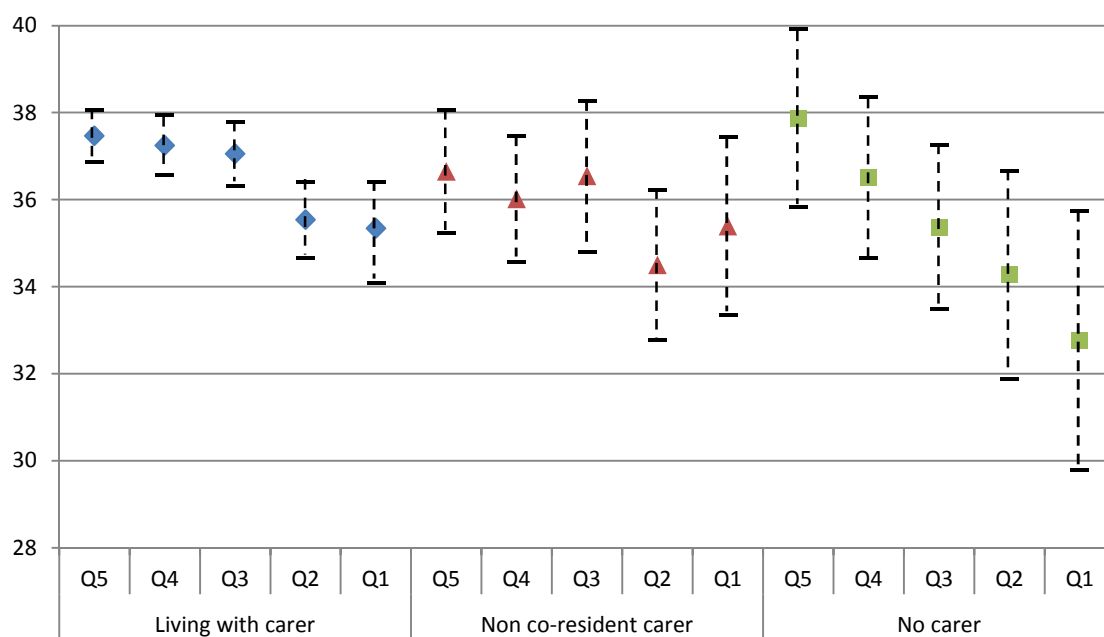
	QoL-AD	SwLS	WHO-5	p.
	Coeff. (95% CI)	Coeff. (95% CI)	Coeff. (95% CI)	
<u>Unadjusted</u>				
Q5 (least deprived)	-	-	-	<0.001
Q4	-0.53 (-1.33, 0.27)	-0.51 (-1.34, 0.33)	-1.53 (-4.31, 1.25)	
Q3	-0.80 (-1.64, 0.03)	-0.74 (-1.61, 0.13)	-2.12 (-4.99, 0.80)	
Q2	-2.29 (-3.21, -1.37)	-1.19 (-2.15, -0.23)	-6.04 (-9.25, -2.82)	
Q1 (most deprived)	-2.51 (-3.66, -1.36)	-1.94 (-3.15, -0.73)	-3.54 (-7.55, 0.46)	
<u>Adjusted 1: age, sex, dementia subtypes</u>				
Q5 (least deprived)	-	-	-	<0.001
Q4	-0.41 (-1.19, 0.37)	-0.28 (-1.09, 0.54)	-0.85 (-3.58, 1.88)	
Q3	-0.58 (-1.40, 0.23)	-0.46 (-1.31, 0.39)	-1.31 (-4.17, 1.55)	
Q2	-2.15 (-3.06, -1.25)	-0.96 (-1.90, -0.02)	-5.39 (-8.54, -2.23)	
Q1 (most deprived)	-2.30 (-3.43, -1.17)	-1.37 (-2.56, -0.18)	-2.83 (-6.80, 1.13)	
<u>Adjusted 2 for age, sex, dementia subtypes, education and social class</u>				
Q5 (least deprived)	-	-	-	0.01
Q4	-0.31 (-1.09, 0.48)	-0.25 (-1.07, 0.57)	-0.60 (-3.36, 2.16)	
Q3	-0.44 (-1.26, 0.38)	-0.44 (-1.30, 0.43)	-0.91 (-3.82, 1.99)	
Q2	-1.81 (-2.73, -0.88)	-0.88 (-1.84, 0.09)	-4.59 (-7.82, -1.36)	
Q1 (most deprived)	-1.77 (-2.93, -0.61)	-1.21 (-2.43, 0.02)	-1.64 (-5.72, 2.44)	
<u>Adjusted 3 for age, sex, dementia subtypes, education, social class and number of comorbidities</u>				
Q5 (least deprived)	-	-	-	0.08
Q4	-0.30 (-1.07, 0.47)	-0.24 (-1.05, 0.58)	-0.58 (-3.29, 2.12)	
Q3	-0.35 (-1.15, 0.46)	-0.38 (-1.23, 0.48)	-0.62 (-3.47, 2.23)	
Q2	-1.41 (-2.31, -0.51)	-0.60 (-1.56, 0.36)	-3.37 (-6.57, -0.18)	
Q1 (most deprived)	-1.62 (-2.76, -0.49)	-1.12 (-2.33, 0.10)	-1.18 (-5.18, 2.83)	

QoL-AD: Quality of Life in Alzheimer's Disease Scale; SwLS: Satisfaction with Life Scale; WHO-5: World

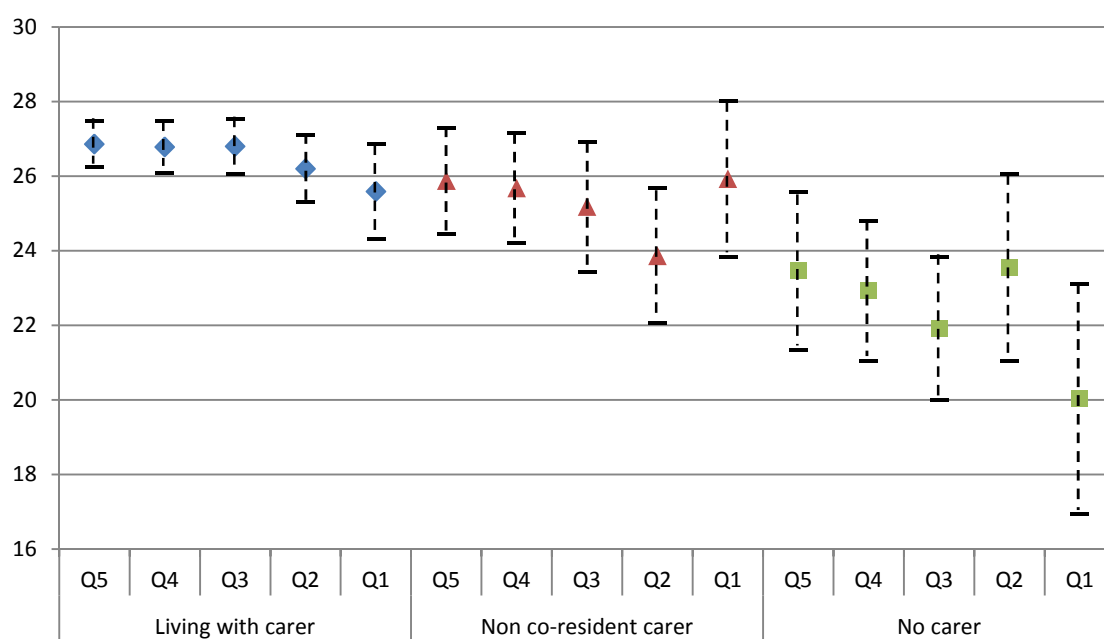
Health Organization Five Well-being Index; p.: p-value of Wald test

Figure 1: Estimated scores of living well measures by deprivation quintiles and availability of a carer (Q5: least deprived quintile; Q1: most deprived quintile)

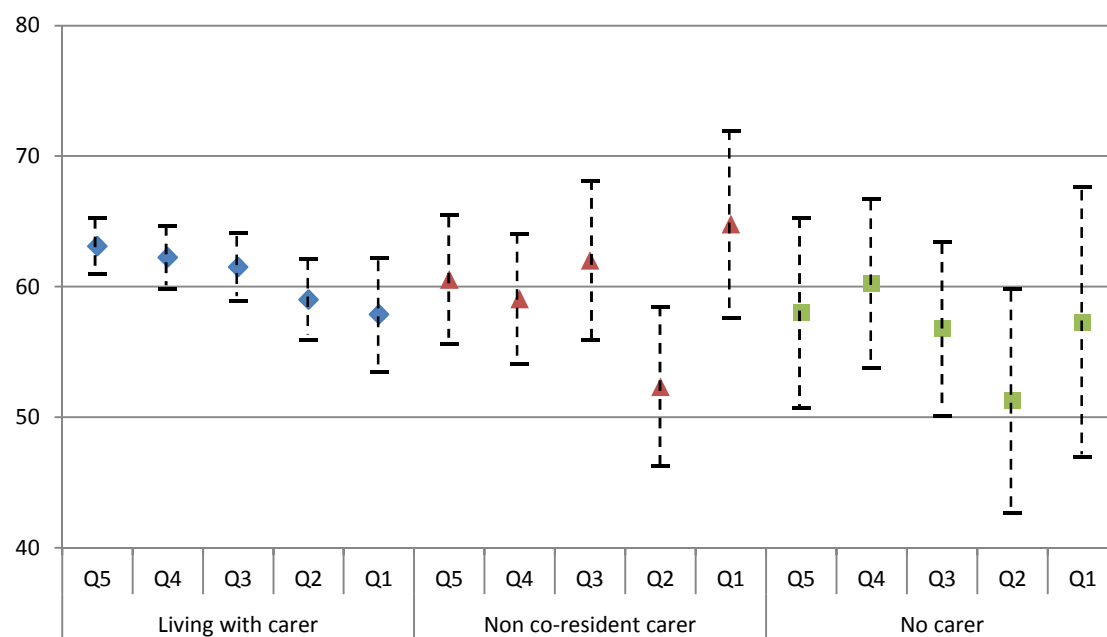
(A) QoL-AD: Quality of Life in Alzheimer's Disease Scale



(B) SwLS: Satisfaction with Life Scale



(C) WHO-5: World Health Organisation Five Well-being Index



All estimates adjusted for age, sex, dementia subtypes and accounting for country and missing data

**Inequalities in living well with dementia – the impact of deprivation on wellbeing,
quality of life and life satisfaction: results from the Improving the experience of
Dementia and Enhancing Active Life (IDEAL) study**

Supporting information

S1. Living well indicators and urban/rural areas

S2. Sensitivity analysis: potential variation across countries

S1. Living well indicators and urban/rural areas

The difference in living well indicators was small across urban and rural areas. Table S1 reports unadjusted and adjusted results of regression modelling and suggests minimal urban/rural variation in quality of life, life satisfaction and wellbeing. Table S2 shows mean and standard deviation for three living well indicators by more detailed urban/rural categories in England, Scotland and Wales. The differences between these categories were generally small and there was a lack of statistical power to formally test variation across different urban/rural categories and countries.

Table S3 shows the association between urban/rural areas and living well indicators by the three situations of access to informal carer. Although participants with no carers generally had lower living well scores compared with urban participants living with carers, there was no clear difference across urban and rural areas.

Table S1: The associations between urban/rural areas and living well in people with dementia (accounting for country and imputed for missing data, N=1547)

	QoL-AD	SwLS	WHO5	p.
<u>Unadjusted</u>				
Urban	-	-	-	0.35
Rural	0.05 (-0.60, 0.70)	-0.34 (-1.01, 0.33)	0.73 (-1.52, 2.97)	
<u>Adjusted 1: age, sex and dementia subtypes</u>				
Urban	-	-	-	0.26
Rural	0.02 (-0.61, 0.65)	-0.39 (-1.04, 0.27)	0.77 (-1.43, 2.97)	
<u>Adjusted 2: age, sex, dementia subtypes, education and social class</u>				
Urban	-	-	-	0.29
Rural	-0.12 (-0.76, 0.52)	-0.44 (-1.10, 0.22)	0.46 (-1.76, 2.68)	
<u>Adjusted 3: age, sex, dementia subtypes, education, social class and number of comorbidities</u>				
Urban	-	-	-	0.28
Rural	-0.06 (-0.68, 0.56)	-0.41 (-1.06, 0.25)	0.65 (-1.52, 2.83)	

QoL-AD: Quality of Life in Alzheimer's Disease; SwLS: Satisfaction with Life Scale; WHO5: World Health Organization Five Well-being Index; p.: p-value of Wald test

Table S2: Mean and standard deviation of three living well measures by urban/rural categories in England and Wales (N=1470)

	N	QoL-AD	SwLS	WHO5
England Wales (N=1470)				
Urban major conurbation	98	35.6 (6.7)	25.4 (6.6)	59.4 (19.8)
Urban minor conurbation	101	36.9 (5.7)	24.8 (6.5)	59.8 (21.2)
Urban city and town	779	36.9 (5.9)	26.4 (5.7)	61.2 (20.4)
Urban city and town (sparse)	3	32.7 (9.3)	22.7 (7.4)	50.7 (32.1)
Rural town and fringe	243	36.8 (5.7)	25.3 (6.5)	61.2 (20.7)
Rural town and fringe (sparse)	16	36.0 (4.9)	25.7 (7.7)	61.0 (18.7)
Rural village and dispersed	202	36.7 (5.9)	26.3 (6.0)	60.6 (20.8)
Rural village and dispersed (sparse)	28	38.2 (4.8)	25.9 (6.3)	68.3 (16.0)
Scotland (N=77)				
Urban areas	61	35.7 (6.5)	26.3 (7.4)	58.3 (23.3)
Accessible rural	14	39.5 (5.3)	29.8 (2.6)	68.3 (19.9)
Remote rural	2	36.0 (5.7)	24.0 (11.3)	50.0 (36.8)

QoL-AD: Quality of Life in Alzheimer's Disease; SwLS: Satisfaction with Life Scale; WHO5: World Health Organization Five Well-being Index

Table S3: The associations between urban/rural areas and living well indicators by access to carer (adjusted for country, age, sex, dementia subtypes, education, social class and number of comorbidities and imputed for missing data, N=1547)

	QoL-AD	SwLS	WHO5
<u>Living with carer</u>			
Urban	-	-	-
Rural	-0.38 (-1.11, 0.36)	-0.64 (-1.40, 0.11)	1.04 (-1.53, 3.61)
<u>Not living with carer</u>			
Urban	-1.29 (-2.25, -0.34)	-1.59 (-2.59, -0.59)	-1.89 (-5.26, 1.49)
Rural	-0.34 (-1.82, 1.13)	-0.91 (-2.45, 0.62)	-0.15 (-3.35, 5.06)
<u>No carer</u>			
Urban	-1.06 (-2.00, -0.12)	-2.84 (-3.81, -1.86)	-2.62 (-5.91, 0.67)
Rural	-0.89 (-2.22, 0.44)	-3.76 (-5.15, -2.38)	-5.50 (-10.17, -0.83)

QoL-AD: Quality of Life in Alzheimer's Disease; SwLS: Satisfaction with Life Scale; WHO5: World Health Organization Five Well-being Index

S2. Sensitivity analysis: potential variation across countries

The sensitivity analyses included interaction terms between area level factors and countries adjusting for individual level factors. Table S4 reports results for deprivation quintiles. Interaction terms between deprivation quintiles and countries did not achieve statistical significance ($p=0.11$). This indicates that the association between deprivation quintiles and living well indicators did not vary across countries. Table S5 shows results for urban/rural areas. Although definitions of urban/rural areas differed across countries, variation between country and urban/rural areas were small and the association between urban/rural areas and living well indicators were similar in England, Scotland and Wales (p -value for interaction terms= 0.31). These results indicate that variation at the country level should have limited impacts on the main findings.

Table S4: The association between deprivation quintiles and living well indicators by the three countries (adjusted for age, sex, dementia subtypes, education, social class and number of comorbidities and imputed for missing data, $N=1547$)

	QoL-AD	SwLS	WHO-5
	Coeff. (95% CI)	Coeff. (95% CI)	Coeff. (95% CI)
<u>England</u>			
Q5 (least deprived)	-	-	-
Q4	-0.23 (-1.03, 0.57)	-0.06 (-0.91, 0.79)	-0.22 (-3.05, 2.61)
Q3	-0.43 (-1.28, 0.42)	-0.50 (-1.40, 0.40)	-1.28 (-4.29, 1.73)
Q2	-1.30 (-2.25, -0.36)	-0.62 (-1.62, 0.38)	-3.76 (-7.10, -0.41)
Q1 (most deprived)	-1.48 (-2.68, -0.28)	-0.60 (-1.89, 0.69)	-0.95 (-5.21, 3.31)
<u>Wales</u>			
Q5 (least deprived)	-1.11 (-3.53, 1.31)	0.21 (-2.35, 2.76)	-1.95 (-10.51, 6.61)
Q4	-1.14 (-3.72, 1.44)	-2.44 (-5.17, 0.29)	-0.86 (-10.00, 8.28)
Q3	-0.22 (-2.62, 2.19)	1.06 (-1.55, 3.68)	3.84 (-4.67, 12.35)
Q2	-1.66 (-5.03, 1.71)	0.42 (-3.12, 3.95)	6.36 (-5.50, 18.22)
Q1 (most deprived)	0.41 (-3.29, 4.11)	-0.96 (-4.87, 2.95)	3.21 (-9.89, 16.31)
<u>Scotland</u>			
Q5 (least deprived)	2.50 (-0.49, 5.49)	3.01 (-0.37, 6.39)	4.21 (-6.59, 15.01)
Q4	-0.44 (-3.12, 2.24)	1.04 (-1.79, 3.87)	-5.95 (-15.28, 3.38)
Q3	0.73 (-1.57, 3.04)	1.77 (-0.69, 4.23)	4.74 (-3.52, 13.01)
Q2	-2.57 (-5.68, 0.55)	1.21 (-2.31, 4.74)	-4.01 (-15.24, 7.22)
Q1 (most deprived)	-5.79 (-9.76, -1.82)	-6.51 (-10.66, -2.37)	-7.60 (-21.50, 6.30)

Table S5: The association between urban/rural areas and living well indicators by the three countries (adjusted for age, sex, dementia subtypes, education, social class and number of comorbidities and imputed for missing data, N=1547)

	QoL-AD	SwLS	WHO-5
	Coeff. (95% CI)	Coeff. (95% CI)	Coeff. (95% CI)
<u>England</u>			
Urban	-	-	-
Rural	-0.28 (-0.93, 0.37)	-0.56 (-1.24, 0.13)	0.34 (-1.94, 2.63)
<u>Wales</u>			
Urban	-1.98 (-4.31, 0.35)	-0.38 (-2.84, 2.07)	-0.15 (-8.36, 8.06)
Rural	0.24 (-1.23, 1.71)	-0.07 (-1.63, 1.49)	3.64 (-1.54, 8.82)
<u>Scotland</u>			
Urban	-0.53 (-1.99, 0.93)	0.51 (-1.11, 2.13)	-0.32 (-5.56, 4.91)
Rural	1.68 (-1.10, 4.46)	2.68 (-0.26, 5.61)	3.53 (-6.28, 13.33)