Predictors of awareness of functional ability in people with dementia: the contribution of personality, cognition, and neuropsychiatric symptoms - findings from the IDEAL programme

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Predictors of awareness of functional ability in people with dementia: the contribution of personality, cognition, and neuropsychiatric symptoms. Findings from the IDEAL programme

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Short Title: Functional discrepancy scores in early-stage dementia

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Abstract

Introduction: Discrepancy scores reflecting the difference between parallel ratings made by people with mild-to-moderate dementia (PwD) and by their informants provide a way to investigate awareness of functional ability in relation to activities of daily living (ADL).

Methods: Two measures of ADL (Functional Activities Questionnaire; Dependence Scale) were completed by 1227 PwD and their informants in the IDEAL cohort study baseline assessment. Self-rated and informant-rated scores were used to calculate discrepancies, which were used as an indicator of awareness of functional ability. Smaller discrepancy scores were considered to reflect greater awareness on the part of the PwD. PwD completed questionnaires on depression, personality, co-morbidities, neuropsychiatric symptoms, and completed a measure of cognition. Informants provided ratings of stress. Univariable and multiple regressions were used to investigate factors related to ADL discrepancy.

Results: A similar pattern of associations were found for both ADL discrepancy scores. Smaller discrepancy scores were associated with higher levels of depression, higher neuroticism, fewer neuropsychiatric symptoms, and higher co-morbidity, lower carer stress, and receipt of less than one hour of care per day from the informant.

Discussion/Conclusion: There was a clear pattern of factors that were associated with greater awareness for both measures of functional ability. These factors associated with smaller discrepancy scores could be used to identify PwD who might benefit from targeted interventions to support their independence.

Introduction

Impairments in activities of daily living (ADL) are a key diagnostic feature in dementia [1, 2], and maintaining functional independence is important for quality of life in people living with dementia (PwD) [3, 4]. Instrumental activities of daily living (iADL), such as using a telephone, managing finances, and medication, may begin declining around ten years prior to a dementia diagnosis [5] with evidence suggesting a link specifically between cognitive impairments and iADL ability [6-9]. In contrast, basic activities of daily living (bADL), for example, bathing, dressing, and eating, tend to be relatively more preserved in early dementia, with less of a cognitive component [10].

The primary method of ADL assessment involves using informant ratings, typically made by family carers, whereas self-ratings made by PwD are rarely used in clinical or research settings [11, 8] despite self-rated functional ability having important clinical implications [12, 13]. The assumption that cognitive impairment [14] and associated lack of awareness [15] may reduce the reliability of self-ratings is a possible explanation for this under-utilisation. Recent evidence suggests that cognition has little effect on self-rated functioning whereas self-rated depression has a larger effect on how PwD rate their own functioning [16]. Meanwhile, PwD consistently report fewer impairments than informants [17-21, 9, 22, 16], with this discrepancy typically viewed as reflecting lack of awareness of functional difficulties [17, 23, 20]. However, recent evidence suggests that when self-ratings are compared with objective performance, PwD may appraise their own functioning more accurately than informants [24]. It is also the case that while informant ratings are generally assumed to be accurate [25], they are subject to a range of biases including greater carer stress/burden [26-29, 24, 16], increased age, and impaired cognitive status of the person with dementia [30, 9]. Therefore, the overall assumption that informant ratings of functional ability are reliable, regardless of potential bias, may not be accurate whereas the influence of

depressive symptomatology may affect how accurate PwD are in rating their own functioning.

Formal methods for calculating discrepancies between self- and informant ratings on ADL scales are frequently used to quantify reduced awareness in PwD [31] with the assumption that carers are an accurate benchmark with which to compare PwD self-appraisal. The majority of studies that have investigated ADL discrepancy have focussed on cognition, reporting moderate associations between greater discrepancies (indicating less awareness) and scores on the Mini-Mental State Examination (MMSE) [32] and for language, memory, attention, and executive functioning [26, 23, 19, 21, 9, 29, 33]. ADL discrepancy has also been associated with a higher number of neuropsychiatric symptoms, including depression [26, 34, 21, 29].

Other factors less frequently considered include for example co-morbidity and personality. PwD tend to have more co-morbidities than age-matched controls [35] and a review found a significant association between co-morbidity and functional ability in dementia [36] suggesting that co-morbidity may be associated with functional ability. Regarding personality, high neuroticism and low conscientiousness have been associated with increased risk of developing dementia [37], and self-rated conscientiousness is related to discrepancy in everyday memory function [38] while informant-reported openness and conscientiousness associate with informant-rated iADL [39]. One study investigated conscientiousness in relation to iADL discrepancy, finding no significant association [21]. However, to our knowledge no other study has investigated the association of aspects of personality with functional discrepancy scores.

To date few studies have considered factors that predict ADL discrepancy scores in PwD beyond cognition and/or neuropsychiatric symptoms [40, 29, 31]. The current study used data from the Improving the experience of Dementia and Enhancing Active Life

(IDEAL) [41] a large cohort of PwD and respective informant carers, to explore the role of cognition, neuropsychiatric symptoms, personality attributes, co-morbidity, carer stress, and background variables as possible predictors of ADL discrepancy in people with early-stage dementia. It is predicted that cognition will be important for iADL but less important for bADL. It is also predicted that more neuropsychiatric symptoms, including depression, and less carer stress will be associated with a smaller ADL discrepancy.

Materials and Methods

Design

IDEAL is a 9-year longitudinal research programme investigating quality of life, satisfaction with life, and well-being in PwD [41, 42]. This paper presents cross-sectional data from version 5 of the baseline IDEAL dataset. IDEAL includes 1537 PwD together with 1277 informants. This analysis focused on the 1277 PwD who had informants involved in the study. PwD were recruited through the UK National Health Service (NHS) research networks in England, Scotland, and Wales. To be included, PwD had to have a diagnosis of dementia as judged by clinicians at recruitment sites, be living in the community, have a score of 15 or above on the MMSE, and be able to communicate verbally in English. Exclusion criteria were co-morbid terminal illness, inability to provide informed consent, and any known potential for home visits to pose a significant risk to researchers. There were no specific inclusion or exclusion criteria for carers other than being willing and available to take part in the study. In IDEAL carers were defined as the primary person who provides practical or emotional unpaid support, usually a family member [43]. 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). The IDEAL study is registered with UKCRN, registration number 16593.

Measures

To measure functional ability a modified 11-item Functional Activities Questionnaire was employed (FAQ) [44] that has been described previously [9, 16]. The FAQ measures iADL and each item is rated on a 0-3 scale; range 0-33. Scores of 5 or more indicate impairment [44, 16]. The Dependence Scale (DS) [45] was used to measure bADL, the first two items are scored 0-2, while the remaining 11 items are scored 0-1; range 0-15. Scores above 0 indicate impairment [45]. For both measures a higher score indicates greater perceived functional difficulties. These measures were both self-rated and informant-rated. By subtracting the self-rated total score from the informant-rated total score a discrepancy score was computed for use in this analysis. A positive score indicates that self-ratings showed greater perceived functional ability than informant ratings and vice versa. A smaller discrepancy between ratings, with similar ratings provided by the PwD and informant, can be interpreted as reflecting greater awareness of functional ability on the part of the PwD.

The present study uses a specific sub-set of measures from the IDEAL dataset. The following additional measures were used in this analysis. The five subscales of the Addenbrooke's Cognitive Examination-III (ACE-III) [46] were used with PwD to measure cognition. The five subscales assess attention (ACE-Attention; range 0-18) verbal fluency (ACE-Verbal fluency; range 0-14), language (ACE-Language; range 0-26), memory (ACE-Memory; range 0-26), and visuospatial (ACE-Visuospatial; range 0-16) aspects of cognition; higher scores indicated better cognitive ability. The Geriatric Depression Scale-10 (GDS-10) [47] was used to measure depression in PwD. The sample was split into not depressed (0-3) and depressed (4-10) groups [48]. The Mini-IPIP [49] was used to measure personality in PwD; each of the five subscales (Agreeableness, Conscientiousness, Extraversion, Intellect and Imagination - subsequently referred to as 'Openness' - and Neuroticism) were included in the analysis and higher scores indicated a stronger trait in each personality subscale; range, 4-20 for each subscale. Number of co-morbid conditions was calculated using the Charlson

Comorbidity Index [50, 51], and the sample was split into three groups (1-2 conditions, 3 conditions, 4+ conditions) [52]. Informants provided information about the number of neuropsychiatric symptoms of the person with dementia by completing the Neuropsychiatric Inventory-Questionnaire (NPI-Q [53, 54] higher scores indicated presence of more neuropsychiatric symptoms; range 0-12. Informants provided information about their own levels of depression by completing the Center for Epidemiologic Studies Depression Scale Revised (CESD-R) [55] dichotomised into depressed (0-15) and not depressed (16-48) [56]. Finally, informants provided information about their own levels of stress by completing the Relatives' Stress Scale (RSS) [57] higher scores indicated greater levels of carer stress; range 0-60.

In addition, information about the PwD covering age, sex, education, diagnostic category, living situation, informant relationship, and hours spent caring per day by the informant was included. PwD were classified into groups on the basis of age (<65, 65-69, 70-74, 75-79, 80+) and education (no qualifications, school leaving certificate at age 16, school leaving certificate at age 18, university). Informant relationship was classified into two groups (spouse/partner, other). Living situation was divided into three groups (living with spouse/partners, living with others, living alone) [58]. Hours of care per day provided by the informant was divided into three groups (<1 hour, 1-10 hours, 10+ hours).

Procedure

PwD and informants were visited at home on three occasions spread over a few weeks. Informed consent was obtained from both PwD and informants. Trained NHS researchers administered all questions and assessments to the PwD. The same NHS researcher collected all the data for each participant. Informants self-completed their questionnaires. The Charlson Comorbidity Index was administered to both PwD and their informants together.

Planned analysis

Analysis was conducted using IBM SPSS Statistics v28. The residuals of each discrepancy score were checked before conducting the analysis and were normally distributed; see Supplementary Figures 1 and 2. Separate univariable regression analysis was conducted for the FAQ and DS discrepancy scores with the same variables included as predictor variables. For ordinal variables total scores were used in analyses. For all categorical variables the group with the largest sample size was used as the reference. Variables were selected for inclusion in multiple regressions based on statistical significance and the size of the coefficient and 95% confidence intervals. Multiple regressions were employed to investigate the combined contribution of important variables, and are the main focus of this study. Variables included in the multiple regression model were checked for multicollinearity.

Multiple imputation was conducted to account for missing data. Ordinal variables were imputed using ordinal regression and categorical variables were imputed using multinomial regression. The imputed model included all variables in the analysis. Estimates from 50 imputed datasets were combined using Rubin's rules [59].

Results

Out of the 1277 dyads in the baseline sample, 50 dyads had missing scores for both FAQ and DS. In addition, there was missing data for 81 dyads on the FAQ and 106 on the DS. Data are therefore reported for the 1227 dyads with complete discrepancy data for either or both measures. See Table 1 for a description of the sample. PwD had a mean age of 76.17 (8.26) years and just over half were male. Alzheimer's disease was the most common dementia diagnosis, most lived with a spouse/partner, and just under a third of the sample scored 4 or more on the GDS-10. Mean MMSE score was 23.05 (3.69); 19% of the sample had MMSE scores below 20, suggesting most of the sample were in the mild stages of

dementia. Informants had a mean age of 69.20 (10.99) years and two-thirds were female, most of them spouses. Mean scores for the FAQ and the DS exceeded the cut-offs for impairment therefore on average both PwD and their carers rated the person as impaired in iADL and bADL.

(((Table 1 around here)))

ADL discrepancy scores

Mean discrepancy scores were positive for FAQ and DS. Thus, in general, self-ratings indicated greater perceived functional ability than informant ratings; see Table 2. For the FAQ, 160 (14.0%) PwD rated themselves as being more functionally impaired and 936 (81.6%) rated themselves as less functionally impaired than did their informants; see Supplementary Figure 1 for the range of responses. For the DS, 174 (15.5%) PwD rated themselves as being more functionally impaired and 780 (69.5%) rated themselves as less functionally impaired than did their informants; see Supplementary Figure 2 for the range of responses. There was complete agreement in ratings for a small percentage of dyads; 50 (4.4%) and 167 (14.9%) on the FAQ and DS, respectively. If agreement is expanded to within ±2 points for the FAQ and ±1 point for the DS, to account for the scoring difference of the two measures, there was agreement for 16.9% (n=207) on the FAQ and 33.4% (n=410) on the DS. The two discrepancy scores were highly correlated, $r(1121)=.59$, $p<.001$. Table 2 shows, for different sub-groups as defined by the categorical variables, mean differences for the FAQ and DS discrepancy scores.

(((Table 2 around here)))

Univariable regressions

Univariable regressions were used to investigate the associations between PwD and informant factors for the FAQ and DS discrepancy scores and to select variables for inclusion in the multiple regressions. There was a similar pattern of associations for discrepancy scores

for both measures of functional ability; see Table 3. The smallest discrepancies were for PwD under 65, PwD that were depressed, PwD with fewer informant-rated neuropsychiatric symptoms, and PwD receiving <1 hour of care per day from the informant. Discrepancies were also smaller where carers were less stressed.

(((Table 3 around here)))

Multiple regressions

After including all the predictive factors from univariable analysis in multiple regressions, the overall models were statistically significant and explained 20.1% of the variance for the FAQ and 17.3% of the variance for the DS; see Table 3. Again, there was a similar pattern of associations for discrepancy scores on both measures of functional ability. Regression coefficients were generally attenuated when compared to the univariable analysis. There was a smaller ADL discrepancy for PwD under 65, PwD that were depressed, PwD with higher neuroticism and lower conscientiousness scores, PwD with four or more co-morbidities, PwD with more informant-rated neuropsychiatric symptoms, PwD receiving <1 hour of care per day from the informant, and carers with less stress. For the FAQ discrepancy score better memory ability, having no educational qualifications, and greater trait openness remained significant in the model, suggesting these are related to better awareness of iADL. For the DS discrepancy score being male and having a diagnosis of vascular dementia remained significant in the model, suggesting that men in general, and people with vascular dementia may have better awareness of their bADL difficulties.

Impact of missing data on the results

The percentage of missing data was between 0.5% and 8.6% across all domains for PwD, and between 0.1% and 3.8% for informants (see Table 1). Coefficients were generally similar to the complete case analysis but standard errors reduced after multiple imputations. Imputation did not alter the relationships but improved the precision of estimates.

Discussion

This is the first study to explore in a large cohort the relative importance of a wide range of predictors of ADL discrepancy scores, used here to indicate awareness of functional ability among PwD. Factors associated with the discrepancy between PwD and their carers in measures of iADL and bADL were examined using baseline data from the large IDEAL cohort study of community-dwelling PwD and their informants. The findings suggest a generally consistent pattern of factors associated with discrepancy scores across both functional measures. Indeed, the two discrepancy scores were highly correlated suggesting that a measure of iADL may be sufficient to investigate awareness of functional ability in people with mild-to-moderate dementia. This study supports previous research by finding an association between greater awareness of functioning and lower mood, fewer neuropsychiatric symptoms, higher cognition, younger age, and the carer being less stressed [26, 23, 34, 19, 21, 9, 29, 60]. Therefore, the hypothesis that neuropsychiatric symptoms, including depression, would be important factors for ADL discrepancy was supported. In addition, this study extends earlier research by also reporting an association between greater awareness of functional difficulties and having four or more co-morbidities, higher neuroticism and lower conscientiousness, and receiving less than one hour of care from the carer taking part in the study. There were a few notable differences between the two types of functional ability. For bADL, men and people with vascular dementia showed greater awareness of functional ability whereas for iADL, those with no educational qualifications, lower openness, and those with better memory ability showed greater awareness of functional ability. This latter finding supports the hypothesis that cognition would be more related to iADL than bADL and is consistent with previous studies where iADL tended to have a greater cognitive component than bADL [6-9].

The findings suggest that there are some factors that are consistently associated with awareness of functioning. For PwD, those who were more depressed, and/or were less cognitively impaired particularly regarding memory, and/or who had fewer neuropsychiatric symptoms, and/or were younger were likely to be more aware of their functional difficulties. Similarly, carers that report less stress may also be more reliable in their appraisals of PwD. The findings support the proposition that people with greater awareness of their functional ability tend to have higher levels of depression especially in the early stages of dementia [34, 61]. This is perhaps more salient considering that mean scores for depression in the IDEAL baseline assessment are low [16], suggesting that even subtle levels of depression can affect how PwD rate their functional ability. This is consistent with the "depressive realism" hypothesis whereby people who are depressed may be more realistic in their judgements of themselves than those who are not depressed [62]. It is also intuitive that PwD with more preserved memory ability have higher awareness of their functional ability, as where memory is more preserved people are more able to remember whether they can or cannot do certain tasks. Similarly, younger PwD tend to have fewer co-morbid health conditions and may perceive themselves as more able to do certain tasks; therefore, when confronted with difficulties performing everyday tasks that they may have previously taken for granted this increased difficulty concomitantly increases accurate appraisal of functional ability.

The finding that scores for certain personality traits are related to functional discrepancy scores is novel. Higher neuroticism and lower conscientiousness were related to increased awareness for both functional ability measures. This is notable as both higher neuroticism and lower conscientiousness have been associated with increased risk of developing dementia [37] and higher neuroticism has been associated with both mental and physical disorders [63]. It is possible that high levels of neuroticism are associated with greater feelings of worry and rumination [64] and it could be this that is related to increased

awareness of functional ability. Investigating whether higher neuroticism is associated with other objects of awareness in dementia is needed as this could be useful clinically.

The finding that having four or more co-morbidities was related to functional discrepancy may be due to some functional abilities being related to physical as well as cognitive health, particularly bADL [65]. It may be that physical difficulties are more apparent than cognitive difficulties to PwD and informants. Physical difficulties may consequently make it more difficult for PwD to undertake some functional tasks thus making it more likely that ratings will be concordant. However, despite the apparent face validity the association between co-morbidities and functioning is rarely considered. In future studies including a measure of co-morbidity may be important to better understand functional ability.

Consistent with earlier studies, the majority of PwD rated themselves as less functionally impaired than their informants [17, 18, 23, 9, 22]. There appeared to be greater consistency for the DS than the FAQ, with 15% concordance for DS but only 4.4% concordance for FAQ in the current study; similar levels of concordance persisted after expanding the definition of agreement to include a slightly wider range around zero. The DS finding of greater agreement between PwD and carers may have been an artefact of the restricted scoring range for the DS compared to the FAQ; most of the DS items are rated as either present or absent, whereas each FAQ item has four scoring options across six different responses. In addition, many of the DS items reflect profound impairments such as needing to be tube fed and needing to be moved or transferred in the more advanced stages of dementia. The DS was included in IDEAL to capture increased functional impairments over the course of the study and therefore the functional items included in the DS were likely to be less relevant for people with mild-to-moderate dementia. Considering that the two discrepancy scores were highly correlated, this suggests that in mild-to-moderate dementia the FAQ may be sufficient to obtain an appraisal of functional ability.

The study has some limitations which should be considered when interpreting the findings. The inclusion of people with different diagnostic subtypes might be regarded as a limitation, as we have discussed previously [9, 29]. However, there were few differences between diagnostic groups with only vascular dementia remaining in the model for the DS. This suggests that people with vascular dementia may be more aware of more basic functional difficulties than other dementia subgroups. Differences in discrepancy score were comparable between people with vascular dementia and people with Parkinson's disease dementia or people with dementia with Lewy bodies; however, the numbers of people in these rarer diagnostic groups were quite small which may have contributed to these differences not being statistically significant. It should be noted however that while the sample sizes for these rarer dementias were small, they were generally comparable with other studies. The use of questionnaires rather than objective assessments of functional ability was a limitation as questionnaire methods are prone to bias; however, calculating the discrepancy score mitigated some of these biases. It is possible that both PwD and carers overestimate or underestimate function, but without an objective measure of functional ability it is not possible to be certain whether either set of ratings is accurate. However, previously PwD were found to be more able to accurately appraise functional ability than carers, with the latter tending to overestimate difficulties [24]. Different carer relationship types could also be considered a limitation, but consistent with our earlier study [9] there was no difference in ratings made by spousal dyads and other family members or friends. In addition, over 80% of the sample were married and nearly 90% were co-resident which may have mitigated any effect from the inclusion of dyads from non-spousal carer relationships. The sample primarily comprised people with mild dementia; therefore, the study is not able to elucidate how aware people with more moderate or advanced dementia are of their functional difficulties. Awareness of functional ability as dementia severity increases will be investigated with

longitudinal data. A final limitation lies in using statistical rather than theoretical methods to determine which measures were included in multiple regressions. As the study included a larger sample than is typical in most ADL discrepancy score studies, the study design was intentionally more exploratory and could include a wider range of potential factors for investigation with sufficient statistical power. In order to identify a smaller subset of factors that exhibit the strongest effects, those that were individually unrelated to ADL discrepancy were dropped from the multivariable model. Whilst reducing the number of variables in the model reduces variance and increases the robustness of the model, using statistical criteria for variable selection has some limitations. A variable could be non-significant due to small sample size, for example when splitting a variable into multiple categories. Some variables may be of importance theoretically and some measures could be important factors to control for, or be part of important interactions despite seeming unimportant statistically. This is why age, sex, diagnosis, and education were included in the multivariable models irrespective of statistical significance.

In conclusion, a third of PwD showed good concordance with informant ratings, which can be taken as an indication of good awareness; this may have been due to the focus on people with mild-to-moderate stages of dementia where bADL is generally preserved. However, there was slightly less concordance between self- and informant ratings for iADL. There was a similar pattern of factors associated with iADL and bADL discrepancy score. Findings suggest that PwD who present at memory clinics with higher depression scores, more co-morbidities, greater neuroticism, fewer neuropsychiatric symptoms, and who are younger may be particularly aware of their functional difficulties and hence likely to respond well to specialist care and rehabilitation. Investigating change over time in awareness of functional ability will elucidate these relationships further.

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Statement of Ethics

This study was conducted in accordance with the Declaration of Helsinki and the guidelines on good clinical practice. All eligible patients who had signed the consent form were included in the study. This study protocol was reviewed and 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). All participants gave written informed consent.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Authors’ contributions

Anthony Martyr is responsible for the data analysis and interpretation, and for drafting the article. Laura D. Gamble advised on the data analysis under the supervision of Fiona Matthews. Anthony Martyr, Sharon M. Nelis, Robin G. Morris, Catherine Quinn, Jennifer M. Rusted, Christina Victor, Jeanette M. Thom, Fiona E. Matthews, and Linda Clare were involved in the original conception, design and funding acquisition of the IDEAL programme. Anthony Martyr and Laura D. Gamble curated the IDEAL datasets. All authors contributed to the critical revision of the article and approved the version to be published.

Data availability

IDEAL data were deposited with the UK Data Archive in April 2020 and will be available to access from April 2023. Details of how the data can be accessed after that date can be found here: http://reshare.ukdataservice.ac.uk/854293/.

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Table 1. Characteristics of the sample

People with dementia factors	n	%	Informant factors	n	%
Sex			**Sex**		
Male	722	58.8	Male	380	31.0
Female	505	41.2	Female	847	69.0
Age			**Age**		
<65	100	8.1	<65	351	28.6
65-69	154	12.6	65-69	201	16.4
70-74	217	17.7	70-74	253	20.6
75-79	292	23.8	75-79	215	17.5
80+	464	37.8	80+	207	16.9
Education			**Education**		
No qualifications	328	26.7	No qualifications	261	21.3
School leaving certificate at age 16	222	18.1	School leaving certificate at age 16	275	22.4
School leaving certificate at age 18	428	34.9	School leaving certificate at age 18	367	29.9
University	243	19.8	University	318	25.9
Missing	6	0.5	Missing	6	0.5
Dementia diagnosis			**Informant Relationship**		
Alzheimer's disease	690	56.2	Spouse/Partner	1007	82.1
Vascular dementia	130	10.6	Other	220	17.9
Mixed Alzheimer's and vascular	251	20.5	**Hours of caring (per day)**		
Frontotemporal dementia	43	3.5	<1 hour	265	21.6
Parkinson's disease dementia	40	3.3	1-10 hours	482	39.3
Lewy body dementia	42	3.4	10+ hours	465	37.9
Unspecified dementia/Other	31	2.5	Missing	15	1.2
Mood			**Mood**		
Not depressed (GDS-10 0-3)	846	68.9	Not depressed (CESD-R 16-48)	1048	85.4
Depressed (GDS-10 4-10)	354	28.9	Depressed (CESD-R 0-15)	152	12.4
Missing	27	2.2	Missing	27	2.2
Living situation					
Living with spouse/partners	1025	83.5			
Living with others	63	5.1			
Living alone	137	11.2			
Missing	2	0.2			
Charlson comorbidity					
1-2 conditions	594	48.5			
3 conditions	263	21.4			
4-11 conditions	297	24.2			
Missing	73	5.9			

	n	Mean (SD; range)	Missing (%)
Self-rated Functional Activities Questionnaire	1201	10.00 (7.84; 0 to 33)	26 (2.1)
Self-rated Dependence Scale	1170	3.70 (2.54; 0 to 15)	57 (4.6)
ACE-Attention	1202	13.75 (3.04; 1 to 18)	25 (2.0)
ACE-Verbal fluency	1207	6.68 (3.10; 0 to 14)	20 (1.6)
ACE-Language	1175	22.46 (3.65; 2 to 26)	52 (4.1)
ACE-Memory	1185	13.54 (5.43; 1 to 26)	42 (3.3)
ACE-Visuospatial	1191	12.48 (3.24; 0 to 16)	36 (2.8)
Mini-IPIP-Agreeableness	1182	15.77 (2.83; 6 to 20)	45 (3.5)

Mini-IPIP-Conscientiousness	1175	13.64 (2.97; 4 to 20)	52 (4.1)
Mini-IPIP-Extraversion	1185	11.69 (3.75; 4 to 20)	42 (3.3)
Mini-IPIP-Openness	1159	12.86 (3.22; 4 to 20)	68 (5.3)
Mini-IPIP-Neuroticism	1178	10.07 (3.47; 4 to 20)	49 (3.8)
Informant ratings about the person with dementia			
Informant-rated Functional Activities Questionnaire	1169	17.83 (8.59; 0 to 33)	58 (4.7)
Informant-rated Dependence Scale	1175	5.63 (2.60; 0 to 14)	52 (4.2)
Neuropsychiatric Inventory-Questionnaire	1184	3.55 (2.46; 0 to 11)	43 (3.4)
Informant ratings about themselves			
Relatives' Stress Scale	1167	19.14 (9.82; 0 to 56)	60 (4.7)

Note: Addenbrooke's Cognitive Examination-III, ACE; Center for Epidemiologic Studies Depression Scale Revised, CESD-R; Geriatric Depression Scale-10, GDS-10.

Table 2. Mean discrepancy scores on the FAQ and DS for categorical variables.

	FAQ mean (SD; range); n	DS mean (SD; range); n
Whole sample	7.84 (8.11; -22 to 33); 1146	1.94 (2.63; -7 to 10); 1121
Person with dementia		
Sex		
Male	7.95 (8.13; -18 to 33); 681	1.79 (2.60; -7 to 10); 650
Female	7.67 (8.08; -22 to 32); 465	2.15 (2.67; -5 to 10); 471
Age		
<65	4.75 (7.64; -22 to 23); 95	1.11 (2.25; -5 to 6); 92
65-69	7.38 (8.34; -16 to 27); 147	1.57 (2.75; -7 to 9); 140
70-74	7.19 (7.93; -11 to 30); 202	1.69 (2.72; -7 to 9); 201
75-79	8.34 (7.56; -11 to 29); 264	2.12 (2.48; -5 to 10); 266
80+	8.65 (8.36; -18 to 33); 438	2.24 (2.67; -5 to 10); 422
Education		
No qualifications	6.85 (7.86; -11 to 28); 298	1.96 (2.64; -5 to 9); 304
School leaving certificate at age 16	7.95 (8.38; -22 to 32); 205	2.06 (2.67; -5 to 10); 202
School leaving certificate at age 18	8.13 (8.09; -18 to 33); 403	1.88 (2.60; -7 to 10); 393
University	8.55 (8.17; -12 to 30); 235	1.88 (2.68; -7 to 10); 216
Diagnosis		
Alzheimer's disease	8.05 (7.86; -13 to 32); 642	2.03 (2.45; -5 to 9); 637
Vascular dementia	6.82 (8.26; -22 to 33); 121	1.27 (2.49; -5 to 8); 122
Mixed Alzheimer's and vascular	8.10 (8.56; -18 to 30); 232	2.07 (2.80; -5 to 10); 226
Frontotemporal dementia	8.74 (8.80; -8 to 27); 43	1.78 (3.00; -5 to 9); 41
Parkinson's disease dementia	5.90 (7.31; -9 to 20); 38	1.15 (3.04; -7 to 7); 33
Dementia with Lewy bodies	6.73 (6.13; -11 to 17); 40	1.78 (2.82; -7 to 6); 36
Unspecified dementia/Other	7.97 (10.78; -13 to 29); 30	3.19 (3.74; -5 to 10); 26
Charlson comorbidity		
1-2 conditions	8.29 (8.11; -18 to 32); 555	2.06 (2.57; -7 to 10); 546
3 conditions	8.02 (7.58; -9 to 29); 247	2.07 (2.54; -4 to 10); 240
4-11 conditions	6.83 (8.45; -22 to 33); 278	1.56 (2.72; -7 to 8); 269
Living situation		
Living with spouse/partners	7.82 (8.05; -22 to 33); 958	1.91 (2.60; -7 to 10); 941
Living with others	9.02 (8.23; -5 to 28); 59	2.29 (2.65; -4 to 8); 56
Living alone	7.65 (8.32; -18 to 32); 127	2.00 (2.91; -5 to 10); 122
Mood		
Not depressed (GDS-10 0-3)	8.66 (7.94; -18 to 33); 791	2.18 (2.47; -5 to 10); 782
Depressed (GDS-10 4-10)	6.01 (8.32; -13 to 32); 329	1.32 (2.91; -7 to 9); 317
Informant		
Sex		
Male	7.19 (8.29; -22 to 32); 355	2.12 (2.68; -5 to 10); 353
Female	8.13 (8.01; -18 to 33); 791	1.85 (2.61; -7 to 10); 768
Age		
<65	7.64 (8.33; -22 to 29); 329	1.84 (2.63; -7 to 10); 316
65-69	7.72 (7.86; -12 to 30); 191	1.81 (2.53; -5 to 9); 184
70-74	6.86 (8.32; -13 to 32); 237	1.85 (2.72; -7 to 10); 233

75-79	8.92 (7.41; -10 to 29); 199	2.06 (2.54; -5 to 10); 198
80+	8.38 (8.29; -11 to 33); 190	2.21 (2.73; -5 to 10); 190
Education		
No qualifications	6.31 (8.21; -22 to 33); 233	1.63 (2.59; -5 to 9); 237
School leaving certificate at age 16	8.24 (8.23; -11 to 30); 255	1.85 (2.47; -5 to 10); 253
School leaving certificate at age 18	7.67 (7.56; -13 to 27); 349	1.94 (2.72; -7 to 10); 332
University	8.85 (8.31; -13 to 32); 304	2.26 (2.67; -7 to 10); 294
Informant Relationship		
Spouse/Partner	7.77 (8.06; -22 to 33); 942	1.90 (2.58; -7 to 10); 924
Other	8.15 (8.33; -18 to 32); 204	2.10 (2.86; -5 to 10); 197
Hours of caring		
<1 hour	4.71 (7.18; -18 to 24); 249	1.13 (2.44; -5 to 9); 252
1-10 hours	8.89 (7.87; -22 to 32); 451	2.06 (2.44; -7 to 10); 441
10+ hours	8.65 (8.37; -16 to 33); 432	2.30 (2.85; -7 to 10); 415
Mood		
Not depressed (CESD-R 16-48)	7.67 (8.15; -22 to 33); 982	1.89 (2.68; -7 to 10); 964
Depressed (CESD-R 0-15)	9.21 (7.72; -18 to 27); 141	2.33 (2.30; -2 to 9); 137

Note: Center for Epidemiologic Studies Depression Scale Revised, CESD-R; Dependence Scale, DS; Functional Activities Questionnaire, FAQ; Geriatric Depression Scale-10, GDS-10; Neuropsychiatric Inventory-Questionnaire, NPI-Q. FAQ range -33 to 33; DS range -15 to 15.

Table 3. Univariable regressions and multiple regressions for FAQ and DS discrepancy scores: unstandardised regression coefficients and 95% confidence intervals

	Univariable regressions		Multiple regressions	
Factor	FAQ (n=1146)	DS (n=1121)	FAQ (n=1146)	DS (n=1121)
	B (95% CI)	B (95% CI)	B (95% CI)	B (95% CI)
Adjusted R^2			Adj R^2 = .20, p <.001	Adj R^2 = .17, p <.001
Person with dementia				
Sex				
Female	-.27 (-1.23, 0.68)	0.36 (0.05, 0.67)*	.45 (0.76, 9.18)	0.52 (0.21, 0.83)***
Age				
<65	-3.91 (-5.69, -2.12)***	-1.13 (-1.72, -0.54)***	-3.73 (-5.47, -2.00)***	-1.02 (-1.59, -0.44)***
65-69	-1.27 (-2.78, 0.23)	-0.67 (-1.17, -0.17)**	-0.96 (-2.38, 0.46)	-0.59 (-1.07, -0.11)*
70-74	-1.47 (-2.81, -0.12)*	-0.55 (-0.98, -0.11)*	-0.66 (-1.90, 0.59)	-0.30 (-0.71, 0.11)
75-79	-0.31 (-1.54, 0.92)	-0.11 (-0.51, 0.29)	-0.08 (-1.21, 1.06)	-0.14 (-0.51, 0.24)
80+	ref	ref	ref	ref
Dementia diagnosis				
Alzheimer's disease	ref	ref	ref	ref
Vascular dementia	-1.23 (-2.81, 0.34)	-0.76 (-1.26, -0.25)**	-0.80 (-2.25, 0.66)	-0.59 (-1.07, -0.11)*
Mixed Alzheimer's and vascular	0.05 (-1.17, 1.27)	0.05 (-0.35, 0.44)	0.05 (-1.08, 1.18)	-0.03 (-0.40, 0.35)
Frontotemporal dementia	0.69 (-1.81, 3.20)	-0.25 (-1.07, 0.58)	0.68 (-1.64, 2.99)	-0.24 (-1.03, 0.54)
Parkinson's disease dementia	-2.16 (-4.81, 0.50)	-0.87 (-1.79, 0.04)	-1.64 (-4.11, 0.83)	-0.59 (-1.46, 0.28)
Dementia with Lewy bodies	-1.33 (-3.91, 1.26)	-0.25 (-1.13, 0.63)	-1.81 (-4.21, 0.59)	-0.19 (-1.02, 0.64)
Unspecified dementia/Other	-0.08 (-3.05, 2.88)	1.17 (0.14, 2.19)*	-0.81 (-4.21, 0.59)	0.85 (-0.11, 1.80)
Education				
No qualifications	-1.26 (-2.47, 0.05)*	0.07 (-0.32, 0.47)	-1.42 (-2.55, -0.28)*	-0.03 (-.41, 0.34)
School leaving certificate at age 16	-.18 (-1.54, 1.18)	0.18 (-0.27, 0.62)	0.06 (-1.19, 1.31)	0.12 (-0.30, 0.46)
School leaving certificate at age 18	ref	ref	ref	ref
University	.42 (-.88, 1.72)	-0.01 (-0.44, 0.43)	0.52 (-0.69, 1.72)	0.05 (-0.35, 0.46)
Charlson comorbidity				
1-2 conditions	ref	ref	ref	ref
3 conditions	-0.24 (-1.44, 0.96)	0.05 (-0.35, 0.44)	-0.02 (-1.09, 1.12)	0.14 (-0.23, 0.51)
4-11 conditions	-1.29 (-2.44, -0.13)*	-0.51 (-0.89, -0.13)**	-1.17 (-2.28, -0.05)*	-0.41 (-0.79, -0.04)*
Living situation				

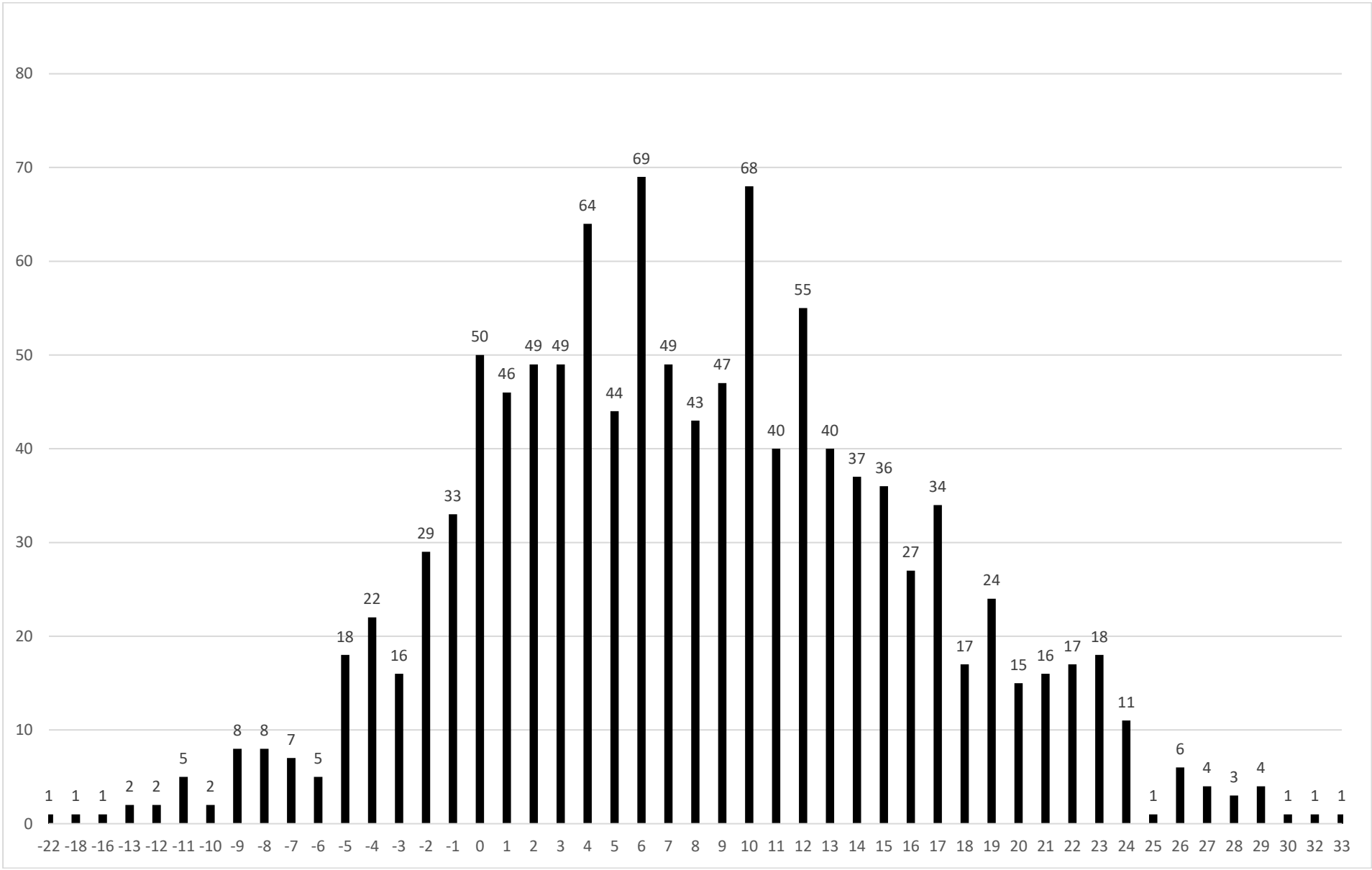
Living with spouse/partners	ref	ref		
Living with others	1.23 (-0.90, 3.36)	0.38 (-0.33, 1.09)		
Living alone	-0.14 (-1.64, 1.36)	0.09 (-0.40, 0.59)		
Mood				
GDS-10 depression	-2.60 (-3.63 -1.58)***	-0.83 (-1.17, -0.49)***	-1.68 (-2.77, -0.59)**	-0.63 (-0.99, -0.27)***
Cognition				
ACE-Attention	-0.19 (-0.34, -0.05)**	-0.07 (-0.12, -0.03)**	0.02 (-0.15, 0.19)	-0.01 (-0.06, 0.05)
ACE-Verbal fluency	-0.17 (-0.32, -0.02)*	-0.07 (-0.12, -0.02)*	-0.00 (-0.17, 0.16)	-0.01 (-0.07, 0.04)
ACE-Language	0.05 (-0.06, 0.15)	-0.01 (-0.04, 0.03)		
ACE-Memory	-0.21 (-0.30, -0.12)***	-0.06 (-0.09, -0.03)***	-0.11 (-0.20, -0.01)*	-0.01 (-0.04, 0.02)
ACE-Visuospatial	-0.04 (-0.18, 0.11)	-0.04 (-0.08, 0.01)		
Personality				
Mini-IPIP-Agreeableness	-0.07 (-0.23, 0.09)	-0.00 (-0.06, 0.05)		
Mini-IPIP-Conscientiousness	0.30 (0.15, 0.46)***	0.13 (0.08, 0.18)***	0.16 (0.01, 0.31)*	0.09 (0.04, 0.14)***
Mini-IPIP-Extraversion	0.08 (-0.04, 0.21)	0.01 (-0.04, 0.05)		
Mini-IPIP-Openness	0.28 (0.14, 0.43)***	0.06 (0.01, 0.11)*	0.17 (0.03, 0.31)*	0.03 (-0.02, 0.08)
Mini-IPIP-Neuroticism	-0.40 (-0.53, -0.26)***	-0.12 (-0.16, -0.07)***	-0.31 (-0.46, -0.17)***	-0.09 (-0.13, -0.04)***
Neuropsychiatric symptoms				
NPI-Q	0.84 (0.65, 1.02)***	0.25 (0.19, 0.31)***	0.65 (0.46, 0.86)***	0.19 (0.12, 0.26)***
Informant				
Sex				
Female	0.93 (-0.08, 1.95)	-0.27 (-0.60, 0.06)		
Age				
<65	ref	ref		
65-69	0.08 (-1.36, 1.52)	-0.03 (-0.50, 0.45)		
70-74	-0.78 (-2.13, 0.57)	0.01 (-0.43, 0.46)		
75-79	1.28 (-0.14, 2.71)	0.22 (-0.25, 0.69)		
80+	0.74 (-0.70, 2.19)	0.38 (-0.10, 0.85)		
Education				
No qualifications	-1.34 (-2.68, 0.00)	-0.31 (-0.75, 0.13)		
School leaving certificate at age 16	0.56 (-0.74, 1.87)	-0.09 (-0.52, 0.34)		
School leaving certificate at age 18	ref	ref		
University	1.15 (-0.09, 2.39)	0.30 (-0.11, 0.72)		

Informant relationship				
Spouse/Partner	0.38 (-0.84, 1.61)	0.19 (-0.21, 0.60)		
Hours of caring (per day)				
<1 hour	-4.13 (-5.36, -2.90)***	-0.92 (-1.32, -0.52)***	-2.79 (-3.99, -1.58)***	-0.50 (-0.89, -0.10)*
1-10 hours	ref	ref	ref	ref
10+ hours	-0.19 (-1.23, 0.86)	0.25 (-0.10, 0.59)	-0.51 (-1.52, 0.49)	0.19 (-0.15, 0.52)
Mood				
CESD-R depression	1.36 (-0.05, 2.77)	0.40 (-0.07, 0.86)		
Carer stress				
Relatives' Stress Scale	0.22 (0.18, 0.27)***	0.06 (0.05, 0.08)***	0.13 (0.08, 0.19)***	0.04 (0.02, 0.06)***

Note: Addenbrooke's Cognitive Examination-III, ACE; Functional Activities Questionnaire, FAQ; Dependence Scale, DS; Geriatric Depression Scale-10, GDS-10; Center for Epidemiologic Studies Depression Scale Revised, CESD-R; Neuropsychiatric Inventory-Questionnaire, NPI-Q. The shaded areas indicate where measures were not included in the multiple regression analysis due to not being statistically significant and the size of the coefficient and 95% confidence intervals.

* p≤.05, ** p≤.01, *** p≤.001

Supplementary Figure 1. Range of Functional Activities Questionnaire discrepancy scores



Supplementary Figure 2. Range of Dependence Scale discrepancy scores