

# Are There Inequalities in the Receipt of Help Among People With Dementia or Cognitive Impairment? Results From the English Longitudinal Study of Ageing

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## Research article

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## Abstract

**Background:** In addition to inequalities related to gender, age and socio-economic background, poor cognitive function may affect receipt of help and impair quality of life. We investigate whether people with dementia or low cognition with a disadvantaged background, experience more unmet need and/or more unrequired help than older people with similar levels of functional limitation, and associations with quality of life.

**Methods:** We studied people aged 50+ in the English Longitudinal Study of Ageing. Cognitive status was divided into three groups: dementia (by physician diagnosis and/or proxy questionnaire,  $n=405$ ); low cognition but no dementia (lowest quartile in the mean of z-scores of orientation, immediate recall and delayed recall,  $n=4,520$ ); and intact cognition ( $n=10,264$ ). Counts of unmet need (not receiving help for the need) and unrequired help (receipt of help without the respective need) were used as outcomes in two-part regressions. Quality of life (CASP-19) was a continuous outcome in a linear regression. Socio-demographic factors (gender, age, having partner/child and socioeconomic status), functional limitation, and their interaction with cognitive status were included in the models.

**Results:** People with dementia or low cognition at lower levels of functional limitation had more unmet need and received more unrequired help. At higher levels of functional limitation, unmet needs were more frequent among the cognitively intact while unrequired help did not differ by cognitive status. Women, younger individuals, and those with a partner had fewer unmet needs but received more unrequired help, mostly among the cognitively intact. Higher socioeconomic status was associated with fewer unmet needs and unrequired help regardless of cognitive status. Both unmet need and unrequired help were associated with poorer quality of life independent of cognitive status.

**Conclusions:** Unmet need may be a particular challenge in early dementia. Unrequired help that may decrease autonomy is a problem at all levels of cognition. Lower socioeconomic status undermines the receipt of sufficient help. Our results highlight the importance of a good-quality timely diagnosis of dementia, comprehensive and accurate needs assessment, and person-centred care planning to identify those with unmet need and receiving unrequired help in order to improve their quality of life.

## Background

People with impaired cognitive function (ranging from poor performance in memory and orientation tasks to the neurodegenerative disorder dementia) often have greater needs for assistance in daily activities compared to older people without cognitive difficulties (1–3). Unmet needs are frequently observed among people with dementia, with over 90% having at least one unmet need (4–9). Unmet needs are also common among people with memory problems not amounting to dementia (10). The most common unmet needs include those related to: safety, health and medical care, daily activities, company, and counselling and legal support (11). These needs are compounded by the functional limitations related to dementia itself and other co-occurring long-term conditions (2).

People with impaired cognitive functioning, including those with dementia, may also experience social inequalities (i.e. disadvantages due to gender, age or socioeconomic position), which, in turn, may affect their level of need and receipt of sufficient help (12–14). Social inequalities and cognitive impairment may act together to complicate identifying and meeting care needs because of a decreased ability to communicate needs (15). Together they may affect care provision and receipt via psychosocial factors (e.g. attitudes, knowledge, social norms, and perceived control), through enabling factors (e.g. availability of support, and financial resources), and through objective and perceived need (16,17). However, when care needs become higher with progression to more severe stages of dementia, this may prompt the identification of both needs related to, and needs unrelated to, cognitive impairment and this may enable access to the help required (18).

Several studies have reported the factors associated with unmet needs and inequalities in receiving help among people with dementia or cognitive impairment. In a Chilean study, those with dementia living in the community were less likely to receive help if they were men and if they had a lower level of education (1). In the community in the United States, higher unmet needs among those with dementia were associated with non-white ethnicity, lower income, less impairment in activities of daily living, and more symptoms of depression (5). A subsequent study from the same group showed non-white ethnicity, lower education, higher cognitive function and more neuropsychiatric symptoms were associated with unmet needs (4). The receipt of sufficient help in the presence of difficulties in everyday activities is important because it allows people to live in the community longer and enhances their quality of life (19,20). This is particularly the case for those with cognitive impairment (21).

However, other studies have found little association between unmet needs and social determinants. In a German sample of people with dementia living in the community there was no significant association between the number of unmet needs and cognitive impairment, living alone, the presence of an informal caregiver, age, gender, or depression (6). The only factor significantly associated with unmet need was a higher level of limitations in activities of daily living (ADLs). In a small sample of Polish people with dementia living at home, apart from women reporting more unmet need than men, no associations were found between unmet need and age, marital status, education, relationship with carer, observed cognitive deficit, or the mean number of met and unmet needs (22).

In terms of outcomes, unmet needs have been found to be associated with poorer quality of life among community living people with dementia in England (7) and the United States (4,5), and in a study of eight European countries (20,23). However there are suggestions that quality of life may be also compromised by the receipt of unrequired help (i.e. help given when the person does not report a respective functional limitation or need). It may lead to waste of care resources, rising expenditure, and dissatisfaction among recipients (24). Previous studies demonstrated that care recipients may perceive caregivers as overprotective, which compromises their autonomy, independence, and quality of life (25,26). Unrequired help and overprotective care are common among people with health conditions such as stroke and vision loss, because these conditions are often associated with falls and injuries (27). The same may apply to dementia, a condition associated with a heightened risk of accidents. Caregivers may strive to take extra caution to eliminate the risk of accidents that may

have negative consequences since, from the perspective of care recipients, the extra attention and help they receive from caregivers may be perceived as unrequired or overprotective.

The extent to which cognitive status and inequalities interact in the receipt of sufficient help is not well understood, the data are often limited to a few inequality indicators, populations of people with dementia only and health care use only, and the results have been mixed and inconclusive. Moreover, there are few data on how this might affect patient-reported outcomes such as quality of life. We therefore studied a representative sample of people aged 50+ living in the community in England to investigate whether people with dementia or low cognition are more likely to have unmet need than older people with similar levels of functional limitations but intact cognition and how this is associated with quality of life in these groups. Our specific aims were to explore: 1) whether unmet need (not receiving help for the need in question) and unrequired help (receiving help when there is no respective need) are more frequent among people with dementia and impaired cognition compared to the general population with the same level of need (functional limitation); 2) whether inequalities related to sociodemographic factors (gender, age, having partner/child, socioeconomic status) in the receipt of help are more pronounced when cognitive status is lower; and 3) whether unmet need and unrequired help are associated with poorer quality of life and how this varies with cognitive status.

## Methods

### Data

We used a sample of men and women aged 50+ from the English Longitudinal Study of Ageing (ELSA), a nationally representative longitudinal study of the older household population of England (28). The first wave of ELSA was conducted in 2002-2003 and consecutive waves were carried out every two years. The description of sampling and data collection is available elsewhere (29). Our analysis is based on data collected at waves six, seven, and eight in 2012-3, 2014-15, and 2016-17 respectively. These waves were selected because they included an in-depth interview on needs for, and receipt of, social care. The data were pooled across the three waves. Including more than one wave allowed for the inclusion of more cases of dementia and low cognition than would otherwise have been possible. The sample in the current study included those aged 50+ living in the community who reported difficulty in any of six items of activities of daily living (ADL), seven instrumental activities of daily living (IADL), or a mobility limitation. These measures were used as a threshold in the study for follow-on questions on the receipt of help (30). To be included in the analysis, the respondents also had to provide a score from cognitive tests or self- or proxy-information on dementia. Participants gave their informed consent to take part in the study. Ethical approval for ELSA was given by the London Multicentre Research Ethics Committee.

### Measures

#### *Cognitive status*

*Dementia* was determined using self-reported or proxy-reported physician diagnosis of dementia or Alzheimer's disease or the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) proxy reports of change in behaviour and cognition (score 3.5 or more) (31).

*Low cognition* was defined as scoring in the lowest (poorest performing) quartile of cognitive tests (2) but excluding those identified as having dementia. Three cognitive tests in ELSA were used: time orientation, immediate recall, and delayed recall. Time orientation was assessed using four questions relating to day and date from the Mini-Mental State Examination (32). Immediate and delayed recall was tested with a word list in which the participant was asked to learn ten common unrelated words (33). The lowest quartile of the distribution of mean z-scores of the three tests was used (cut-off at z-score < -0.3).

The *no dementia or low cognition* group comprised those who did not have dementia and whose mean z-scores of the three cognitive tests was higher than the cut-off for the lowest quartile.

#### *Need for and receipt of help*

People were considered to need help if they (or informants) reported difficulty with one or more of six items of Activities of Daily Living (ADLs), four items of Instrumental Activities of Daily Living (IADLs) or three items of mobility (see items in Table 1). Where any of these ADL, IADL or mobility difficulties were experienced, respondents were asked about receipt of help for this need (30). If they reported need but did not receive help for the respective need, the item was coded *unmet need* (0= received help for the respective need, 1= did not receive help for the respective need), and if they received help without need, the item was coded *unrequired help* (0= did not have need and did not receive help, 1= received help when no respective need mentioned). For those who scored 1 in the binary items above, variables were derived for the number of needs in which the need was not met and the number of ADL, IADL or mobility limitations for which unrequired help was received.

-Table 1 about here-

#### *Socio-demographic factors*

*Age* was measured in years. *Gender* (0=male, 1=female), and whether the respondent had a partner (0=no, 1=yes) and/or child(ren) (0=no, 1=yes) were binary variables. A binary measure was also used for *educational level*; 0 indicating having any qualification (college or university diploma or degree, O' or A' levels or equivalent public examinations taken in secondary schools at around ages 16 and 18 respectively or vocational or foreign qualifications) and 1 indicating having no qualification. *Occupational social class* was based on the National Statistics Socio-economic Classification (NS-SEC) using three classes: 1) routine and manual, 2) intermediate, and 3) higher managerial, administrative and professional occupations (34). *Wealth* quintiles were calculated using non-pension wealth comprising financial, physical, and housing wealth net of debt. Wealth quintile was treated as continuous in the analysis. *Home ownership* was a binary measure, with 1 indicating owning home outright or with mortgage or shared-ownership, and 0 renting, living rent free or squatting.

### *Functional limitations*

The *number of functional limitations* was used to measure the frequency of functional difficulties. All 24 items of ADL, IADL and mobility difficulties available in the dataset were used (see the items in Table 1). The items for ADLs, IADLs and mobility difficulties were highly correlated and combining the three scales showed good internal consistency (Cronbach's alpha = 0.79).

### *Quality of life*

Quality of life was assessed with the CASP-19 questionnaire (35). It has 19 items measuring four dimensions: control in life (four items, e.g. 'I feel that what happens to me is out of my control'), autonomy (five items, e.g. 'I can do the things I want to do'), pleasure (five items, e.g. 'I look forward to each day'), and self-realisation (five items, e.g. 'I feel that life is full of opportunities'). Each item is rated on a four-point scale that ranges from 'often' to 'never'. Items were reverse coded so that a higher score indicated a higher quality of life. Mean score for all 19 items to measure the general level of quality of life was calculated. The internal consistency of the score was good (Cronbach's alpha = 0.89).

## **Analysis**

We carried out two-part regressions to investigate whether unmet need and unrequired help differed between the three groups of cognitive status by their sociodemographic background and number of functional limitations. The first part of each model was estimated using a logit model (whether or not the person has an unmet need or received unrequired help). The second part using a Generalized Linear Model (GLM) with a log link and a gamma distribution (the count of unmet needs or needs for which unrequired help was received) to account for the non-normal distribution of the number of unmet needs and number of tasks for which unrequired help was received. Linear regression was used to investigate quality of life (CASP-19) as an outcome variable. The regressions were carried out within the wave and standard errors were clustered (36) at both the level of the household (usually partners living at the same address) and the time point (an individual answering in several waves) to account for the intra-household and intra-temporal correlations in the sample.

We included age, gender, whether the person had a partner, whether the person had children, socio-economic variables (educational level, occupational social class, wealth quintile and home ownership) and functional limitations to investigate whether they were associated with the receipt of help. We also included an interaction between cognitive status and the socio-demographic variables and number of functional limitations to investigate whether the association between the demographic and socio-economic variables and receipt of help differed by cognitive status, e.g. whether the combination of poorer cognition and social disadvantage was associated with unmet need or unrequired help. To determine whether adding the interaction term improved the fit of the model, the Wald test for the interaction term was carried out. A p-value smaller than 0.05 was used as an indication of a significant interaction effect. To illustrate the interactions, we used the average marginal effects. For the interactions of those variables with definable classes, the estimated margins were shown as percentage or mean in tables, and for those interactions with continuous variables the estimated margins were shown in figures, both with 95% confidence intervals.

## **Results**

### **Descriptive results**

The numbers of those living in the community who provided a score from cognitive tests or self or proxy information on dementia were 9,826 for Wave 6, 9,602 for Wave 7, and 8,387 for Wave 8. In the pooled data there were 405 with dementia, 4,520 with low cognition, and 10,264 with intact cognition (no dementia or low cognition). These numbers excluded those who reported no ADL, IADL or mobility difficulties and were therefore not asked about receipt of help (11% of those with dementia, 33% with low cognition, and 50% with intact cognition). Table 2 shows the distribution of variables between the three cognition groups. People with dementia or low cognition tended to be older, less likely to own their homes, to have no qualifications, to belong to a lower occupational social class (NS-SEC), to be in the lower wealth quintile, and to have more functional limitations than those with intact cognition.

The cognitive scores in orientation and recall tasks were understandably lower among those with dementia and those with low cognition compared to those with intact cognition (Table 2). Fewer people with dementia participated in the cognitive tests (n.b. the cognitive scores were not used to identify the group with dementia and are shown for descriptive purposes only). A higher proportion of people with dementia or low cognition reported unmet need and unrequired help compared to those with intact cognition (Table 2). Quality of life was lowest among those with dementia and highest among those with intact cognition. The distributions of the individual unmet need and unrequired help items are shown in Supplementary Figure 1.

There were no missing data on gender, age, and having partner/children in the sample; 0.03% had missing data on functional limitation, 1-2% on education, home ownership and receipt of help, 6% on wealth quintile, and 18% had missing quality of life scores. The last two items were more often missing because determining wealth quintile required detailed information on financial assets which proxies did not necessarily know, and quality of life was a self-completion task which was not always completed by those with limited functioning. Missingness resulted in some differences between the distributions, for example the analytic sample with no items missing used for the model for unmet need included a higher proportion of people with dementia living with a partner and a lower proportion with unmet needs compared to all available data (see Table 2). However, when we ran the regression models with data using multiple imputation, the results for the associations between the variables were very similar between the imputed and unimputed datasets. Missingness in the predictors was generally low and affected only one of the outcomes, quality of life, in which case multiple imputation has very little effect and missing data can be ignored (37). In this paper, we therefore present the regressions for the unimputed data.

### **Differences in receipt of help by cognitive status**

Unmet need was more likely (logit model) to be reported by those participants who were: older, living in rented housing, in the lower wealth quintile, and with more functional limitations (Table 3). The number of unmet needs (GLM model) was higher those who were: male, without a partner, living in rented housing, in a lower wealth quintile, and who had more functional limitations. People with dementia were less likely on average to have an unmet need and tended to have a lower number of unmet needs than those with no dementia. However, there were interactions between cognitive status and age (Wald test = 19.69, degrees of freedom (df) = 4,  $p < 0.001$ ), and cognitive status and number of functional limitations (Wald test = 328.86, df = 4,  $p < 0.001$ ) (see the estimates for the interaction model in Supplementary Table 1). Unmet need increased with age among people with intact cognition, but not among those with dementia or low cognition. The apparent contradiction in results on unmet need and cognitive status is explained by the finding that people with dementia at the lowest levels of functional limitations (1-2 limitations) were more likely to have unmet need, whereas at the higher levels of functional limitations (7+ limitations) those with no dementia had a higher number of unmet needs (Figure 1). The profiles of unmet need at the lower levels of limitations suggest that some ADL limitations (help with walking, stairs, bathing and getting in and out bed) were more often met for those with no dementia compared to those with dementia (Supplementary Figure 2). At higher levels of limitations, the profiles of unmet need show that those with dementia received help more often in all 13 limitations compared to those with no dementia (Supplementary Figure 3).

Unrequired help (logit model) was more common among: women, older people, those with a partner, those in the routine/manual compared to intermediate occupational social class, those who were not home owners, those in lower wealth quintiles, and those with more functional limitations (Table 4). The number of areas for which unrequired help was received (GLM model) was higher among: those with a partner, and those in the lower wealth quintile. People with low cognition or dementia were more likely to receive unrequired help compared to people with intact cognition. The interactions showed that, although women and those with a partner more often received unrequired help in the cognitively intact group and among those with low cognition, there were no differences by gender (Wald test = 9.81, df = 4,  $p = 0.044$ ) or partnership status (Wald test = 11.07, df = 4,  $p = 0.026$ ) among those with dementia. This was due to a large variation in the receipt of unrequired help by gender and partnership (see the estimates and marginal effects for the interactions in Supplementary Table 2a and 2b). The interaction between functional limitations and cognitive status (Wald test = 83.40, df = 4,  $p < 0.001$ ) showed that a higher number of functional limitations among those with no dementia increased the likelihood of unrequired help, whereas among those with dementia there was very little difference in the frequency of unrequired help by the number of functional limitations (Figure 2). The profiles of unrequired help showed that at lower levels of functional limitation unrequired help for IADL tasks, especially help with shopping and housework, was more frequent among those with dementia compared to those with no dementia (Supplementary Figure 4). At higher levels of functional limitations, those with dementia tended to have somewhat higher levels of unrequired help, apart from help with dressing and housework, compared to people with intact cognition (Supplementary Figure 5).

### Associations with quality of life (CASP-19)

Both unmet need and unrequired help were associated with lower quality of life (Table 5). Quality of life was lower among those with dementia or low cognitive functioning compared to those with intact cognition. Being female, higher age, having a partner, higher socioeconomic status and lower levels of functional limitations were associated with higher quality of life. However, among those with dementia or low cognitive functioning only female gender, older age and, to some extent, higher levels of wealth and functional limitations were associated with higher quality of life. The analysis of interactions between cognitive status and having a partner (Wald test = 4.81, df = 2,  $p = 0.008$ ), occupational social class (Wald test = 3.64, df = 4,  $p = 0.006$ ), home ownership (Wald test = 8.72, df = 2,  $p < 0.001$ ), and wealth (Wald test = 9.37, df = 2,  $p < 0.001$ ) showed that statistically significant associations were most evident among those with intact cognition (see the estimates and marginal effects for the interactions in Supplementary Table 3a and 3b). The interaction between cognitive status and functional limitations showed that poorer cognitive status was associated with lower quality of life at lower levels of functional limitations but this association disappeared at higher levels of functional limitation (Wald test = 4.02, df = 2,  $p = 0.018$ ) (Figure 3).

## Discussion

In this study we investigated unmet need and unrequired help and quality of life by cognitive status comprehensively in a large representative sample of older adults, taking account of level of functioning and socio-demographic factors. Our main findings are that people with dementia and those with cognitive impairment who had low levels of functional limitation (i.e. those with earlier stages of dementia and milder cognitive impairment) had more unmet needs compared with those with intact cognition. At higher levels of functional limitation (i.e. those with later stages of dementia and more severe cognitive impairment), poorer cognitive status was associated with fewer unmet needs. Those with dementia and those with lower cognitive function also received more unrequired help than those with no cognitive impairment. More severe cognitive impairment was therefore associated with an increased likelihood that needs were met but also that unneeded help was received. Socio-economic inequalities were similar among those with dementia or low cognition compared to those with intact cognition. Poorer cognitive status combined with disadvantaged background did not appear to increase inequalities due to age, gender, having a partner or socioeconomic status in receiving help. People with dementia or low cognition reported lower quality of life compared to those cognitively intact. The difference was particularly large at lower levels of functional limitations (i.e. those with earlier stages of dementia and milder cognitive impairment). Our results highlight the importance of a good-quality timely diagnosis of dementia, with comprehensive and accurate needs assessment, and person-centred care planning to identify those with unmet need and receiving unrequired help in order to maximise their quality of life.

## Limitations

These analyses have important limitations. First, there were gaps in the domains measured. It was not possible to include measures of depression, since data on self-reported depression was missing in the dataset for a large number of those with cognitive problems. Equally, the lack of data on neuropsychiatric symptoms or on severity of dementia in the dataset are important omissions. This means that we are assuming when interpreting these data that those with fewer functional limitations are on average those who are at earlier stages of dementia and therefore have milder cognitive impairment. Given that dementia is a progressive disorder that by definition causes increasing functional impairment over time as there is increasing cognitive impairment, we believe this to be a useful and tenable interpretation. However, it must be acknowledged that there are sources of functional limitation unrelated to cognition. Second, unmet

needs were measured with 13 items included in ELSA, which differ from measures used in other studies for investigating unmet need. For instance, the ELSA data does not permit assessment of unmet needs related to specific areas of unmet need investigated in the previous studies, such as unmet needs in medical care (6), counselling, social integration, dementia diagnosis and treatment (5), or psychological or behavioural factors (7,8). Unrequired help excludes those who did not report any functional difficulties: therefore it is possible that some more people would receive unrequired help if it was asked from everyone. Third, the identification of dementia here was not based on clinical assessment but on self- or proxy-reported physician diagnosis or proxy-reported change in memory and behaviour over the last two years. The IQCODE system is robust and widely used, but it is possible that dementia was underestimated, because respondents or proxies did not disclose it or did not know it. Fourth, those with cognitive problems are more likely to have dropped out of ELSA, which affects the numbers of those with dementia and those with low cognition in the sample. Moreover, the reports of those with cognitive impairment may be subject to greater error than those with intact cognition. Finally, the associations are cross-sectional and may be subject to reverse causality (e.g. quality of life may affect the reporting of receipt of help).

### ***Unmet need and unrequired help***

These analyses suggest that unmet needs and unrequired help were more frequent in the groups with cognitive impairment compared to those with intact cognition when only few functional limitations were reported. Unmet needs in these groups were especially related to help in walking 100m, getting in and out of bed, and bathing (i.e. ADLs), while unrequired help clustered around help with shopping, taking medication, housework and handling money (i.e. IADLs). When functional limitations were high in number, the needs of those with dementia or lower cognition tended to be more often met and the receipt of unrequired help was similar compared to those with intact cognition. These results point to potential problems of meeting the needs of those who have cognitive impairment but few functional needs. Those with mild dementia may not have insight into their problems and may find it difficult to express what they need (38,39). Their dementia may go undiagnosed, and in cases where dementia is diagnosed, needs may not be met if they do not relate to problems assumed to be associated with dementia such as poor orientation and memory, i.e. IADLs (15,17).

It is interesting that much of the help that was actually offered may in fact have not been needed, suggesting that caregivers may become overprotective and provide more care than necessary in the early stages of dementia. Mismatch between reported need and help received may also result from different expectations between people with dementia and their carers where carers may have an expectation of dependence once the diagnosis is made, especially if they belong to different age cohorts (40,41). Not admitting a need for help may be motivated by a sense of dignity and independence as well as a lack of insight (42). Our findings are in line with studies that have shown that unmet needs are more common in those with mild dementia compared to those with more advanced dementia (4,5). People with more severe dementia may be more likely to be diagnosed and therefore to come to the attention of services. The needs of those with more severe dementia may be more apparent to carers and services and so more likely to be met (18).

### ***Inequalities and quality of life***

We found that inequalities related to socio-economic factors were similar among those with dementia or low cognition compared to those with intact cognition. Unmet needs were associated with lower socioeconomic status, but less so with age and gender, which is in line with previous findings (4,5). In terms of outcomes, our findings confirm that unmet need is associated with poorer quality of life among people with dementia (4,5,7). In addition, we found that unrequired help had a similar adverse effect on quality of life to unmet need. People with dementia or low cognition reported lower quality of life compared to those who were in the cognitively intact group. The difference was again particularly large at lower levels of functional limitations. It is possible that people with cognitive problems recognise and report their needs differently from their carers (or those who provide help) (43), which may contribute to unmet need or unrequired help. People receiving unrequired help may feel dependent on other people which may compromise their sense of independence (44). Our findings are in line with accumulating evidence that socio-demographic factors play little role in the quality of life of people with dementia (45).

Our finding of a mismatch between the type of need experienced and help received, particularly in earlier stages of dementia, with consequent lower quality of life points to the importance of effective and timely diagnosis, needs assessment, and care planning. We need care planning and service delivery that empowers people with cognitive impairment rather than actions that foster or encourage dependency (43). Enabling autonomy by giving the opportunity to carry out meaningful everyday tasks and to make decisions on care is a vital component of person-centred care (46,47).

## **Conclusions**

Our findings have important implications for those planning and providing services for people with dementia. They demonstrate that unmet need may be a particular challenge in early dementia and that unrequired help that may decrease autonomy is a problem at all stages of cognitive impairment as is low quality of life. Although demographic factors, such as gender, age and having partner, have very little effect on the receipt of sufficient help among those with dementia, the inequalities related to socioeconomic status such as not owning a house and lower wealth hampers the receipt of help among those with dementia the same way as among those with intact or low cognition. The findings highlight the importance of good-quality and timely diagnosis of dementia and comprehensive needs assessment and person-centred care planning to identify those with unmet need and those receiving unrequired help in order to maximise their quality of life.

## **List Of Abbreviations**

ADL = Activity of Daily Living

IADL = Instrumental Activity of Daily Living

ELSA = English Longitudinal Study of Ageing

NS-SEC = National Statistics Socio-economic Classification

CASP-19 = A quality-of-life measure comprising 19 items in four domains: 'Control', 'Autonomy', 'Self-realization' and 'Pleasure'

GLM = Generalized Linear Model

df = degrees of freedom

IQCODE = Informant Questionnaire on Cognitive Decline in the Elderly

## Declarations

### Ethics approval and consent to participate:

Ethical approval for the DETERMIND study, of which the analyses presented in our paper is part, was obtained from The London: Brighton and Sussex Research Ethics Committee (REC 19/LO/0528). Our analyses were conducted on previously collected, publicly available data from the English Longitudinal Study of Ageing (ELSA). ELSA was approved by the London Multicentre Research Ethics Committee (MREC/01/2/91), and written informed consent was obtained from all participants. Our work comprised re-analysis of de-identified data. No new ethical approval or consent was required for it.

### Consent for publication:

Not applicable

### Availability of data and materials:

The ELSA datasets analysed during the current study are available in the UK Data Service, <https://beta.ukdataservice.ac.uk/datacatalogue/series/series?id=200011>

### Competing interests:

The authors declare that they have no competing interests.

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### Authors' contributions:

SR designed the study, analysed the data, wrote the first draft of the manuscript and revised the further versions of the manuscript. BH and RW contributed to the design and statistical analysis. BH, JD, NB, RW and SB contributed to the interpretation of the findings, and drafting and commenting the manuscript. All authors read and approved the final manuscript.

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## Tables

Table 1. Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs) and mobility items in ELSA.

ADLs	IADLs	Mobility
Difficulty in:	Difficulty in:	Difficulty in:
Dressing*	Shopping for groceries*	Walking 100 yards*
Walking across a room*	Taking medication*	Climbing several flights of stairs without resting*
Bathing or showering*	Doing work around the house or garden*	Climbing one flight of stairs without resting*
Eating*	Managing money*	Sitting for about two hours
Getting in and out of bed*	Using a map	Getting up from a chair after sitting for a long period
Using the toilet*	Recognising when in physical danger	Stooping
	Preparing hot meals	Kneeling or crouching
	Making phone calls	Reaching or extending
	Communication	Pulling or pushing large objects
		Lifting or carrying weights over 10 pounds
		Picking up a 5p coin

\* Used in coding unmet need and unrequired help

Table 2. Descriptives of socio-demographic variables, cognition, receipt of help and quality of life among people with ADL/IADL/mobility difficulty<sup>a</sup> in pooled ELSA data waves 6, 7 and 8.

	People with dementia <sup>b</sup>			People in the lowest cognitive quartile <sup>c</sup>			People with intact cognition		
	All	Complete <sup>d</sup>		All	Complete <sup>d</sup>		All	Complete <sup>d</sup>	
	<i>n</i>	<i>n</i> = 337		<i>n</i>	<i>n</i> = 3,896		<i>n</i>	<i>n</i> = 8,523	
		M(SD)/ %	M(SD)/ %		M(SD)/ %	M(SD)/ %		M(SD)/ %	M(SD)/ %
Female	403	53	54	4,505	54	55	10,198	64	65
Age	403	78.6 (9.1)	78.9 (8.61)	4,505	74.3 (10.1)	75.3 (9.4)	10,198	68.0 (9.0)	69.2 (8.6)
Has partner	403	62	79	4,505	57	75	10,198	69	69
Has child(ren)	403	89	88	4,505	88	88	10,198	88	88
No qualification	403	47	46	4,505	44	45	10,035	23	23
Occupational social class	375			4,522			9,703		
Professional/managerial		27	29		22	22		34	34
Intermediate		25	26		23	23		27	27
Routine		47	45		55	55		39	39
Home owner	394	76	75	4,493	72	73	10,179	82	82
Wealth quintile	368	2.6 (1.2)	2.7 (1.2)	4,122	2.7 (1.3)	2.7 (1.3)	8,908	3.1 (1.4)	3.1 (1.4)
N of functional limitations <sup>e</sup>	403	11.6 (6.6)	11.7 (6.6)	4,505	6.1 (5.0)	5.9 (4.8)	10,198	4.3 (4.0)	4.3 (4.0)
Cognition									
Orientation	236	2.0 (1.6)	2.1 (1.6)	4,505	3.3 (1.0)	3.3 (0.9)	9,839	3.9 (0.3)	3.9 (0.3)
Immediate recall	229	2.8 (2.2)	2.9 (2.2)	4,461	3.8 (1.6)	3.8 (1.5)	9,838	6.5 (1.2)	6.5 (1.2)
Delayed recall	235	1.2 (2.0)	1.3 (2.1)	4,498	2.1 (1.7)	2.1 (1.7)	9,838	5.4 (1.5)	5.3 (1.5)
Unmet need	403	72	63	4,505	73	73	10,198	62	73
Unrequired help	403	51	52	4,505	27	27	10,198	16	16
Unmet need count	403	2.1 (2.2)	2.2 (2.2)	4,505	1.8 (1.8)	1.8 (1.8)	10,198	1.3 (1.6)	1.3 (1.6)
Unrequired help count	403	0.9 (1.3)	0.9 (1.4)	4,505	0.4 (0.9)	0.4 (0.9)	10,198	0.2 (0.7)	0.2 (0.7)
Quality of life (CASP-19)	161	2.7 (0.4)	-	3,717	2.9 (0.5)	-	9,078	3.1 (0.5)	-

<sup>a</sup> Difficulties in any of the 13 items of ADL, IADL or mobility according to the ELSA interview protocol; <sup>b</sup> Self or proxy-reported diagnosed dementia and/or the IQCODE proxy score 3.5 or more; <sup>c</sup> belonging to the lowest quartile of the average z-score of orientation, and immediate and delayed recall in the sample. <sup>d</sup> Complete case sample for unmet need and unrequired help as outcome. <sup>e</sup> Number of 24 ADL, IADL and mobility difficulties. M=mean, SD=standard deviation

Table 3. Two-part regression on unmet need (did not receive help for the need in question) pooled data from ELSA waves 6, 7 and 8.

	First part (logit model)	Second part (GLM model)
Female	0.08 (0.050)	-0.10 (0.011)***
Age	0.02 (0.003)***	0.00 (0.001)
Has partner	-0.02 (0.057)	-0.09 (0.013)***
Has child(ren)	-0.12 (0.078)	-0.01 (0.017)
No qualification	-0.08 (0.058)	0.00 (0.013)
Occupational social class (ref=routine)		
Intermediate	-0.10 (0.062)	0.01 (0.014)
Professional/managerial	-0.03 (0.061)	-0.01 (0.014)
Home owner	-0.26 (0.070)***	-0.04 (0.014)**
Higher wealth quintile	-0.04 (0.019)*	-0.01 (0.004)**
N of functional limitations	0.33 (0.017)***	0.11 (0.002)***
Cognitive status (ref=Intact cognition)		
Low cognition <sup>a</sup>	-0.03 (0.051)	-0.01 (0.0112)
Dementia <sup>b</sup>	-1.65 (0.254)***	-0.28 (0.041)***

<sup>a</sup> Belonging to the lowest quartile of the average z-score of orientation, and immediate and delayed recall in the sample; <sup>b</sup> Self or proxy-reported diagnosed dementia and/or the IQCODE proxy score 3.5 or more. First part (logit model): *n* of observations = 12,756, *n* of clusters of time points = 8,490, *n* of clusters of households = 6,100; Second part (GLM model): *n* of observations = 8,490, *n* of clusters of time points = 4,584, *n* of clusters of households = 5,016. \*  $p < 0.05$ , \*\*  $p < 0.05$ , \*\*\*  $p < 0.05$

Table 4. Two-part regression on unrequired help (receipt of help without need) pooled data from ELSA waves 6, 7 and 8.

	First part (logit model)	Second part (GLM model)
Female	0.46 (0.056)***	0.01 (0.030)
Age	0.04 (0.003)***	-0.00 (0.002)
Has partner	0.15 (0.061)*	0.15 (0.031)***
Has child(ren)	0.11 (0.090)	0.08 (0.040)
No qualification	0.08 (0.061)	0.01 (0.030)
Occupational social class (ref=routine)		
Intermediate	-0.17 (0.067)*	0.01 (0.035)
Professional/managerial	-0.08 (0.069)	0.02 (0.040)
Home owner	-0.15 (0.069)*	-0.01 (0.035)
Higher wealth quintile	-0.06 (0.023)**	-0.03 (0.012)*
N of functional limitations	0.12 (0.006)***	-0.00 (0.003)
Cognitive status (ref=Intact cognition)		
Low cognition <sup>a</sup>	0.25 (0.053)***	0.07 (0.029)*
Dementia <sup>b</sup>	0.65 (0.148)***	0.22 (0.065)**

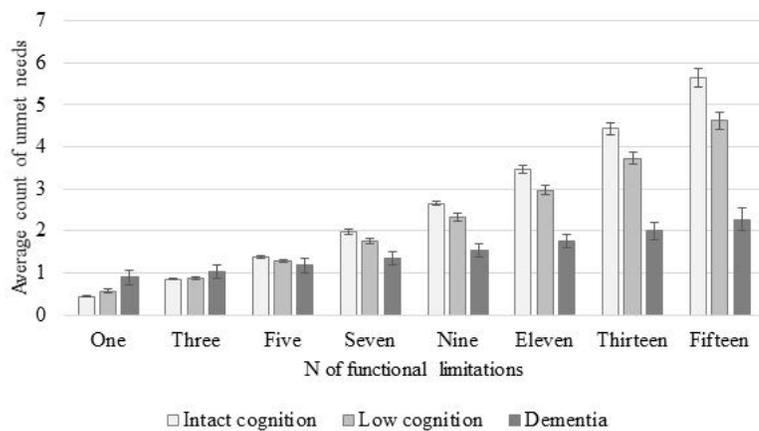
<sup>a</sup> Belonging to the lowest quartile of the average z-score of orientation, and immediate and delayed recall in the sample; <sup>b</sup> Self or proxy-reported diagnosed dementia and/or the IQCODE proxy score 3.5 or more. First part (logit model): *n* of observations = 12,754, *n* of clusters of time points = 6,260, *n* of clusters of households = 6,100; Second part (GLM model): *n* of observations = 2,616, *n* of clusters of time points = 1,935, *n* of clusters of households = 2,195. \* *p* < 0.05, \*\* *p* < 0.05, \*\*\* *p* < 0.05

Table 5. Linear regression on quality of life, pooled data from ELSA waves 6, 7 and 8.

	Quality of life (CASP-19 score)
Female	0.09 (0.011)***
Age	0.001 (0.0006)*
Has partner	0.06 (0.013)***
Has child(ren)	-0.01 ((0.018)
No qualification	0.01 (0.013)
Occupational social class (ref=routine)	
Intermediate	0.02 (0.014)
Professional/managerial	0.04 (0.014)**
Home owner	0.04 (0.017)*
Higher wealth quintile	0.05 (0.004)***
N of functional limitations	-0.04 (0.002)***
Unmet needs	-0.02 (0.004)***
Unrequired help	-0.03 (0.007)***
Cognitive status (ref=Intact cognition)	
Low cognition <sup>a</sup>	-0.04 (0.010)***
Dementia <sup>b</sup>	-0.11 (0.035)**

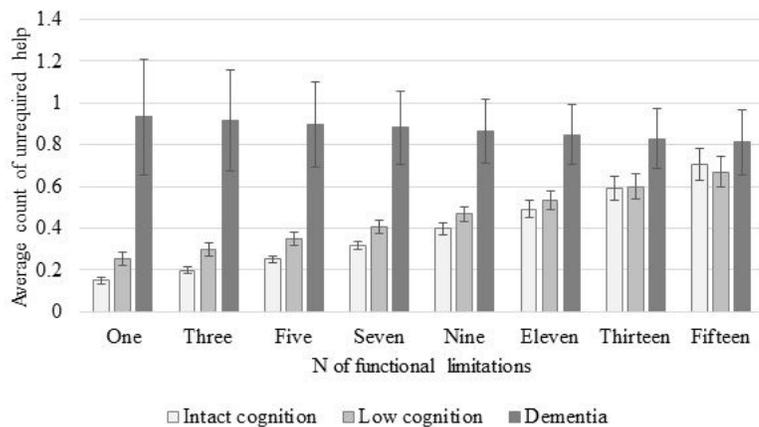
<sup>a</sup> Belonging to the lowest quartile of the average z-score of orientation, and immediate and delayed recall in the sample; <sup>b</sup> Self or proxy-reported diagnosed dementia and/or the IQCODE proxy score 3.5 or more. *n* of observations = 11,122, *n* of clusters of time points = 5,712, *n* of clusters of households = 5,756. \* *p* < 0.05, \*\* *p* < 0.05, \*\*\* *p* < 0.05

## Figures



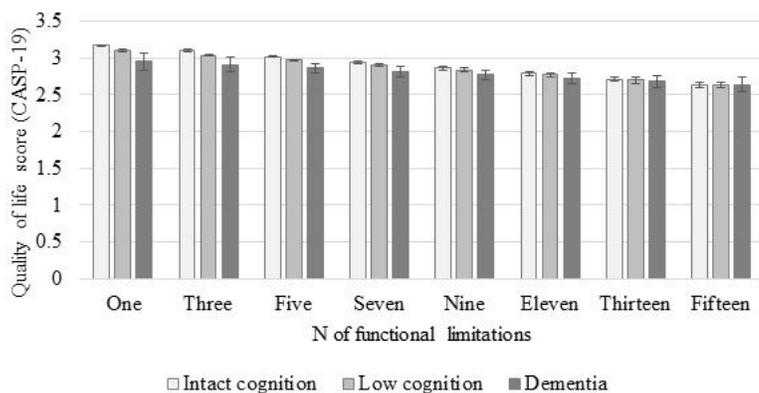
**Figure 1**

The association between unmet needs and level of functional limitations by cognitive status.



**Figure 2**

The association between unrequired help and level of functional limitations by cognitive status.



**Figure 3**

The association between quality of life (CAS-19) and level of functional limitations by cognitive status.

## Supplementary Files

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