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Receipt of help by people with cognitive impairment: results from the English Longitudinal Study of Ageing

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ABSTRACT

Objectives: We investigated whether people with dementia or low memory/orientation reported more help misaligned with needs – more unmet need and/or more unrequired help – than other people with similar levels of functional limitation, and examined associations with quality of life.

Methods: From pooled English Longitudinal Study of Ageing data from waves 6, 7, and 8, we identified community-dwelling people aged 50+ with: dementia ($n = 405$); low memory/orientation but no dementia ($n = 4520$); and intact memory/orientation ($n = 10,264$). Unmet need (not receiving help for the functional limitation) and unrequired help (receipt of help without the respective functional limitation) were used as outcomes in two-part regressions. Quality of life (CASP-19) was used as a continuous outcome in a linear regression. Functional limitation and its interaction with cognitive status and socio-demographic factors were included in the models.

Results: Those with dementia or low memory/orientation but few functional limitations reported more unmet needs and unrequired help than their counterparts with intact memory/orientation. At high levels of limitations, the needs of those with dementia or lower memory/orientation were met more often and the receipt of unrequired help was similar compared to those with intact memory/orientation. Unmet need and unrequired help were associated with poorer quality of life.

Conclusions: Unmet need and unrequired help were particular challenges for those with poorer cognition and potentially at early stages of dementia; they were associated with lower quality of life. Our results highlight the importance of good-quality timely diagnosis, identification of needs, and person-centred assessment to help improve quality of life.

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quality of life;
dementia;
cognitive impairment;
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Introduction

In the general population, there is a distribution of cognitive ability at all ages with higher levels of impairment seen in older populations: very many maintain high performance into older age, while others acquire static impairments (for example through stroke or head injury) and others develop progressive cognitive decline (for example through Alzheimer's disease) (Deary et al., 2009; Vincent et al., 2014). The causes of cognitive impairment are, therefore, complex and have high heterogeneity but include those who meet criteria for dementia (HOAG, 2021). People with impaired cognitive function are more likely to have for a need for assistance with daily activities than people without cognitive difficulties (Blaum et al., 2002; Ferreira et al., 2016; Zhou et al., 2018). However, the help they receive may not meet their particular needs. People may also 'step in', and provide help where help is not needed (unrequired help). The receipt of help and how needs are recognised may vary by cognitive and functional status.

Unmet needs are frequently observed among people with dementia, with over 90% having at least one unmet need (Abreu et al., 2019; Black et al., 2019, 2013; Eichler et al., 2016; Miranda-Castillo et al., 2010; Tapia Muñoz et al., 2019). Unmet needs are also common among people with memory problems not amounting to dementia (Aaltonen & Van Aerschoot, 2021).

The most common unmet needs include those related to: safety, health and medical care, daily activities, company, and counselling and legal support (Morrisby et al., 2018). These needs are compounded by the functional limitations related to dementia itself and other co-occurring long-term conditions (Blaum et al., 2002).

Much less is known about the frequency of unrequired help among people with dementia or impaired cognition. 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 (Cimarolli et al., 2006). The same is likely to apply to those with dementia, a condition associated with a heightened risk of accidents or lack of time and patience on the part of the carer (Chen et al., 2018; Schwarz, 2020).

Unmet needs are associated with functional level among those with dementia, although the results have been mixed. One study used both activities of daily living (ADL) and instrumental ADL (IADL) and found that people with dementia who had more unmet needs had fewer ADL limitations (Black et al., 2013). In another study from the same authors but using different datasets, the initial association between ADL and IADL limitations and unmet needs was also negative, but in the adjusted model, the functional level was not associated with unmet needs (Black et al., 2019). A study using ADL scale only

found the opposite that a higher unmet need among people with dementia were associated with more ADL limitations (Eichler et al., 2016). The role of functional limitations are important to investigate; when care needs increase with progression to more severe stages of cognitive impairment, this may prompt the identification of both needs for help related to dementia such as taking medication or paying bills on time, and needs unrelated to cognitive impairment such as difficulties with walking due to co-morbidities, and this may enable access to the help required (Van Der Ploeg et al., 2013). The evidence base lacks data on the interaction between the number of functional limitations and cognitive status: whether the receipt of help differs by cognitive status at the early and later stages of functional decline (i.e. when the needs become more frequent).

The receipt of sufficient help in the presence of difficulties in everyday activities is thought beneficial, allowing people to live in the community longer, and enhances their quality of life (Beach et al., 2020; Janssen et al., 2018). This is particularly the case for those with cognitive impairment (Kerpershoek et al., 2018). Unmet needs have been found to be associated with poorer quality of life among community living people with dementia (Black et al., 2019, 2013; Handels et al., 2018; Janssen et al., 2018; Miranda-Castillo et al., 2010). Less is known about the associations between unrequired care and quality of life. Unrequired help may lead to waste of care resources, rising expenditure, and dissatisfaction among recipients (Campbell et al., 2014). Care recipients may perceive caregivers as overprotective, which compromises their autonomy, independence, and quality of life (Kniejska, 2018; Niemann-Mirmehdi et al., 2019).

The extent to which cognitive status plays a role in the receipt of sufficient help and further quality of life is not well understood. The data are often limited to populations of people with dementia, and health care use only, excluding social care. Very little is known about the role of functional limitations apart from using them as adjusting factors. We, therefore, conducted a cross-sectional analysis of the *English Longitudinal Study on Ageing* (ELSA) waves 6–8 of its community-dwelling people aged 50+. We hypothesised that: (1) unmet need and unrequired help were more frequent in people with dementia and impaired memory compared to the general population, especially at the early stages of dementia; and (2) unmet need and unrequired help were associated with poorer quality of life. We sought to include a range of socio-demographic characteristics in the models because they are known to be associated with receipt of help (Black et al., 2013, 2019; Zhou et al., 2018), functional limitations (Pongiglione et al., 2015), cognitive status (Fratiglioni & Wang, 2007), and quality of life (Zaninotto et al., 2009).

Methods

Data

We drew on data from the sixth, seventh, and eighth waves of ELSA, a nationally representative longitudinal study of the household population aged 50+ in England (Stephens et al., 2013). The first wave of ELSA was conducted in 2002–2003 and consecutive waves were carried out every 2 years. The description of sampling and data collection is available elsewhere (Marmot et al., 2003). The waves from which our analysis derives took place in 2012–2013, 2014–2015, and 2016–2017, respectively. These waves were selected because they included an in-depth quantitative 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 refreshments samples and more cases of dementia and low memory/orientation than would otherwise have been possible. Cognitive status was identified at each wave and data from each wave was linked to current cognitive status (e.g. the respondent could have been coded as having intact memory/orientation in wave 6 and 7 and with dementia in wave 8). Each wave was treated as cross-sectional, but the repeated inclusion of respondents over the waves (as well as inclusion of several respondents from the same household) was taken into account by using standard errors adjusted for these two forms of clusters in the analysis.

The sample in this study included those aged 50+ living in the community who reported, themselves or by a proxy, difficulty in any of six items of ADL, seven IADL, or a mobility limitation (see Table S1 for the items and Table 1 for the distributions of the proxy interviews). While people aged 50–64 are less likely to need care or develop cognitive problems compared to those aged 65+, some do, and, therefore, these age ranges were included in the study.

These measures were used as a threshold in ELSA for follow-up questions on the receipt of help (Vlachantoni et al., 2011). To be included in the analysis, the respondents also had to provide a score from cognitive tests or self- or proxy-information on dementia (56% reported by a proxy). Participants gave written informed consent to participate in ELSA. Ethical approval for ELSA was given by the National Research and Ethics Committee (London Multicentre Research Ethics Committee) (MREC/01/2/91).

Measures

Cognitive status

Three groups were identified: (1) *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) (Cadar et al., 2018). (2) *Low memory/orientation* was defined as scoring in the lowest (poorest performing) quartile of cognitive tests (Blaum et al., 2002) measuring orientation and memory but excluding those identified as having dementia. Three cognitive tests which measure memory functions in ELSA (Huppert et al., 2006) 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* (Folstein et al., 1975). Immediate and delayed recall was tested with a word list in which the participant was asked to learn ten common unrelated words (Huppert et al., 2006). The lowest quartile of the distribution of mean z-scores of the three tests was used (cut-off at z-score < -0.3). These tests were used because they measure the types of cognitive impairment related to developing dementia (Tsoi et al., 2015) and were available in all three of the waves of ELSA. (3) The *no dementia or low memory/orientation* group comprised those who did not have dementia and whose mean z-scores on the three cognitive tests was higher than the cut-off for the lowest quartile.

Perceived need for and receipt of help

People were considered to need help if they (or proxies) reported difficulty with one or more of six items of basic ADLs, four items of IADLs, or three items of mobility (see items in Table S1). Where

Table 1. Means (M) and standard deviations (SDs) of socio-demographic variables, memory, receipt of help, and quality of life among people aged 50+ with functional limitations^a in pooled waves 6, 7, and 8 in the English Longitudinal Study of Ageing (ELSA).

	People with dementia ^b			People in the lowest memory/ orientation quartile ^c			People with intact memory/ orientation			Missing cognitive status	
	All ^d	Complete ^d		All ^d	Complete ^d		All ^d	Complete ^d		n	Mean
	n	Mean	Mean	n	Mean	Mean	n	Mean	Mean	n	Mean
		n= 337			n= 3896			n= 8523			
Female	403	0.53	0.54	4505	0.54	0.55	10,198	0.64	0.65	176	0.41
Age	403	78.55	78.87	4505	74.30	75.26	10,198	68.01	69.15	176	69.30
Has partner	403	0.62	0.79	4505	0.57	0.75	10,198	0.69	0.69	176	0.84
Has child(ren)	403	0.89	0.88	4505	0.88	0.88	10,198	0.88	0.88	176	0.91
No qualification	403	0.47	0.46	4505	0.44	0.45	10,035	0.23	0.23	164	0.54
Occupational social class	375			4502			9,703			130	
Professional/ managerial		0.27	0.29		0.22	0.22		0.34	0.34		0.22
Intermediate		0.25	0.26		0.23	0.23		0.27	0.27		0.22
Routine		0.47	0.45		0.55	0.55		0.39	0.39		0.56
Home owner	394	0.76	0.75	4493	0.72	0.73	10,179	0.82	0.82	168	0.81
Wealth quintile	368	2.65	2.69	4122	2.68	2.70	8,908	3.08	3.10	120	3.08
N of functional limitations ^e	403	11.61	11.72	4505	6.06	5.94	10,198	4.26	4.28	176	6.70
Cognitive tests											
Orientation	236	2.06	2.07	4505	3.27	3.31	9,839	3.91	3.91	–	–
Immediate recall	229	2.82	2.86	4461	3.79	3.81	9,838	6.53	6.51	–	–
Delayed recall	235	1.30	1.29	4498	2.13	2.12	9,838	5.37	5.34	–	–
Unmet need	403	0.72	0.63	4505	0.73	0.73	10,198	0.62	0.73	169	0.69
Unrequired help	403	0.51	0.52	4505	0.27	0.27	10,198	0.16	0.16	169	0.28
Unmet need count	403	2.11	2.16	4505	1.79	1.77	10,198	1.28	1.32	169	1.60
Unrequired help count	403	0.92	0.94	4505	0.44	0.43	10,198	0.25	0.24	169	0.60
Quality of life (CASP-19)	161	2.74	–	3717	2.91	–	9,078	3.07	–	–	–
Proxy interview ^f	403	0.37	0.38	4505	0.06	0.07	10,198	0.02	0.02	–	–

^aDifficulties in any of the 13 items of basic activities of daily living (ADLs), instrumental activities of daily living (IADLs), or mobility according to the ELSA interview protocol; ^b Self or proxy-reported diagnosed dementia and/or the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) proxy score 3.5 or more; ^cBelonging to the lowest quartile of the average z-score of orientation, and immediate and delayed recall in the sample. ^dAll refers to all available data; complete refers to the sample for unmet need and unrequired help as outcome with no missing data. ^eNumber of basic ADL, IADL, and mobility difficulties. ^fProxy-reported functional limitations and receipt of help.

any of these ADL, IADL, or mobility difficulties were experienced, respondents were asked about receipt of help for this need (Vlachantoni et al., 2011). 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 expressed need, the item was coded *unrequired help* (0 = did not have need and did not receive help or had need and received 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 basic ADL, IADL, or mobility limitations for which study defined unrequired help was received.

Socio-demographic factors

Age was measured in years. Gender, and whether the respondent had a partner and/or child(ren) were binary variables. A binary measure was also used for *educational level* (having any qualifications or 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 (Rose & Pevalin, 2003). *Wealth* quintiles were calculated using non-pension wealth comprising household financial, physical, and housing wealth net of debt (1 = lowest to 5 = highest wealth quintile). Wealth quintile was treated as continuous in the analysis. *Home ownership* was a binary measure (owning home outright or with mortgage or shared-ownership versus renting, living rent free or squatting).

Functional limitations

The number of functional limitations was measured with 26 binary items of basic ADL, IADL, and mobility difficulties (see the items

in Table S1). The items for basic 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 (Hyde et al., 2003). It has 19 items rated on a four-point scale that ranges from 'often' to 'never'. Higher scores indicate a higher quality of life. The internal consistency of the score was good (Cronbach's alpha = 0.89).

Analysis

After showing the distributions of the variables, we carried out two-part regressions (STATA version 14.2) to investigate whether unmet need and unrequired help differed between the three cognitive status groups by the number of functional limitations. The first part of each model was estimated using a logit model to examine factors associated with whether or not the person had an unmet need or received unrequired help. The second part used a *generalised linear model* (GLM) with a log link and a gamma distribution to examine factors associated with the number of unmet needs or unrequired help experienced by those who had at least one unmet need or unrequired help. We used GLM 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 in the pooled data within each wave and standard errors were clustered (Gu & Yoo, 2019) 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 conducted the analyses

using complete datasets. Sensitivity analyses were also carried out to evaluate the impact of missingness.

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 interactions between cognitive status and functional limitations variables to investigate whether the receipt of help by cognitive status different depending on the number of functional limitations (i.e. level of needs). To determine whether adding the interaction term was necessary in 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. Linear regression was used to assess the associations of unmet need and unrequired care with quality of life. The model was adjusted for sociodemographic factors, functional limitations and cognitive status.

Results

Descriptive results

Table 1 shows the distribution of variables between the three cognition groups and those with missing cognitive status. People with dementia, low memory/orientation or missing cognitive status reported more unmet need (average count 2.1, 1.8, and 1.6, respectively) and unrequired help (average count 0.9, 0.9, and 0.6, respectively) compared to those with intact memory/orientation (1.3 and 0.2, respectively). Quality of life was lowest among those with dementia and highest among those with intact memory/orientation. The distributions of the individual unmet need and unrequired help items are shown in Figure S1. A detailed description of the distributions of included, excluded, and missing data is in Supplementary text file S1.

Differences in receipt of help by cognitive status

Unmet need was more likely (logit model) to be reported by those participants (or by their proxies) who were: older, living in rented housing, and had more functional limitations (Table 2). The number of unmet needs (GLM model) was higher among

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 more likely on average to have an unmet need but tended to have a lower number of unmet needs than those with no dementia. However, there was an interaction between cognitive status and number of functional limitations (Wald test = 328.86, $df = 4$, $p < .001$). People with dementia at the lowest levels of functional limitation (1–2 limitations) were more likely to have unmet need (on average 0.9 unmet needs compared to 0.4 unmet needs in the intact memory/orientation group), whereas at the higher levels of functional limitation (7+ limitations) those with no dementia had a higher number of unmet needs (e.g. on average 2.3 unmet needs in dementia group compared to 5.6 unmet needs in the intact memory/orientation group having 15 functional limitations) (Figure 1). The profiles of unmet need at the lower levels of limitation 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 (Figure S2). At higher levels of limitation, the profiles of unmet need show that those with dementia received help more often in all 13 limitations compared to those with no dementia (Figure S3).

Unrequired help (logit model) was more common among: women, older people, those with a partner, those in routine/manual compared to intermediate occupational social class, those in lower wealth quintiles, and those with more functional limitations (Table 3). The number of tasks 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 memory/orientation or dementia were more likely to receive unrequired help compared to people with intact memory/orientation.

The interaction between functional limitations and cognitive status (Wald test = 83.40, $df = 4$, $p < .001$) showed that at the lowest levels of functional limitations people with dementia received more unrequired help compared to those with intact or low memory/orientation. For example, among those with one functional limitation, the count of unrequired help was 0.9 for those with dementia compared to 0.2 and 0.3 for those with intact or low memory/orientation, respectively (Figure S4). At higher levels of functional limitations, the difference in the receipt of unrequired help by cognitive status

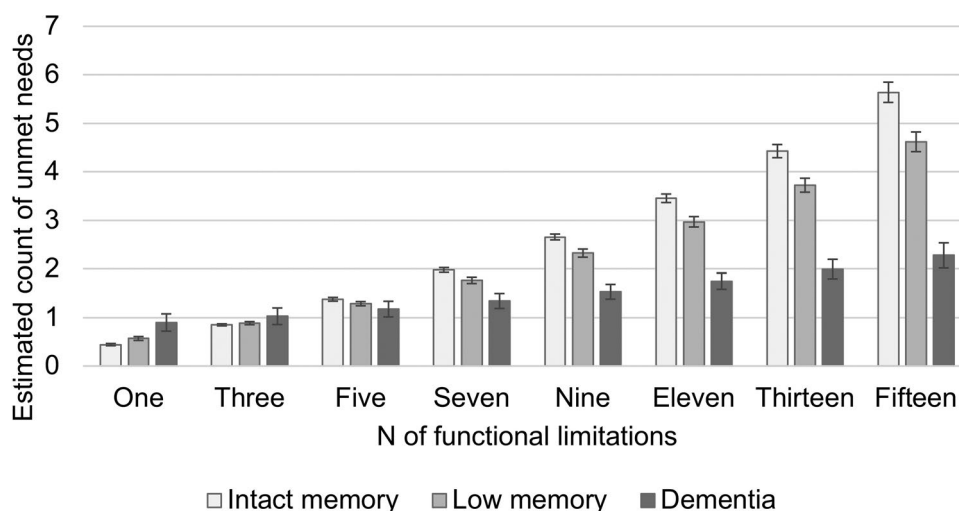


Figure 1. The association between unmet needs and level of functional limitations by cognitive status, pooled waves 6, 7, and 8 in the English Longitudinal Study of Ageing (ELSA).

Table 2. Two-part regression on unmet need (did not receive help for the need in question) and interaction terms, pooled data from ELSA waves 6, 7, and 8.

	First part (logit model)	Second part (GLM model)
	Coef. (Robust SE)	Coef. (Robust SE)
Female	0.07 (0.050)	-0.10 (0.109)***
Age	0.02 (0.003)***	0.00 (0.001)
Has partner	-0.03 (0.057)	-0.09 (0.012)***
Has child(ren)	-0.12 (0.079)	-0.00 (0.016)
No qualification	-0.08 (0.059)	0.00 (0.012)
Occupational social class (ref=routine)		
Intermediate	-0.09 (0.062)	0.02 (0.014)
Professional/managerial	-0.02 (0.062)	-0.01 (0.013)
Home owner	-0.23 (0.070)**	-0.03 (0.014)*
Higher wealth quintile	-0.03 (0.020)	-0.01 (0.004)**
N of functional limitations	0.44 (0.026)***	0.12 (0.002)***
Cognitive status (ref=Intact)		
Low memory/orientation ^a	1.05 (0.414)*	0.37 (0.089)***
Dementia ^b	2.48 (1.219)*	1.12 (0.308)***
Cognitive status (ref=Intact)#N of functional limitations		
Low memory/orientation ^a	-0.16 (0.036)***	-0.02 (0.003)***
Dementia ^b	-0.41 (0.034)***	-0.06 (0.006)***

^aBelonging to the lowest quartile of the average z-score of orientation, and immediate and delayed recall in the sample; ^bSelf or proxy-reported diagnosed dementia and/or the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) proxy score 3.5 or more. First part (logit model): *n* of observations = 12,756, *n* of clusters of time points = 8490, *n* of clusters of households = 6,100; Second part (GLM model): *n* of observations = 8490, *n* of clusters of time points = 4,584, *n* of clusters of households = 5016. # = in interaction with, Coef = Coefficient, SE: standard error, adjusted for wave (Wave 6 as reference).

p* < .05, *p* < .05, ****p* < .05.

Table 3. Two-part regression on unrequired help (receipt of help without need) and interaction terms, pooled data from ELSA waves 6, 7, and 8.

	First part (logit model)	Second part (GLM model)
	Coef. (Robust SE)	Coef. (Robust SE)
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 (0.039)
No qualification	0.08 (0.060)	0.02 (0.029)
Occupational social class (ref=routine)		
Intermediate	-0.16 (0.067)*	0.01 (0.035)
Professional/managerial	-0.07 (0.069)	0.03 (0.039)
Home owner	-0.13 (0.069)	-0.01 (0.035)
Higher wealth quintile	-0.06 (0.023)***	-0.02 (0.012)*
N of functional limitations	0.14 (0.008)***	0.01 (0.005)
Cognitive status (ref=Intact)		
Low memory/orientation ^a	0.71 (0.142)***	0.04 (0.076)
Dementia ^b	2.50 (0.361)***	0.28 (0.195)
Cognitive status (ref=Intact)#N of functional limitations		
Low memory/orientation ^a	-0.03 (0.011)**	-0.01 (0.006)**
Dementia ^b	-0.16 (0.019)***	-0.01 (0.010)

^aBelonging to the lowest quartile of the average z-score of orientation, and immediate and delayed recall in the sample; ^bSelf or proxy-reported diagnosed dementia and/or the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) proxy score 3.5 or more. First part (logit model): *n* of observations = 12,754, *n* of clusters of time points = 6260, *n* of clusters of households = 6,100; Second part (GLM model): *n* of observations = 2616, *n* of clusters of time points = 1935, *n* of clusters of households = 2,195. # = in interaction with, Coef = Coefficient, SE: standard error, adjusted for wave (Wave 6 as reference).

p* < .05, *p* < .05, ****p* < 0.05.

was small: e.g. among those with 15 functional limitations the count of unrequired help was 0.8 for people with dementia compared to 0.7 in both intact or low memory/orientation group.

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 (Figure S5). At higher levels of functional limitation, those with dementia tended to have higher levels of all types of unrequired help, apart from help with dressing and housework, compared to people with intact memory/orientation (Figure S6).

Associations with quality of life (CASP-19)

Both unmet need and unrequired help were associated with lower quality of life (Table 4). Quality of life was lower among

those with dementia or low memory/orientation compared to those with intact memory/orientation. Being female, higher age, having a partner, higher socioeconomic status, and lower levels of functional limitations were associated with higher quality of life.

Discussion

Our main findings were that people with dementia and those with low memory/orientation with few reported functional limitations had more unmet needs compared to those with intact memory/orientation. Those with more reported functional limitations (i.e. those with later stages of dementia and more severe cognitive impairment) and with memory/orientation impairment had fewer unmet needs compared to those with intact memory/orientation. Those with dementia or low memory/orientation also reported receiving more unrequired help than those with intact memory/orientation. More severe cognitive

Table 4. Linear regression on quality of life, pooled data from ELSA waves 6, 7, and 8.

	Quality of life (CASP-19 score)
	Coef. (Robust SE)
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 ^a	-0.04 (0.010)***
Dementia ^b	-0.11 (0.035)**

^aBelonging to the lowest quartile of the average z-score of orientation, and immediate and delayed recall in the sample; ^bSelf 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 = 5712, *n* of clusters of households = 5756. Coef=Coefficient, SE=Standard Error, adjusted for wave (Wave 6 as reference).

* $p < .05$, ** $p < .05$, *** $p < .05$.

impairment was therefore associated with an increased likelihood that needs were met but also that unneeded help was received. Both unmet need and unrequired help were associated with lower quality of life.

Unmet need and unrequired help

Unmet needs and unrequired help were more frequent in the groups with cognitive impairment compared to those with intact memory/orientation when only few functional limitations were reported. Unmet needs in these groups related especially to help in walking 100 m, getting in and out of bed and bathing (basic ADLs), while unrequired help clustered around help with shopping, taking medication, housework, and handling money (IADLs). When functional limitations were high in number, the needs of those with dementia or lower memory tended to be met more often and the receipt of unrequired help was similar compared to those with intact memory/orientation. Needs are better met when the number of functional limitations is higher, presumably at later stages of dementia, than when there are fewer functional limitations, when compared to those with intact cognition but the same number of functional limitations. To our knowledge, this is the first study to examine how the number of unmet needs, among people with dementia, relative to people without dementia, varies with the number of functional limitations. Previous studies have not looked into the interaction between unmet needs, functional limitations, and dementia.

These results point to the 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 (Dong et al., 2010; Wilkins et al., 2014). 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 (Bieber et al., 2019; Boustani et al., 2003; Cohen-Mansfield et al., 2015). At low levels of limitation, it is also possible that coping without help is a chosen strategy to maintain independence.

It is interesting that much of the help that was 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 (Bleich et al., 2009; Brimblecombe et al., 2017; Curnow et al., 2021). Not admitting a need for help may be motivated by a sense of dignity and independence as well as a lack of insight (Brimblecombe et al., 2018). 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 (Black et al., 2019, 2013). 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 (Van Der Ploeg et al., 2013).

Previous research has also shown that unmet needs are associated with functional level among those with dementia, although the results have been mixed (Black et al., 2019, 2013; Eichler et al., 2016). In this study, we used both basic ADL and IADL scales, and in addition to them mobility scale, but because of high inter-correlations between the scales it was suitable to use the total count of all limitations and analyse the profiles after the analysis. These profiles revealed that the unmet needs tended to cluster more around basic ADL limitations among those with dementia, especially when the number of limitations is lower. The increase in unmet needs with increasing functional limitations was slower among those with dementia compared to those without dementia. The separation of basic ADL and IADL (if tested in different models, the results not shown), also suggested that among those with dementia unmet needs did not increase with IADL needs. The results together point to the importance of taking into account the level and content of functional needs.

Quality of life

Our findings confirm that unmet need is associated with poorer quality of life among people with dementia (Black et al., 2019, 2013; Miranda-Castillo et al., 2010). In addition, we found that unrequired help had a similar adverse effect on quality of life to unmet need. People receiving unrequired help may feel dependent on other people which may compromise their sense of independence (Yates et al., 2019).

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. People with cognitive impairment need care planning and service delivery that empowers them rather than actions that foster or encourage dependency (Curnow et al., 2021). 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 (Daly et al., 2018; Shiells et al., 2020).

Limitations

These analyses have important limitations. Due to the use of pooled data including the refreshment samples, 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). The repeated measures from the same individual over the three waves and individuals living in the same household were however taken into account using clustering. 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 memory/orientation in the sample. Longitudinal study is needed to assess the directions of the effects and changes over time.

The lack of data on neuropsychiatric symptoms or on severity of dementia in the dataset is important omissions. The limitations in the data on cognition mean that we assumed when interpreting these data that those with fewer functional limitations were on average likely to be those at earlier stages of dementia and therefore have milder cognitive impairment. Given that dementia is a progressive disorder that causes increasing functional impairment over time as there is increasing cognitive impairment, we believe this to be tenable. However, it must be acknowledged that there are multiple sources of functional limitation unrelated to memory and that multimorbidity is common in later life.

Unmet needs were measured with the 13 items included in ELSA, which differ from measures used in other studies for investigating unmet need. For instance, ELSA does not assess unmet needs related to some types of need investigated in previous studies, such as unmet needs for: medical care (Eichler et al., 2016), counselling, social integration, dementia diagnosis, and treatment (Black et al., 2013), or psychological or behavioural factors (Miranda-Castillo et al., 2010; Tapia Muñoz et al., 2019). Unrequired help excludes those who did not report any functional difficulties: it is possible that more people would report unrequired help if the entire sample and not just those with functional limitations were asked about receipt of help they did not require.

The identification of dementia in ELSA 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 2 years. The IQCODE system is robust, well validated, and widely used, but it is possible that dementia was underestimated, because respondents or proxies did not disclose it or did not know it. Furthermore, the quality of life measure used in ELSA is a generic measure of quality of life, which may work less well than disorder-specific measures in those with cognitive impairment (Banerjee et al., 2009) and so there may be differential measurement error across the three cognitive groups. More generally, the reports of those with memory problems may be subject to greater error than those with intact memory/orientation. Proxy interviews on background and receipt of help were, however, obtained for those who could not be interviewed because of cognitive impairment.

Conclusions

Our findings have implications for those planning and providing services for people with dementia. They demonstrate that unmet need and unrequired help that may decrease autonomy may be particular challenges in early dementia, both contributing to low quality of life. 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.

Disclosure statement

No potential competing interest was reported by the authors. 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, CB, and SB contributed to the interpretation of the findings, and to drafting and commenting on the manuscript. All authors read and approved the final manuscript.



Data availability statement

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

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