Socio-demographic characteristics, cognitive function and health-related quality of life of patients referred to Memory Assessment Services in England

Short title: Characteristics of referrals to Memory Assessment Services

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Abstract

National policy in England is to encourage referral of people with suspected dementia to Memory Assessment Services (MAS). However, little is known about the characteristics of new referrals, which limits our capacity to evaluate these services. The objectives were to: describe the characteristics (age, sex, ethnicity, socio-economic deprivation, comorbidity) of referred patients, and examine the relationships between these characteristics and cognitive function (tertiles of MMSE score) and health-related quality of life (HRQL) (DEMQOL, DEMQOL-Proxy).

We used multivariable regression methods to analyze data from 1,420 patients from 73 MAS, and their lay carers (n=1,020). The mean age of patients was 78 years; 42% had cognitive function equivalent to MMSE<24. Characteristics associated with lower function were: older age, being female, deprivation, and non-white ethnicity. Deprivation and non-white ethnicity were also associated with lower self-reported HRQL, as was having multiple comorbidities; older age was associated with better self-reported HRQL. Lower proxy-reported HRQL was associated with being female, deprivation and comorbidities, but not age and ethnicity.

A large proportion of study participants had moderate or high cognitive function scores, suggesting that these patients were referred early to MAS. Research is needed to identify why apparent socio-demographic inequalities in use of MAS exist.

Key words: Cognitive Function; Dementia; Memory Assessment Services; Memory Clinics; Health-related Quality of Life

INTRODUCTION

The 2009 National Dementia Strategy for England identified early diagnosis and treatment of dementia as a key priority for the NHS.[1] This was mandated in the Prime Minister's Challenge on Dementia 2012, which called for the national diagnosis rate to reach two thirds of people with dementia.[2] To facilitate this, a model of care centred around Memory Assessment Services (MASs) was advocated, in which MASs act as a single point of referral for people with suspected dementia and provide access to a range of assessment, treatment and rehabilitation services.[3] The potential benefits of MASs include reduced delays to diagnosis and treatment,[4] improved quality of life for people with dementia and their carers due to early provision of support, and reduced inequalities in use of care.[5]

A national audit in 2013 estimated that there were more than 200 MASs (also referred to as memory clinics) in England.[6] There is an emerging body of evidence that describes the variations in the structural characteristics and services provided by MASs.[6-9] A few studies have also described the characteristics of patients attending memory clinics,[4,8,10] but it is not clear how generalizable these findings are across England. In order to assess the impact of MASs it is necessary to characterize the population that uses these services. Furthermore, the profile of new referrals may point to patterns of use which are of interest to service providers and policy makers.

The primary aim of this study was to describe the socio-demographic characteristics, cognitive function and health-related quality of life (HRQL) of patients newly referred to MASs for suspected dementia in England. The secondary aim was to examine the relationships between patients' socio-demographic characteristics and their assessed cognitive function and HRQL.

METHODS

Pilot phase

The study protocol was piloted at four MASs to assess feasibility of recruitment and data collection (National Research Ethics Service reference for pilot phase: 13/LO/0544). Modifications were made to the questionnaires and study procedure based on the findings of this pilot phase.

Recruitment and data collection

Initially, 80 MASs were randomly selected from 212 clinics identified by the Royal College of Psychiatrists in their national audit;[6] those that declined to participate were replaced by random selection from remaining clinics. Of the 78 MASs which finally took part in the study, five sites that each recruited fewer than six patients were excluded from the analysis. The sample had a wide geographical spread, including all regions of the country, and was representative of all MASs in England when compared with the National Audit: volume of new referrals per month (63 versus 72 nationally); mean waiting time for first appointment (5.8 v 5.2 weeks); and accredited by the Royal College of Psychiatrists (26% v 30%).[6]

Patients with suspected dementia who were attending for a first referral at one of the 73 sites (either in the clinic or at a home visit) and their lay carers (if present) were eligible for inclusion in the study. Patients or carers with insufficient English to understand the consent process or study materials (n=43) were not eligible to take part.

Data collection took place between September 2014 and April 2015. Each site recruited consecutive participants until 25 patients were included, or until the end of the data collection period. The maximum number of 25 patients per site (and minimum of 6) was

chosen based on the sample size required to detect a standardised change of 0.15 in HRQL with 90% power while ensuring a sufficient number of sites to enable analysis of the effects of organisational (service-level) characteristics on outcomes. Consecutive eligible patients, identified from referral lists, were invited to take part in the study when they received their MAS appointment letter. Patients and carers who were willing to take part were asked to provide written consent; when research staff considered a patient to lack mental capacity to consent to research, their carer was invited to provide consent on behalf of the patient. Data on socio-demographic characteristics (age, sex and postcode) of non-participants were available from referral lists for most sites (51 sites recorded sex, 45 recorded age, and 35 recorded postcode).

Questionnaires for patients and carers were completed before the initial clinical consultation (i.e. before a diagnosis was made), either at the patient's home (65% of patients) or at the clinic (35%). The patient questionnaire was interviewer administered and included items on socio-demographic characteristics, disease specific HRQL (DEMQOL[11]) and generic HRQL (EQ-5D-3L[12]). Interviewers attended a half-day regional training event at which they received training in taking informed consent, questionnaire administration, data handling and data return procedures. The carer questionnaire was self-administered and included self-reported HRQL (EQ-5D-3L), carer burden (Zarit Burden Interview[13]), proxy-reported HRQL of the patient (DEMQOL-Proxy and EQ-5D-3L proxy) and socio-demographic characteristics. Following the consultation, clinic staff completed a questionnaire on clinical characteristics of the patient (cognitive function and current comorbidity) using data from the patient's records.

Description of variables

Socio-demographic characteristics

Patient age was grouped into four 5-year age categories, each representing around one quarter of the data: <75 years, 75-79 years, 80-84 years, ≥85 years. Ethnicity was recorded using the five main census categories. Due to the small number of participants in minority ethnic groups, two categories were considered in the analysis: white or white British and other (South Asian, black, Chinese, mixed or other). Socio-economic status (SES) was measured using the English Index of Multiple Deprivation (IMD) 2010 based on patients' residential postcodes.[14] Patient IMD scores were assigned to quintiles of the national ranking of IMD scores.

Clinical characteristics

A three-category cognitive function variable was derived from scores routinely collected by services. Most of the sites had data on one or more of the following instruments: Mini-Mental State Examination (MMSE),[15,16] Addenbrooke's Cognitive Examination-III (ACE-III),[17] Addenbrooke's Cognitive Examination-Revised (ACE-R), [18] Mini-Addenbrooke's Cognitive Examination (M-ACE),[19] Montreal Cognitive Assessment (MOCA) [20] and the Kendrick Object Learning Test (KOLT).[21] MMSE is one of the best established and most widely used tests for cognitive function in dementia.[22] Cognitive function was therefore categorized as tertiles of MMSE score: category 1 (highest function) equivalent to MMSE score ≥28, category 2 MMSE score 24-27 and category 3 (lowest function) MMSE score <24. Scores derived from other tests (ACE-III, ACE-R, M-ACE, MOCA and KOLT) were assigned to categories based on predicted MMSE score using linear regression models fitted to data from patients with both an MMSE score and another score.

Clinic staff recorded whether the patient had any of the following comorbid conditions: heart disease, high blood pressure, problems caused by stroke, leg pain due to poor circulation, lung disease, diabetes, kidney disease, disease of the nervous system, liver disease, cancer within the last 5 years, depression or arthritis. The number of comorbidities was categorized as: 0, 1, 2, 3, and 4 or more.

Health-related quality of life (HQRL)

Patients' self-reported HRQL was assessed using DEMQOL and EQ-5D-3L. DEMQOL is an interviewer-administered, 28-item dementia-specific HRQL measure, which was developed for a UK population.[11] Each item is scored on a four-point scale, with a higher score indicating better HRQL. We used a recently improved scoring algorithm based on modern psychometric methods (Rasch Measurement Theory) to generate scores.[23] For analysis, the scores derived using this algorithm (referred to as equated scores) were linearly transformed to range from 0 to 100.

EQ-5D-3L [12] is a generic HRQL instrument which is recommended for use in other clinical areas in the NHS.[24] EQ-5D-3L has five items, each covering one domain: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each item has three levels of response. A summary EQ-5D-3L index score was calculated using value sets derived from a UK general population survey to weight and combine responses. A score of 0 represents death and 1 represents perfect health, with scores less than 0 permitted.[25]

Proxy-reported patient HRQL was assessed using DEMQOL-Proxy and EQ-5D-3L proxy. DEMQOL-Proxy has 31 items with responses on the same four-point Likert scale as DEMQOL;[11] equated scores were derived using the revised scoring algorithm described

above.[23] EQ-5D-3L proxy has the same items as self-reported EQ-5D-3L and is scored in the same way.

Statistical analysis

Chi-squared tests were used to compare characteristics of study participants (age, sex, IMD) with those of non-participating eligible patients who had been invited to take part in the study. Cognitive function data were not available for non-participants, therefore we compared cognitive function of participants at the 20 sites with lowest recruitment (mean recruitment rate 25%) with that of participants at the 20 sites with highest recruitment (mean rate 72%). Participating patients' characteristics were summarized as means and standard deviations (SDs) or percentages. For variables with more than 10% missing values, rates of missing data by patient characteristics were compared using chi-squared tests.

We used multivariable ordered logistic regression to examine the relationships between patient characteristics (age, sex, ethnicity, SES and number of comorbidities) and cognitive function measured in tertiles of MMSE score, simultaneously adjusting for all patient characteristics. Results from logistic regression analyses are presented as odds ratios (ORs) with 95% confidence intervals (CIs). Multivariable linear regression was used to examine the relationships between patient characteristics and HRQL measured with DEMQOL and DEMQOL-Proxy, adjusting for all patient characteristics; results are presented as differences in mean equated scores with 95% CIs. We accounted for clustering of patients within MASs by using robust (clustered) standard errors. To assess the effects of missing data, sensitivity analyses were conducted using data that excluded MASs with more than 30% missing outcome data. All analyses were conducted using Stata V.14 (StataCorp, College station, Texas, USA).

The study protocol was approved by the National Research Ethics Service Committee London (reference: 14/LO/1146) and the London School of Hygiene & Tropical Medicine ethics committee (reference: 8418).

RESULTS

Recruitment and response

In total, 1,420 patients and 1,020 carers took part in the study (recruitment rate: 42% of eligible referrals approached to take part in the study). Based on referral lists from 55 MAS, the study sample (n=1,042) was slightly younger (mean age 78 versus 80 years, p<0.001) and had a higher proportion of men (48% versus 40% male, p<0.001) than non-participating patients (n=1,772), but there was no significant difference in socio-economic status (p=0.27). There was also evidence of lower participation rates among patients with worse cognitive function: across sites with low recruitment rates, 37% of participants had low cognitive function (MMSE score<24), compared to 50% across sites with high recruitment (p=0.006).

For most variables the proportion of missing data was less than 5%, with one exception. Data on cognitive function were missing for 21% of respondents; there was little or no association with most patient characteristics (age, sex, ethnicity, SES) but cognitive function data were more likely to be missing for those with no comorbidities (35%) than for those with 4 or more comorbid conditions (17%) (difference p<0.001). Patients without a proxy (28%) were more likely to be women (33% of women did not have a companion compared to 23% of men p<0.001).

Patient characteristics

The characteristics of participants are summarized in Table 1. The mean age of patients was 77.9 years (SD 8.5 years, range 42-98 years), with 6% of patients (n=91) aged under 65 years. There were similar proportions of men (48%) and women (52%) in the sample, and a small proportion of patients from non-white ethnic groups (6%). The distribution of deprivation was similar to that among the population aged 65 and over in England: 16% of patients were in the most deprived IMD quintile compared with 15% nationally, and 25% in the least deprived quintile compared with 23% nationally.[26]

The largest proportion of patients (42%) were in the lowest cognitive function category (equivalent to MMSE score <24). Most patients (78%) had at least one comorbidity; 12% had four or more.

Patients' HRQL

Using the transformed equated scores, mean DEMQOL score was 65.0 (SD 12.1) and the mean DEMQOL-Proxy score was 56.4 (SD 16.4) (Table 1). The distribution of DEMQOL scores was broadly normal with a few outliers with very high HRQL; DEMQOL-Proxy scores were also normally distributed but had fewer high outliers (Figure 1).

Mean patient-reported EQ-5D-3L index score was 0.7 (SD 0.3) and EQ-5D-3L Proxy index score was 0.6 (SD 0.3). The distributions of both patient- and proxy-reported EQ-5D-3L were bi-modal, with the majority of data above 0.5 and a smaller peak between -0.5 and 0.5 (Figure 1). Patient-reported EQ-5D-3L index score showed very high HRQL among a subset of patients, with over 20% reporting no health problems across any of the five domains.

Relationships between patient characteristics and cognitive function

Four characteristics of patients were associated with lower cognitive function at presentation at MAS: older age (adjusted OR for patients ≥ 85 years vs. <70 years: 2.6, 95% CI 1.8 to 3.7); living in a more deprived area (adjusted OR for patients in most deprived vs. least deprived quintile 1.8, 95% CI 1.4 to 3.2); being female (adjusted OR for women vs. men: 1.4, 95% CI 1.2 to 1.8); and non-white ethnicity (adjusted OR for non-white vs white ethnicity: 1.3, 95% CI 1.1 to 1.7). These associations remained after adjusting for all of the other patient characteristics (Table 2).

Cognitive function was not associated with the number of comorbidities before or after adjustment for other characteristics. Sensitivity analyses excluding 17 MAS with more than 30% missing data on cognitive function produced similar adjusted ORs.

Relationships between patient characteristics and HRQL

Non-white ethnicity and greater deprivation were associated with lower self-reported HRQL (DEMQOL), although these differences were small (Table 3): adjusted mean scores were 2.9 points (95% CI 0.4 to 5.4) or 0.25 of a standard deviation lower among patients from non-white vs. white ethnic groups and 2.0 points (95% CI 0.1 to 4.0) lower for patients living in the most deprived vs. least deprived areas. In contrast, older age was associated with better HRQL: adjusted difference 4.6 points (0.38 SD) higher, 95% CI 2.7 to 6.4 for patients ≥ 85 years vs <75 years. There was no difference in self-reported HRQL between women and men. Whilst the number of comorbidities was not associated with cognitive function, HRQL was lower among patients with four or more comorbidities compared to patients with no comorbidities (adjusted mean difference -3.9, 95% CI -6.5 to -1.4).

Greater deprivation and having four or more comorbidities were also associated with worse proxy-reported HRQL (DEMQOL-Proxy), with similar effect sizes as observed for self-

reported HRQL: the adjusted difference for patients living in most vs. least deprived areas was -2.5 (95% CI -4.9 to -0.1), and for four or more comorbidities vs. no comorbidities was -3.2 (95% CI -5.5 to -1.0) (Table 4). In contrast to self-reported HRQL, proxy-reported HRQL was not associated with patient age or ethnicity, while women had lower proxy-reported HRQL than men (mean difference -2.4, 95% CI -3.8 to -1.1).

DISCUSSION

Main findings

Referrals to MAS were generally for suspected late-onset dementia (patients aged 65 years or above), with a mean age of 78 years. The majority of people had relatively high cognitive function and HRQL. People who were older, female, from non-white ethnic groups or living in the most deprived areas were more likely to present with lower cognitive function compared to the youngest, male, white and least socio-economically deprived patients. Deprivation and non-white ethnicity were also associated with worse self-reported HRQL at presentation, as was having four or more comorbidities, indicating a potential difference in use of MASs. However, there was no difference between men and women, and increasing age was associated with better self-reported HRQL. Lower proxy-reported HRQL was associated with greater deprivation, having four or more comorbidities and being female; in contrast to self-reported HRQL, proxy-reported HRQL was not associated with patient age or ethnicity.

Comparison with other studies

The large proportion of patients in our sample with an MMSE score of 24 and above suggests that the government aim of early referral for memory problems is largely being

achieved,[1] although this could also potentially include a number of inappropriate referrals. Some study participants were missing data on cognitive function which may reflect the data not being available either because testing took place after the initial consultation when the study data were collected or because a non-standard test was used. Alternatively it is possible that the cognitive function of some patients was never assessed, though this is unlikely and there are no published accounts with which to compare our data.

Patient-reported HRQL was relatively high in our sample, with mean EQ-5D index scores comparable to self-ratings by people with mild to moderate dementia,[27] diabetes and epilepsy,[28] and higher than scores for people with chronic obstructive pulmonary disease, heart failure or stroke.[28] However, a ceiling effect in EQ-5D-3L has been observed in many settings including among people with dementia,[27] which limits our ability to discriminate between individuals at the upper end of the scale and interpret mean scores. Proxy-reported HRQL was lower than self-reported HRQL for both dementia-specific and generic measures, a relationship which is consistently reported in comparisons of proxy- and patient-reported measures of HRQL in dementia.[29,30]

Lower cognitive function among certain groups at presentation may indicate differences in health care seeking behaviors or referral pathways. Younger patients are more likely to seek help from their GP at early signs of memory problems while decline in cognitive function at older ages is often perceived as normal age-related memory loss, resulting in delays in seeking health care.[31] Among older people, women are more likely to live alone than men[32] (this is reflected in the higher proportion of women in the study who attended MAS without a carer/proxy) and may therefore be less likely to be prompted by others to seek help for memory problems, leading to further delays among women. Qualitative research suggests

that carers of people with dementia from minority ethnic groups tend to delay help-seeking until they are unable to cope or experience a crisis, in part due to beliefs that families should care for their elders and partly because of negative beliefs and stigma associated with psychiatry.[33] Such delays are likely to contribute to the observed difference in cognitive function between white and non-white patients.

Differences in cognitive function by age, deprivation, sex and ethnicity may also reflect differential functioning of MMSE across these groups. Studies of adults in the general population show that people with more years of education perform better on the MMSE,[34] which could partly explain socioeconomic differences in MMSE score on presentation at MAS. Similarly, differences in MMSE score by ethnic group have been observed in the general population, related to particular items with possible cultural biases, which may account for lower scores among non-white ethnic groups at referral.[35]

As with cognitive function, the observed relationships between socio-demographic variables and HRQL may be explained in part by differences in health care seeking behavior. Although data on use of dementia services in the UK are limited, socioeconomic deprivation and non-white ethnicity have been identified as risk factors for delayed presentation for other chronic conditions, which may be reflected in worse patient-reported outcomes.[36,37] Experiencing a greater number of comorbidities has been shown to be associated with lower HRQL in other clinical populations of older people,[36] but interactions between common long term conditions appear to be less than additive[38] which may explain why in our sample an effect on HRQL was not seen until the number of comorbidities was four or more.

Poorer patient reported outcomes have been reported for women compared to men among people with heart failure [36] and hip and knee replacement patients,[37] a difference which was observed for proxy-reported HRQL but not self-reported measures. One possible explanation for this is that women are more likely to perceive their illnesses in terms of how they impact on others, and may downplay their health problems as a response to gendered norms relating to selflessness and care.[39] Similarly, the finding that older age is associated with better self-reported HRQL but not with proxy-reported HRQL may be related to older people adapting to and normalizing ill health and making comparisons to their peers in their assessment of wellbeing, [39,40] whereas proxies view the patient in terms of their former health.

Strengths and limitations

This is the largest multi-centre study of patients attending MASs in England, covering a third of all services across all regions, including those serving ethnically diverse populations. There are three potential limitations. First, the patient recruitment rate was 42%, with women and older patients being underrepresented in our sample. The lack of data on cognitive function of non-participants limits our ability to explore directly whether our sample was representative in this regard. Indirect evidence comes from comparison of sites with the lowest and highest recruitment rates which showed that participants with lower cognitive function were underrepresented at sites with low recruitment, suggesting that at these sites more impaired patients were less likely to take part in the study. The only other source of evidence comes from comparing the distribution of cognitive function scores in our sample to that reported in a previous service evaluation of a London memory clinic: among all consecutive referrals to that service over 18 months the distribution was similar

to our sample: 45% had MMSE score 25-30 (v 53% in our study sample), 32% (v 28%) 19-24, 20% (v 15%) 10-18 and 2% (v 3%) 0-9 (p-value from chi-squared test=0.07).[5]

Second, the exclusion of non-English speakers may have underestimated the association between ethnic group and cognitive function and HRQL at MAS referral, although the number of patients excluded was small.

The final limitation relates to the use of MMSE score to measure cognitive function; although MMSE is often used in research studies as an indicator of dementia severity, the clinical significance of specific cut-offs is not well established and MMSE may perform differently across patient groups. Although there was a substantial proportion of missing data on cognitive function, analyses excluding MASs with high rates of missing data produced similar results to those from analyses including all sites.

Implications for research

This study suggests three potentially productive areas for further research. First, research that explores patterns of presentation and referral to MAS is needed to identify whether observed inequalities in the use of services arise from systematic differences in patient behaviour or in health care policy and practice, and to identify environmental or structural factors that may influence these behaviors.

Second, recent attempts have been made to improve the measurement of both cognitive function and HRQOL in dementia using modern psychometric methods;[23,41] similar methodological work in these areas could help to solve some of the problems associated with current measures.

Third, in addition to patient characteristics, other factors including proxy characteristics, the patient-proxy relationship and carer burden may explain differences between patient- and proxy-reported HRQL. These relationships need to be explored more fully.

Conclusions

A large proportion of study participants had moderate or high cognitive function scores, suggesting that these patients were referred early to MAS. However, there are socio-demographic differences in cognitive function and HRQL at referral, which point to potential inequalities in the use of MASs. It is not possible to determine the relative contributions of supply factors (due to the provider) and demand factors (due to patients) to this disparity.

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Figure legend

Figure 1: Distributions of a) DEMQOL equated score (linearly transformed to range from 0 to 100); b) DEMQOL-Proxy equated score (linearly transformed to range from 0 to 100); c) self-reported EQ-5D-3L index score among referrals; and d) Proxy-reported EQ-5D-3L index score among referrals to MAS for suspected dementia

Table 1: Socio-demographic and clinical characteristics of patients referred to memory assessment services (MAS) for suspected dementia across 73 sites in England, September 2014 – April 2015 (n=1,420)

Patient characteristic	Mean (SD) or n (%)
Age (years)	77.9 (8.48)
<75	432 (30.4%)
75-79	320 (22.5%)
80-84	349 (24.6%)
≥85	319 (22.5%)
Sex	
Male	677 (47.7%)
Female	743 (52.3%)
Ethnicity	
White/White British	1,332 (94.5%)
Other ethnicity	78 (5.5%)
Missing	10
Deprivation quintiles [a]	
1 – least deprived	349 (24.9%)
2	299 (21.4%)
3	280 (20.0%)
4	253 (18.1%)
5 – most deprived	219 (15.6%)
Missing	20
Cognitive function [b]	
1 – highest function (equivalent to MMSE score≥28)	317 (28.5%)
2	329 (29.5%)
3 – lowest function (equivalent to MMSE score<24)	468 (42.0%)
Missing	306
Number of comorbidities [c]	
0	313 (22.1%)
1	376 (26.6%)
2	327 (23.1%)
3	230 (16.3%)
4 or more	169 (11.9%)
Missing	5
DEMQOL equated score [d] (n=1,415)	65.0 (12.1)
DEMQOL-Proxy equated score [d] (n=1,011)	56.4 (9.5)
EQ-5D-3L index score [e] (n=1,394)	0.7 (0.3)
EQ-5D-3L Proxy index score [e] (n=975)	0.6 (0.3)

[a] Based on Index of Multiple Deprivation (IMD) 2010 score; [b] Where MMSE score not available, ACE-III, ACE-R, MOCA, M-ACE or KOLT score used, with cut-offs based on

predicted MMSE; [c] Selected from the following list of chronic conditions: heart disease, high blood pressure, problems caused by stroke, leg pain due to poor circulation, lung disease (e.g. asthma, chronic bronchitis, emphysema), diabetes, kidney disease, disease of the nervous system (e.g. Parkinson, MS), liver disease, cancer within last 5 years, depression or arthritis; [d] Equated score derived using Rasch analysis, linearly transformed to have range 0-100; [e] Index score based on UK general population valuation surveys using time trade-off.

Table 2: Relative odds of lower cognitive function at first MAS appointment by patient characteristics

Patient characteristics	Number with outcome	Number missing	Cognitive function category (row %) [a]			Unadjusted OR [b]	Adjusted OR [c]	95% CI
			1 Highest function	2	3 Lowest function			
Age (years)								
<75	342	90	42.4	27.8	29.8	Reference	Reference	
75-79	258	62	26.7	29.1	44.2	**2.0**	**2.1**	**(1.4 to 3.0)**
80-84	267	82	19.9	30.7	49.4	**2.6**	**2.7**	**(1.9 to 3.9)**
≥85	247	72	20.2	31.2	48.6	**2.5**	**2.6**	**(1.8 to 3.7)**
Sex								
Male	528	149	32.9	30.7	36.4	Reference	Reference	
Female	586	157	24.4	28.5	47.1	**1.5**	**1.4**	**(1.2 to 1.8)**
Ethnicity - grouped								
White/White British	1,049	283	29.4	29.9	40.7	Reference	Reference	
Other ethnicity	59	19	10.2	23.7	66.1	**1.3**	**1.3**	**(1.1 to 1.7)**
Deprivation (quintiles of IMD)								
1 – least deprived	295	54	30.2	36.3	33.5	Reference	Reference	
2	228	71	29.8	25.0	45.2	1.3	**1.4**	**(1.0 to 2.0)**
3	213	67	36.6	25.4	38.0	1.0	1.0	(0.7 to 1.4)
4	191	62	24.1	28.3	47.6	**1.6**	**1.7**	**(1.2 to 2.6)**
5 – most deprived	175	44	19.4	31.4	49.2	**1.8**	**2.1**	**(1.4 to 3.1)**
Number of comorbidities								
0	208	105	26.4	29.8	43.8	Reference	Reference	
1	302	74	25.8	32.1	42.1	1.0	0.8	(0.6 to 1.1)
2	280	47	31.8	27.1	41.1	0.8	0.8	(0.5 to 1.2)
3	182	48	28.6	28.0	43.4	1.0	0.8	(0.6 to 1.2)
4 or more	140	29	30.7	30.7	38.6	0.8	0.8	(0.5 to 1.2)

Results from ordered logistic regression analyses. [a] Highest cognitive function equivalent to MMSE score≥28, lowest cognitive function equivalent to MMSE score <24; [b] Adjusted for clustering by clinic; [c] Adjusted for all other characteristics in table and clustering by clinic, n=1,094; ORs in **bold** indicate statistically significant association at 5% level.

Table 3: Differences in DEMQOL mean equated score by patient characteristics

Patient characteristics	Number with outcome	Number missing	DEMQOL Mean equated score (SD)	Unadjusted mean difference [a]	Adjusted mean difference [b]	95% CI
Age (years)						
<75	431	1	62.4 (12.1)	Reference	Reference	
75-79	320	0	64.5 (11.1)	**2.1**	**2.0**	**(0.2 to 3.9)**
80-84	347	2	66.6 (12.5)	**4.2**	**4.0**	**(2.1 to 5.9)**
≥85	317	2	67.6 (12.0)	**4.8**	**4.6**	**(2.7 to 6.4)**
Sex						
Male	675	2	64.6 (12.1)	Reference	Reference	
Female	740	3	65.3 (12.0)	0.6	0.2	(-0.9 to 1.4)
Ethnicity - grouped						
White/White British	1,330	2	65.2 (12.1)	Reference	Reference	
Other ethnicity	78	0	62.0 (11.7)	**-3.1**	**-2.9**	**(-5.4 to -0.4)**
Deprivation (quintiles of IMD)						
1 – least deprived	348	1	67.3 (12.1)	Reference	Reference	
2	298	1	64.3 (11.6)	**-3.0**	**-2.7**	**(-4.4 to -1.0)**
3	278	2	65.2 (11.9)	**-2.0**	**-1.8**	**(-3.6 to -0.1)**
4	253	0	62.8 (11.8)	**-4.4**	**-3.9**	**(-6.0 to -1.9)**
5 – most deprived	218	1	64.5 (12.8)	**-2.7**	**-2.0**	**(-4.0 to -0.1)**
Number of comorbidities						
0	311	2	65.5 (11.5)	Reference	Reference	
1	376	0	65.8 (11.5)	0.3	0.2	(-1.5 to 2.0)
2	327	0	65.9 (11.5)	0.4	0.1	(-1.8 to 2.0)
3	230	0	64.2 (12.2)	-1.3	-1.3	(-3.3 to 0.6)
4 or more	169	0	61.5 (12.2)	**-4.0**	**-3.9**	**(-6.5 to -1.4)**

Results from linear regression analyses. [a] Adjusted for clustering by clinic; [b] Adjusted for all other characteristics in table and clustering by clinic, n=1,386; ORs in **bold** indicate statistically significant association at 5% level.

Table 4: Differences in DEMQOL Proxy mean equated score by patient characteristics

Patient characteristics	Number with outcome	Number missing	DEMQOL Proxy Mean equated score (SD)	Unadjusted mean difference [a]	Adjusted mean difference [b]	95% CI
Age (years)						
<75	297	135	56.7 (10.9)	Reference	Reference	
75-79	239	81	56.1 (8.2)	-0.6	-0.9	(-2.5 to 0.6)
80-84	251	98	57.0 (8.7)	0.2	0.3	(-1.3 to 1.9)
≥85	224	95	55.6 (9.7)	-1.1	-1.0	(-2.7 to 0.7)
Sex						
Male	518	159	57.6 (9.8)	Reference	Reference	
Female	493	250	55.2 (9.0)	**-2.4**	**-2.4**	**(-3.8 to -1.1)**
Ethnicity - grouped						
White/White British	962	370	56.6 (9.4)	Reference	Reference	
Other ethnicity	49	29	52.7 (11.5)	-3.9	-3.3	(-7.1 to 0.4)
Deprivation (quintiles of IMD)						
1 – least deprived	257	92	57.6 (8.9)	Reference	Reference	
2	204	95	56.3 (8.4)	-1.3	-1.5	(-3.3 to 0.3)
3	205	75	57.5 (9.8)	-0.1	-0.2	(-1.8 to 1.5)
4	179	74	55.2 (9.6)	-2.4	-2.0	(-4.3 to 0.3)
5 – most deprived	152	67	54.6 (10.8)	**-3.0**	**-2.5**	**(-4.9 to -0.1)**
Number of comorbidities						
0	219	94	57.5 (9.6)	Reference	Reference	
1	259	117	56.4 (8.6)	-1.1	-1.3	(-2.9 to 0.4)
2	243	84	57.1 (9.5)	-0.4	-0.7	(-2.6 to 1.1)
3	174	56	55.5 (9.5)	-1.9	-1.9	(-4.0 to 0.2)
4 or more	115	54	54.4 (10.9)	**-3.0**	**-3.2**	**(-5.5 to -1.0)**

Results from linear regression analyses. [a] Adjusted for clustering by clinic; [b] Adjusted for all other characteristics in table and clustering by clinic, n=996; ORs in **bold** indicate statistically significant association at 5% level.

Figure 1: Distributions of a) DEMQOL equated score; b) DEMQOL-Proxy equated score; c) Self-reported EQ-5D-3L index score; and d) Proxy-reported EQ-5D-3L index score