Featured Article

Use and costs of services and unpaid care for people with mild-to-moderate dementia: Baseline results from the IDEAL cohort study

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Abstract

Introduction: We examined 3-month service use and costs of care for people with mild-to-moderate dementia in Great Britain.

Methods: We analyzed Improving the experience of Dementia and Enhancing Active Life cohort study baseline data on paid care, out-of-pocket expenditure, and unpaid care from participants with dementia (N = 1547) and their carers (N = 1283). In regression analyses, we estimated per-group mean costs of diagnostic and sociodemographic subgroups.

Results: Use of services apart from primary and outpatient hospital care was low. Unpaid care accounted for three-quarters of total costs (mean, £4008 [standard error, £130] per participant). Most participants (87%) received unpaid care equating to 36 hours weekly. Estimated costs for people with Parkinson's dementia were £8609, £4359 for participants with mixed dementia, and £3484 for those with Alzheimer's disease. Total costs were lower for participants with dementia living alone than living with others (£2484 vs. £4360); costs were lower for female than for male participants (£3607 vs. £4272).

Discussion: Costs varied by dementia subtype, carer status, and living arrangement. Policy makers should recognize the high costs of unpaid care for people with dementia, who do not always get the support that they need or would like to receive.

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Keywords: Dementia; Costs; Health services; Social care; Unpaid care

1. Introduction

In the United Kingdom, 850,000 people live with dementia; in parallel with global trends, this number looks set to

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double in the next 20 years [1,2]. The symptoms of dementia can affect individuals' personal and social circumstances, creating challenges to living well [3]. Supporting people with dementia brings its own challenges, and unpaid carers may require support to maintain social roles and resources [4]. Individuals living with the condition may need to make demands on the time and resources of unpaid carers and on services provided by health and social care. Projected growth in the number of people living with dementia will have major cost consequences worldwide [1]. Although costs of dementia care to society are high, the burden of care falls disproportionately on unpaid carers [5–8]. Previous UK person-level studies of care for people with dementia [9–15] have used relatively small samples, covered limited geographical areas, or focused on unconfirmed diagnoses or diagnosis of a single dementia type. This limits the information available to decision makers planning how to meet the needs of people living with dementia and their families [16,17].

This study aims to contribute new evidence on use and associated costs of health, social and unpaid care for people with mild-to-moderate dementia, drawing on baseline data from a large British cohort. We explore associations between diagnostic and sociodemographic characteristics of people with dementia and costs of care.

2. Methods

2.1. Design and sample

We used baseline data from the Improving the experience of Dementia and Enhancing Active Life (IDEAL) program [18,19] (data set version 2.0), following yearly for up to 6 years a cohort of people with mild-to-moderate dementia from baseline (hereafter participants) and, where available, a primary carer (relative/friend providing unpaid support to the participant; hereafter carers) [18]. The first phase of IDEAL, covering the first three time points, was approved by Wales Research Ethics Committee 5 (13/WA/0405) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014-11684) and is registered with the UK Clinical Research Network (16593).

Participants were recruited from National Health Service (NHS) clinics and Join Dementia Research [20] (NHS-funded portal supporting dementia research) in 29 sites across England, Scotland, and Wales. Any community-dwelling person with a clinical dementia diagnosis and Mini-Mental State Examination (MMSE) score >14 was eligible for inclusion [18]. Baseline questionnaires were administered by trained researchers (July 2014–August 2016) using face-to-face interviews with participants. One section, on paid and unpaid care, was administered to both the participant and carer, if the latter was available. Carers self-completed separate questionnaires.

Sample size was powered on planned structural equation model analyses of measures of capability of living well and was large enough to permit subgroup analyses for age, sex, dementia subtype, whether people lived alone, living situation, and relationship with carer [18]. The baseline sample comprised 1547 participants and 1283 carers. Most participants with dementia were recruited from England (90%), with 5% each from Scotland and Wales.

2.2. Measures

Questionnaire measures and costing methods are summarized herewith (details in Supplementary Material 1).

2.2.1. Use of paid and unpaid care

Information on health and social care services, medications, assistive equipment, unpaid care, and costs to carers of missing work was collected using an adapted Client Service Receipt Inventory [21]. Questions on health and social care services and unpaid care were asked of participant and carer, or only the participant where no carer was involved in the study. Carer questionnaires asked about working time given up to provide care (*lost working time*).

2.3. Sociodemographic characteristics

We examined associations of baseline costs with sociodemographic characteristics and dementia subtype. We do not focus on dementia-related needs here (activities of daily living, cognition, behavior, and comorbidities), as these were measured at baseline and therefore up to 3 months *after* costs were incurred (explored elsewhere in IDEAL study [22–25]). Participant characteristics examined were age groups, sex, dementia subtype, education, National Statistics Socio-economic Classification 5 variable version [26], quintiles of gross annual income (participant and spouse/partner), household tenure, living alone/with others, and participating carer status (none, spousal [spouse/partner], or nonspousal [friend/other family]). Separate regressions examined associations of lost working time costs with carer characteristics: age groups, sex, carer status, socioeconomic status, and education.

2.4. Costing methods

Community health and social care contacts and assistive equipment were weighted by nationally applicable unit costs [27]. Base year for prices was 2014/15. For hospital costs, we applied NHS Reference Costs figures [28]. Mental health medication costs were taken from NHS prescription costs analysis [29]. Hours of unpaid care provided by relatives/friends during the previous 3 months were valued at opportunity cost, applying the minimum wage (in England) [30,31]. Costs of carers' and other relatives/friends' lost working time during the previous 3 months were calculated using Annual Survey of Hours and Earnings data [32]. Paid and unpaid care and out-of-pocket costs were estimated from participant questionnaires. Individual cost items were summed to give category subtotals

Table 1
Mean costs (£) of care during prior 3 months

Cost categories (£)	Mean	SE
Health and social care (N = 1547)		
Primary and community health care costs	142	7
Community mental health costs	67	4
Community social care costs[*]	175	15
Day care services costs	143	12
Hospital costs	404	39
Total medication costs[†]	62	3
Costs of equipment paid for by social services[‡]	10	1
Costs of equipment paid for by NHS[‡]	6	1
Total services and medication costs[§]	1008	48
Out-of-pocket costs to the person and to relatives and friends (N = 1547)		
Costs of equipment purchased by self or family	41	2
Costs of condition-related travel to participant & carers[¶]	10	2
Costs of unpaid care and lost working time		
From carer questionnaires (N = 1283)		
Lost working time costs to carers[#]	158	24
From participant with dementia questionnaires (N = 1547)		
Unpaid care costs[**]	2928	114
Lost working time costs to carers[††]	20	2
Total costs of paid and unpaid care (N = 1547)		
Total paid and unpaid carer costs[‡‡]	4008	130

NOTE. Results of multiply imputed data (34 complete data sets).
Abbreviations: SE, standard error; NHS, National Health Service.

[*]Includes costs of respite in residential accommodation.

[†]Costs of dementia and central nervous system medications.

[‡]Costs over prior 3 months.

[§]Assumes all community care costs fall to social services.

[¶]Costs of travel to appointments related to problems with thinking, memory, and behavior by participant and carer or participant only if no carer was involved.

[#]Production costs to carers—variables for participating carer from carer questionnaire respondents.

[**]Unpaid carer costs include costs of hours of unpaid care by unpaid carer and by other friends and relatives.

[††]Lost working time costs to carers—from participant questionnaire respondents (other friends and relatives' lost working time).

[‡‡]All costs derived from participant questionnaire data: includes all paid service and medications costs, out-of-pocket costs, unpaid carer costs, and lost working time costs to other friends and relatives.

(Table 1), in turn summed to give overall paid and unpaid care cost totals. Costs of lost working time were calculated and reported separately.

2.5. Missing data and data imputation

Missing data and imputation models are described in Supplementary Material 1. Proportions of cases missing service use data ran at 4% to 5%; 9% of cases were missing data on care provided by carers; 6% to 8% of cases were missing carer questionnaire data on lost earnings. Imputation by chained equations was carried out in Stata 15 (StataCorp LP, College Station, TX) [33,34]. Equations for imputing

variables from participant questionnaires included use, costs, and characteristics to be used in regression analyses. Equations for imputing carers' questionnaire variables included carer socioeconomic status, lost earnings, and employment.

2.6. Analyses

Differences in costs for sociodemographic and diagnostic subgroups were examined through multivariate regressions. Generalized linear models [35] were fitted to cost subcategories and total costs, assuming gamma distribution and log-link function to accommodate anticipated skew in cost data distribution. Two-part models were fitted to cost data with substantial numbers of zeros using the user-written Stata command <<twopm>> [36]. In the first part, logit models were applied to a binary indicator for nonzero costs (henceforth, *models of receipt*); in the second, generalized linear models were applied to positive costs. The same vector of covariates was used in each part. For factor variables with more than two levels, we tested joint significance of all levels by following a previously described procedure [37] implemented in Stata's multiple imputation suite of commands [33] to obtain a *P* value across regression estimates from multiply imputed data sets. A 5% significance level was applied to tests of model coefficients. We estimated average marginal effects (henceforth, *estimated means*), for each level of each factor at observed values of each case. Differences in costs between subgroups were judged significant if 95% confidence intervals (95% CIs) of subgroup estimated means did not overlap. Results of analyses conducted on each complete data set generated by imputation were combined using Rubin's rules [38].

3. Results

3.1. Sample

More than half of the participants were aged older than 74 years, whereas 9% were aged younger than 65 years (Table 2). Mean age was 76.4 (standard deviation, 8.6). There were more men (56%) than women. More than half of the participants (55%) had Alzheimer's disease. A fifth lived alone. Two-thirds (67%) had a spousal carer; 17% had no participating carer. Of participants living with others, 10% did not have a participating carer. Participants with no carer had mean baseline MMSE 1.07 points higher than those with carers (24.12; 95% CI, 23.74–24.50 vs. 23.05; 95% CI, 22.83–23.25; $t = 4.34$; $P < .001$, N = 1474). Carers were younger than participants (mean age, 69.1 years; standard deviation, 11.1); 69% were females. On National Statistics Socio-economic Classification 5, 43% of carers (and 41% of participants) were in the top category. About 53% of carers aged younger than 65 years were in paid employment, whereas this proportion dropped to 12% in the 65 to 69 age band and less than 3%

Table 2
Demographic and socioeconomic characteristics

Participants with dementia (N = 1547)	N (%)
Age bands (y)	
Younger than 65	136 (9)
65–69	178 (12)
70–74	260 (17)
75–79	370 (24)
80+	603 (39)
Sex	
Male	872 (56)
Female	675 (44)
Carer status	
Spouse/partner	1039 (67)
Family/friend	244 (16)
No carer involved	264 (17)
Dementia subtypes	
Alzheimer's disease	858 (55)
Vascular dementia	171 (11)
Mixed (Alzheimer's and vascular)	326 (21)
Frontotemporal dementia	54 (3)
Parkinson's disease dementia	44 (3)
Dementia with Lewy bodies	53 (3)
Unspecified/other	41 (3)
Socioeconomic classification[*]	
Managerial, administrative, and professional occupations	639 (41)
Intermediate occupations	271 (18)
Small employers and own account workers	173 (11)
Lower supervisory and technical occupations	151 (10)
Semiroutine and routine occupations	313 (20)
Lives alone (self-reported)[*]	
No	1241 (80)
Yes	306 (20)
Income quintiles[†]	
First quintile (lowest)	431 (28)
Second quintile	277 (18)
Third quintile	257 (17)
Fourth quintile	330 (21)
Fifth quintile (highest)	252 (16)
Education	
No qualification	430 (28)
School certificate age 16	274 (18)
School certificate age 18	529 (34)
College-level	314 (20)
Tenure	
Rents and other forms of tenure	249 (16)
Owns	1298 (84)

Carers (N = 1283)	N (%)
Age bands (y)	
Younger than 65	369 (29)
65–69	208 (16)
70–74	267 (21)
75–79	223 (17)
80+	216 (17)
Sex	
Male	402 (31)
Female	881 (69)
Socioeconomic classification[*]	
Managerial, administrative, and professional occupations	549 (43)
Intermediate occupations	335 (26)
	(Continued)

Table 2
Demographic and socioeconomic characteristics *(Continued)*

Carers (N = 1283)	N (%)
Small employers and own account workers	92 (7)
Lower supervisory and technical occupations	92 (7)
Semiroutine and routine occupations	216 (17)
Education[*]	
No qualification	275 (21)
School certificate age 16	285 (22)
School certificate age 18	390 (30)
College-level	333 (26)

NOTE. Socioeconomic classification = National Statistics Socio-economic Classification 5 levels.
[*]Proportions and numbers of observations estimated from imputed data sets.
[†]Joint income of the person with dementia and spouse/partner.

in the 70+ age bands. Most nonspousal carers (83%) were the adult children of participants.

3.2. Use and costs of individual resource items

3.2.1. Paid care services, medications, assistive equipment, and adaptations

During the prior 3 months, 65% of participants saw a general practitioner, 48% a practice nurse, and 16% a community mental health nurse or psychiatrist (Table 3). Other health professionals (e.g., specialist nurses, psychologists) were seen by 10% or fewer. Just more than half had hospital outpatient or day-case treatment; 14% visited an accident and emergency department. Only 6% had an inpatient admission, staying a week on average. Seventy-one percent had taken dementia medications; 23% had taken other central nervous system medications.

Use of home-based social care was generally low. More participants reported using services of a cleaner (24%) than a home carer (11%). Overall day center attendance was modest (12%), but day center users averaged 18 attendances during 3 months or 2.6 times weekly; day center costs constituted the largest element of social care costs (£133, standard error [SE], £12). Of home care users, 53% reported that they or their families paid all, and 13% paid some, of the costs. All paid the full costs of cleaners. Two-thirds reported using equipment and adaptations (Supplementary Material 2, Table S2.1): most commonly mobility aids but also pendant alarms (13%) and calendar clocks (12%).

3.2.2. Unpaid care and lost working time

Most participants (87%) received weekly help from friends/relatives, averaging 470 (SE, 18.2) hours during 3 months (i.e., 36 hours per week). Thirty percent (N = 456) of friends/relatives assisted participants with personal care; 44% (N = 678) made sure participants were safe; 68% (N = 1048) helped with finances; 70% (N = 1078) with

Table 3
Use of paid and unpaid care and costs: means (SE) across the sample and for users of each type of care during the prior 3 months

Item	All		Users					
	Intensity	Costs (£)	Observations*			Intensity	Costs (£)
	Mean (SE)		Minimum	Maximum	%	Mean (SE)	
Paid care							
Primary and community health[†]							
GP—office	1.38 (0.05)	68 (2)	995	1012	65	2.12 (0.06)	104 (3)
GP—home	0.09 (0.01)	7 (1)	79	88	5	1.63 (0.13)	139 (11)
GP—telephone	0.33 (0.03)	7 (1)	268	282	18	1.83 (0.1)	40 (2)
Practice nurse	0.95 (0.05)	11 (1)	725	749	48	1.98 (0.08)	24 (1)
District nurse	0.6 (0.15)	22 (5)	125	136	8	7.15 (1.6)	264 (59)
Physiotherapist/occupational therapist	0.3 (0.03)	16 (2)	169	180	11	2.68 (0.21)	139 (11)
Specialist nurse	0.15 (0.02)	10 (1)	120	131	8	1.86 (0.16)	130 (11)
Community mental health[†]							
Community mental health nurse	0.3 (0.03)	10 (1)	242	258	16	1.86 (0.11)	63 (4)
Psychiatrist	0.19 (0.01)	44 (3)	236	249	16	1.22 (0.04)	281 (9)
Psychologist	0.1 (0.02)	13 (3)	50	61	4	2.75 (0.49)	379 (67)
Social care[†]							
Social work	0.11 (0.02)	6 (1)	70	76	5	2.25 (0.32)	124 (18)
Home care	7.76 (0.86)	76 (8)	168	178	11	69.3 (5.76)	681 (57)
Meals on wheels	0.73 (0.19)	4 (1)	23	29	2	44.4 (7.43)	260 (43)
Cleaner	2.73 (0.18)	26 (2)	354	372	24	11.55 (0.52)	108 (5)
Laundry service	0.37 (0.07)	10 (2)	45	52	3	11.74 (1.35)	313 (36)
Sitting service	0.3 (0.08)	13 (4)	34	38	2	13.11 (2.86)	575 (126)
Carer support	0.69 (0.2)	30 (9)	48	56	3	20.79 (5.12)	913 (225)
Respite days[‡]	0.08 (0.02)	9 (3)	16	18	1	7.5 (0.97)	880 (113)
Day center days	2.25 (0.2)	133 (12)	187	194	12	18.23 (1.07)	1076 (63)
Lunch club visits	1.3 (0.16)	10 (1)	135	147	9	14.34 (1.3)	112 (10)
Hospital care							
ED visits	0.14 (0.01)	27 (2)	149	161	10	1.41 (0.09)	275 (13)
Admission 1, days	0.41 (0.1)	160 (36)	84	92	6	7.21 (1.6)	2824 (548)
Admission 2, days	0.02 (0.01)	11 (5)	12	14	1	2.92 (0.59)	1344 (466)
Admission 3, days	0 (0)	1 (0)	3	4	0	0.72 (0.33)	260 (128)
Outpatients[§]	1.46 (0.07)	205 (9)	789	802	52	2.83 (0.12)	398 (13)
Medications							
CNS	0.28 (0.02)	10 (2)	353	367	23	1.2 (0.03)	38 (6)
Dementia	0.75 (0.01)	52 (3)	1096	1109	71	1.05 (0.01)	71 (4)
Unpaid care and travel to appointments							
Unpaid carer							
Hours helping	410.6 (16.54)[¶]	2675 (107)[¶]	1226	1246	87	470.03 (18.21)[¶]	3052 (118)[#]
Work weeks lost[**]	0.08 (0.03)	43 (14)	12	16	1	7.48 (0.97)	4146 (602)
Hours cut down[††]	11.32 (1.57)	115 (20)	76	83	6	184.02 (15.1)	1878 (256)
Other friends/relatives							
Hours helping	31.79 (4.29)	207 (28)	374	394	25	128.22 (16.31)	833 (106)
Days lost work	0.23 (0.03)	20 (2)	103	113	7	3.3 (0.24)	294 (21)
Travel to appointments							
Number of trips	1.45 (0.08)	10 (2)	752	765	49	2.95 (0.13)	21 (3)

NOTE. People with dementia questionnaire N = 1547; carers questionnaire N = 1283 unless otherwise indicated. Results of multiply imputed data (34 complete data sets).

Abbreviations: SE, standard error; GP, general practitioner; ED, emergency department; CNS, central nervous system.

*The number of cases with use of each item varied over the 34 complete data sets produced by the multiple imputation process, as indicated by the columns for minimum and maximum observations. Percentage (%) reflects the estimated mean proportion of the sample across the combined 34 data sets.

[†]Items are face-to-face visits unless otherwise stated; items report responses from the participant with dementia questionnaire data set unless otherwise stated.

[‡]Respite in residential homes.

[§]Outpatient visits and procedures.

[¶]Hour estimates exclude respondents reporting other numbers of hours caring per week, N = 1412.

[#]Costs reported exclude respondents reporting other numbers of hours caring per week, N = 1412. Over the full sample, N = 1547, the imputed cost of unpaid hours helping was £2721 (SE, £107); the cost of unpaid hours helping by those with nonzero costs (minimum N = 1352, maximum N = 1375) was £3087 (SE, £119).

[**]Days lost over the prior 3 months (variable from the carer questionnaire).

[††]All hours cut down are assumed to have occurred over the prior 3 months (variable from the carer questionnaire).

practical matters; and 74% (N = 1140) with escorting to appointments. Only 1% of carers completing carers' questionnaires had given up work (past 3 months), and 6% had cut down work; 7% of other friends/relatives completing participant questionnaires cut down on work.

3.3. Subtotal and total costs

Mean 3-month cost of health and social care was £1004 (SE, £48) (Table 1). Hospital care (accident and emergency department, inpatient, and outpatient) contributed most to this total, followed by community social services (home care and residential respite care). Unpaid care costs were far higher than paid care costs (£2928; SE, £114). Total costs (paid, unpaid, out-of-pocket costs) were £4008 (SE, £130).

Almost all participants (99%) incurred some costs during 3 months (Supplementary Material 2, Fig. S2.1). A third had some community social care costs. Subtotal and total costs of paid and unpaid care were summarized by sociodemographic and diagnostic subgroups (Supplementary Material 2, Tables S2.2–S2.3). Mean total costs for participants with Parkinson's dementia (Fig. 1) were substantially greater than costs for participants with other dementias. Examining carer data on lost working time (Supplementary Material 2, Table S2.4), costs of carers aged younger than 65 years were more than six times higher than those aged older than 74 years, as might be expected.

3.4. Model results

Relationships between paid and unpaid care and socioeconomic and diagnostic factors were explored in two-part models (Supplementary Material 2, Tables S2.5a, S2.5b, S2.6). Estimated mean costs are presented in Tables 4 and 5.

3.4.1. Receipt and costs of paid care

In first-part models (Tables S2.5a, S2.5b), diagnostic subtype was associated with receipt of most service categories except mental health services. Age was associated with receipt of mental health and social care services. Relationship to carer, living alone, socio-economic classification, and income were also related to receiving social care, people living alone being nearly twice as likely as those living with others to use social care. Second-part models indicated that diagnostic subtype was associated with primary and community care, mental health care, hospital care, and medication costs.

Examining marginal effects of diagnostic subtypes (Table 3), costs of primary and community health care, social care, and medication were highest for those with Parkinson's dementia compared with other dementias. Mental health costs were higher in younger than 65 years age group than in other age groups. Social care costs of participants with nonspousal carers (£317) were 2.7 times higher than of those with spousal carers (£117). Social care costs of participants aged 80+ were higher than those of participants in other age bands. Total paid care costs were highest in those with Parkinson's dementia (£2001): 2.3 times those of participants with Alzheimer's disease (£852) and 2.2 times those of participants with vascular dementia (£890). Costs of participants with nonspousal carers (£1320) were 27% higher than costs of those with spousal carers (£958); and 47% higher than costs of participants with no carer (£895).

3.4.2. Unpaid care

First-part models (Table S2.6) indicated that people with nonspousal carers were three times more likely to have unpaid care than people with spousal carers. People without a participating carer were half as likely as people with spousal
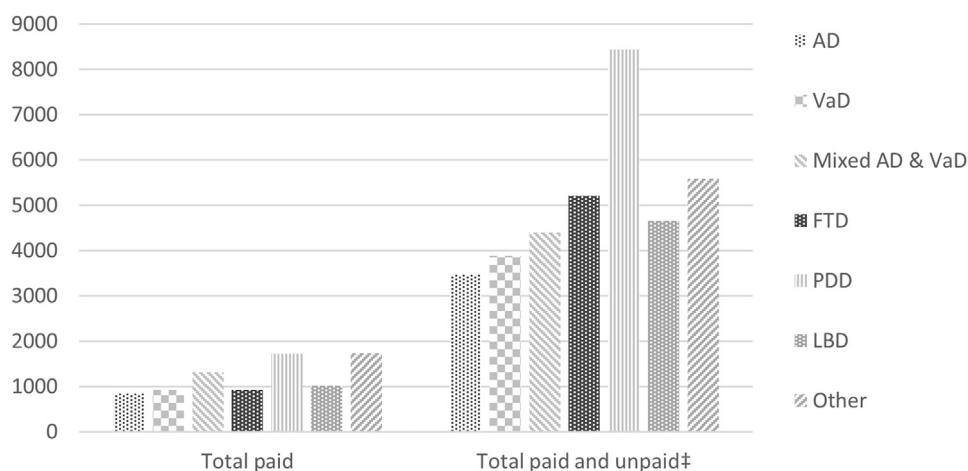

Fig. 1. Paid care costs and total costs of paid, out-of-pocket, and unpaid care (£) of participants with dementia, by diagnostic subtype. NOTE. Costs derived from participant with dementia questionnaires. Abbreviations: AD, Alzheimer's disease; VaD, vascular dementia; FTD, frontotemporal dementia; PDD, Parkinson's disease dementia; LBD, dementia with Lewy bodies; Other, unspecified/other. ‡Unpaid care and lost working time costs derived from participant with dementia questionnaires.

Table 4
Marginal means (95% CIs) (£) from two-part models of paid care cost categories and GLM of total paid care costs

Variable	Primary care	Mental health	Social care	Day services	Hospital	Medications	Equipment	Total paid
	Mean (95% CI)							
Sex								
Male	146 (129, 163)	69 (57, 82)	171 (127, 216)	160 (121, 199)	436 (340, 533)	60 (51, 69)	15 (11, 19)	1059 (928, 1189)
Female	137 (119, 155)	65 (50, 79)	183 (138, 229)	125 (87, 164)	358 (273, 443)	65 (54, 77)	18 (13, 22)	949 (831, 1068)
Age bands (y)								
Younger than 65	190 (131, 249)	144 (96, 192)	132 (50, 213)	88 (30, 145)	428 (226, 631)	64 (40, 89)	12 (5, 20)	1046 (765, 1326)
65–69	139 (107, 172)	63 (39, 86)	111 (43, 179)	80 (30, 131)	396 (218, 573)	56 (38, 74)	11 (5, 18)	856 (643, 1069)
70–74	133 (107, 158)	85 (60, 109)	133 (70, 195)	153 (81, 226)	418 (284, 552)	64 (48, 79)	13 (7, 18)	992 (807, 1176)
75–79	131 (110, 152)	46 (33, 60)	98 (59, 138)	162 (99, 225)	461 (326, 596)	59 (47, 72)	13 (9, 18)	942 (790, 1094)
80+	144 (125, 163)	59 (46, 72)	255 (196, 313)	163 (121, 205)	359 (264, 454)	66 (54, 78)	21 (15, 27)	1086 (940, 1232)
Diagnosis								
AD	127 (113, 141)	61 (50, 71)	149 (113, 185)	127 (94, 159)	312 (249, 374)	63 (55, 72)	13 (10, 16)	852 (760, 944)
VaD	147 (111, 184)	51 (29, 73)	177 (97, 257)	202 (116, 288)	286 (152, 420)	20 (9, 31)	14 (8, 20)	890 (678, 1102)
Mixed	163 (136, 190)	90 (64, 116)	175 (115, 235)	136 (84, 188)	621 (415, 826)	77 (59, 94)	17 (11, 22)	1256 (1022, 1490)
FTD	86 (48, 124)	36 (12, 61)	298 (48, 548)	323 (34, 611)	345 (125, 564)	24 (4, 45)	24 (−4, 52)	1025 (616, 1435)
PDD	328 (190, 466)	68 (24, 113)	556 (117, 994)	205 (28, 383)	650 (176, 1123)	105 (39, 171)	67 (27, 106)	2001 (1107, 2895)
DLB	173 (100, 247)	130 (51, 210)	220 (49, 391)	118 (−2, 238)	310 (89, 530)	86 (39, 133)	21 (4, 37)	1026 (607, 1445)
Unspecified/ other	128 (64, 192)	91 (20, 163)	397 (47, 747)	134 (−29, 297)	1028 (16, 2040)	78 (24, 132)	43 (9, 77)	1839 (851, 2828)
Carer relationship								
Spouse/partner	144 (126, 162)	72 (59, 84)	117 (81, 153)	138 (102, 175)	397 (302, 492)	67 (57, 78)	14 (10, 18)	958 (835, 1081)
Family/friend	162 (120, 204)	57 (31, 82)	317 (185, 448)	221 (118, 325)	491 (308, 674)	48 (32, 65)	21 (13, 29)	1320 (1023, 1616)
No carer involved	117 (91, 143)	59 (36, 83)	208 (123, 293)	94 (43, 145)	344 (195, 492)	58 (41, 75)	17 (11, 24)	895 (696, 1095)
Level of education								
No qualifications	144 (119, 170)	71 (52, 89)	149 (93, 205)	153 (99, 208)	354 (245, 463)	71 (55, 86)	18 (13, 23)	977 (809, 1146)
School certificate age 16	132 (107, 157)	68 (46, 90)	171 (100, 242)	166 (96, 236)	346 (230, 463)	54 (40, 68)	14 (8, 20)	955 (773, 1136)
School certificate age 18	150 (129, 171)	65 (51, 80)	190 (134, 246)	160 (115, 206)	437 (319, 555)	65 (53, 76)	16 (11, 21)	1081 (922, 1240)
College-level	133 (106, 160)	66 (45, 88)	210 (127, 293)	78 (36, 120)	458 (288, 629)	56 (41, 71)	16 (7, 24)	977 (779, 1174)
Household status								
Lives with others	134 (120, 148)	67 (57, 77)	150 (112, 189)	147 (114, 180)	397 (325, 468)	63 (55, 71)	15 (11, 19)	965 (864, 1066)
Lives alone	173 (131, 214)	68 (38, 98)	236 (148, 323)	137 (72, 202)	428 (225, 632)	60 (41, 80)	19 (12, 25)	1162 (884, 1441)
Socioeconomic classification								
Managerial	138 (118, 158)	61 (47, 74)	196 (141, 251)	158 (105, 211)	382 (279, 486)	69 (56, 82)	15 (10, 21)	1029 (875, 1183)
Intermediate	153 (122, 184)	82 (58, 107)	139 (82, 197)	125 (69, 181)	512 (334, 690)	63 (46, 81)	15 (8, 21)	1081 (865, 1296)
Small employers	139 (106, 173)	71 (42, 99)	173 (76, 270)	126 (55, 196)	321 (168, 475)	48 (31, 65)	18 (9, 26)	886 (669, 1102)
Lower supervisory	123 (92, 154)	73 (43, 103)	163 (57, 268)	171 (81, 262)	503 (263, 742)	49 (30, 67)	23 (11, 35)	1069 (782, 1355)
Semiroutine	150 (119, 180)	65 (43, 86)	185 (105, 265)	138 (82, 195)	347 (228, 466)	64 (46, 82)	16 (10, 22)	953 (773, 1133)
Tenure								
Rental tenant and other tenure	147 (116, 177)	62 (41, 84)	270 (142, 397)	159 (90, 228)	520 (315, 726)	66 (46, 87)	43 (28, 59)	1252 (981, 1524)
Owner-occupier	141 (128, 154)	68 (59, 78)	155 (123, 187)	141 (113, 169)	381 (313, 450)	62 (55, 69)	10 (8, 12)	959 (867, 1051)
Income quintile								
First quintile	145 (120, 171)	60 (41, 78)	161 (101, 220)	169 (103, 234)	407 (266, 548)	68 (51, 85)	16 (11, 21)	1016 (822, 1211)
Second quintile	138 (109, 167)	66 (45, 88)	180 (95, 265)	186 (111, 262)	349 (223, 474)	64 (46, 82)	22 (13, 31)	1031 (829, 1233)
Third quintile	154 (122, 185)	50 (31, 70)	155 (80, 231)	163 (82, 244)	393 (253, 533)	56 (41, 71)	16 (9, 24)	976 (780, 1173)

(Continued)

Table 4
Marginal means (95% CIs) (£) from two-part models of paid care cost categories and GLM of total paid care costs (*Continued*)

	Primary care	Mental health	Social care	Day services	Hospital	Medications	Equipment	Total paid
Variable	Mean (95% CI)							
Fourth quintile	143 (116, 169)	71 (47, 94)	222 (121, 323)	102 (43, 161)	442 (273, 612)	61 (46, 76)	12 (6, 17)	1029 (810, 1247)
Fifth quintile	126 (96, 155)	95 (61, 128)	176 (78, 275)	83 (32, 134)	411 (247, 574)	61 (42, 79)	13 (4, 22)	972 (738, 1207)

NOTE. Results using multiply imputed data (34 complete data sets).

Abbreviations: 95% CIs, 95% confidence intervals; GLM, generalized linear model; AD, Alzheimer's disease; VaD, vascular dementia; FTD, frontotemporal dementia; PDD, Parkinson's disease dementia; DLB, dementia with Lewy bodies; Other, unspecified/other; Managerial, managerial, administrative, and professional occupations; Small employers, small employers and own account workers; Lower supervisory, lower supervisory and technical; Semiroutine, semiroutine and routine.

carers to have unpaid care. People living alone were 77% less likely to have unpaid care than those living with others. In the second-part unpaid care models, no characteristics showed significant associations with costs. Estimated mean costs of unpaid care (Table 4) for participants with no participating carer were £1461: 60% less than costs of participants with nonspousal carers (£3645) and half the costs of participants with spousal carers (£3052). The estimated mean cost of unpaid care for participants living alone was less than a third of the cost of care for participants living with others.

In a model of carers' lost working time (Table S2.7), the likelihood of carers aged 65+ having lost working time was significantly lower than that of carers younger than 65 years (Table S2.7), unsurprisingly given carers' age and employment profiles. The estimated cost (Table S2.8) of lost working time was £387 (95% CI, 205–569) for carers younger than 65 years, far higher than for older carers.

3.4.3. Total costs

Participant sex and diagnosis and carer status were significantly associated with total paid, unpaid, and out-of-pocket costs (Table S2.6). Costs of female participants were 16% lower than those of males. The costs of Parkinson's dementia were nearly 2.5 times the costs of Alzheimer's disease and one quarter more than those of participants with mixed dementia. Relative to costs of people with spousal carers, costs for participants without carers were 40% lower and costs for participants with nonspousal carers were 22% higher. Costs of participants living alone were 44% lower than of those living with others.

Marginal effects estimates of total costs (Table 5) for women were lower than for men (£3607 vs. £4272). Estimated costs for people with Parkinson's dementia were £8609, £4359 for participants with mixed dementia, and £3484 for those with Alzheimer's disease. Estimates for participants without participating carers were £2467, less than half of those of participants with nonspousal carers (£5037) and 60% less than those for participants with spousal carers (£4120). Estimated costs for participants with dementia living alone (£2484)

were £1876 less than for participants living with others (£4360).

4. Discussion

In this large-scale British cohort of people with dementia and their carers, we examined receipt and costs of health and social care services and unpaid care. Most participants visited a general practitioner (65%), and half attended outpatient appointments; use of other individual health and care services was low. Dementia subtype was associated with receipt and costs across sectors. In particular, Parkinson's disease dementia was associated with higher probability of paid care receipt and higher paid care costs. Living alone was positively associated with receipt of social care and negatively associated with receipt of unpaid carer time, receipt and costs of friends/relatives' lost working time, and total costs. Carer status was associated with receipt of several categories of paid and unpaid care, but direction of association varied among spousal, nonspousal, and no-carer groups. Total costs for women, adjusting for diagnosis, socioeconomic characteristics, and carer status, were lower than for men. This trend was also seen in unpaid care costs but not total paid care costs. Similarly, Del Bono et al. [39] found that older women supply more care hours than older men, suggesting that gender-related differences in providing care might act as a driver. The proportion of women was much larger in the sample of carers than in the sample of people with dementia. Given that more men than women participants were recruited and that there were many spousal carers, it is unsurprising that more than two-thirds of carers were females, and this preponderance may have boosted overall unpaid care cost estimates. Numerous studies have reported similar proportions of female carers of people with dementia [8,40].

Relatively little individual-level information has been collected previously on care use and costs of people with dementia in Britain. Jones et al. [9] estimated 3-month costs of health and social care of people with dementia as £1159 (2014/15 prices). Comparisons are not straightforward as

Table 5
Marginal means (95% CIs) (£) from two-part models of out-of-pocket, unpaid care time, and lost work time costs and GLM of total costs of paid and unpaid care

Variable	Out-of-pocket	Unpaid care time	Lost work time	Total paid and unpaid
	Mean (95% CI)			
Sex				
Male	53 (47, 60)	3107 (2759, 3455)	15 (9, 22)	4272 (3883, 4662)
Female	50 (43, 57)	2639 (2273, 3006)	25 (17, 34)	3607 (3219, 3995)
Age bands (y)				
Younger than 65	36 (25, 47)	3546 (2508, 4583)	53 (17, 89)	4748 (3661, 5835)
65–69	39 (29, 50)	2357 (1798, 2915)	28 (10, 46)	3346 (2735, 3957)
70–74	46 (35, 56)	2699 (2168, 3231)	8 (1, 15)	3774 (3188, 4360)
75–79	50 (41, 58)	2902 (2427, 3378)	18 (8, 27)	3876 (3378, 4374)
80+	63 (55, 71)	3084 (2631, 3537)	19 (12, 27)	4215 (3743, 4686)
Dementia subtype				
AD	46 (41, 52)	2591 (2291, 2890)	18 (12, 24)	3498 (3189, 3807)
VaD	47 (34, 60)	2855 (2140, 3570)	25 (9, 42)	3773 (3046, 4500)
Mixed AD & VaD	53 (43, 63)	2973 (2445, 3502)	19 (8, 30)	4337 (3715, 4958)
FTD	68 (37, 100)	3838 (2228, 5448)	22 (−2, 47)	4783 (3189, 6378)
PDD	117 (72, 163)	6258 (3441, 9075)	17 (−11, 46)	8572 (5380, 11,763)
DLB	72 (43, 101)	3368 (1988, 4749)	63 (2, 124)	4618 (3065, 6172)
Other	52 (28, 75)	3761 (1932, 5591)	21 (−33, 74)	5684 (3480, 7888)
Carer status				
Spouse/partner	51 (45, 57)	3052 (2745, 3359)	9 (5, 13)	4120 (3771, 4469)
Family/friend	64 (49, 80)	3645 (2654, 4637)	95 (50, 139)	5037 (3988, 6086)
No carer involved	41 (31, 52)	1461 (1050, 1871)	17 (3, 31)	2467 (2003, 2931)
Level of education				
No qualifications	49 (40, 57)	3140 (2583, 3697)	22 (11, 33)	4266 (3663, 4870)
School certificate age 16	51 (40, 61)	2435 (1953, 2918)	11 (3, 20)	3411 (2881, 3941)
School certificate age 18	53 (45, 60)	3005 (2579, 3430)	23 (13, 33)	4163 (3697, 4630)
College-level	55 (43, 67)	2925 (2298, 3553)	22 (9, 36)	3846 (3210, 4481)
Household status				
Lives with others	51 (46, 57)	3333 (3003, 3662)	29 (19, 38)	4360 (4007, 4713)
Lives alone	52 (39, 66)	1033 (724, 1342)	12 (6, 17)	2484 (1980, 2989)
Socioeconomic classification				
Managerial	50 (43, 57)	2685 (2270, 3101)	19 (10, 27)	3857 (3383, 4331)
Intermediate	57 (46, 69)	3242 (2516, 3967)	21 (10, 33)	4336 (3590, 5083)
Small employers and own account workers	46 (33, 59)	2709 (2001, 3417)	25 (5, 46)	3549 (2830, 4268)
Lower supervisory and technical	50 (36, 64)	2898 (2138, 3657)	14 (−2, 30)	4028 (3184, 4872)
Semiroutine	56 (43, 68)	3284 (2605, 3963)	22 (10, 35)	4250 (3563, 4938)
Tenure				
Rental tenant and other tenure	41 (32, 51)	3112 (2440, 3783)	29 (14, 43)	4503 (3746, 5260)
Owner-occupier	54 (49, 59)	2884 (2618, 3150)	18 (13, 24)	3899 (3615, 4183)
Income quintile				
First quintile	48 (38, 58)	3375 (2754, 3996)	16 (8, 23)	4414 (3769, 5060)
Second quintile	59 (45, 72)	3025 (2413, 3637)	22 (9, 35)	4063 (3407, 4719)
Third quintile	51 (40, 63)	3185 (2497, 3873)	25 (7, 42)	4261 (3541, 4982)
Fourth quintile	56 (45, 67)	2632 (2109, 3155)	26 (7, 46)	3750 (3147, 4354)
Fifth quintile	45 (33, 58)	2294 (1728, 2859)	25 (2, 48)	3325 (2659, 3990)

NOTE. Results using multiply imputed data (34 complete data sets).
Abbreviations: 95% CIs, 95% confidence intervals; GLM, generalized linear model; AD, Alzheimer's disease; VaD, vascular dementia; FTD, frontotemporal dementia; PDD, Parkinson's disease dementia; DLB, dementia with Lewy bodies; Other, unspecified/other; Managerial, managerial, administrative, and professional occupations; Semiroutine, semiroutine and routine.

that study's sample (N = 249) was smaller than ours and recruited people with lower MMSE scores (3–26), who could be in residential care. In a study comparing service use in two small dementia samples in 2001 (N = 122) and 2010 (N = 84) [11], 53% saw a practice nurse, comparable to that found here. However, reported proportions in contact with other services were much higher than for the IDEAL cohort: 26% saw a district nurse, 31% a home care worker, and 54% a social worker. Gustavsson et al. [10] examined

costs of people with Alzheimer's dementia, finding total monthly costs of care in the UK sample (2014/15 prices, uprated from 2007) to be £951 (mild dementia; N = 86) and £1361 (moderate dementia; N = 81). These figures appear comparable to those for the baseline IDEAL sample (mild-to-moderate dementia).

In line with other evidence [1,2,6,41], we found that unpaid care costs of dementia were much higher than paid service costs, accounting for three-quarters of the total. Recent

cost-of-illness calculations [42] estimated that 42% of total costs of all individuals with dementia in England fell to unpaid care; another 25% were social care costs borne by individuals themselves. A recent systematic review [6] reported the share of total costs of dementia attributable to unpaid care as between 60% and 70%. Our estimate is for community-dwelling individuals and is higher than in some studies: in the study by Gustavsson et al. [10], the share of total costs attributable to unpaid care was 64% (mild dementia) and 57% (moderate dementia). Differences between these and our estimates may reflect different methods for calculating unpaid care costs, different sample bases, and shrinkage of paid care available between 2007 and 2014, leaving unpaid carers to fill the gap [14]. Although we valued unpaid care time at minimum wage, the proportion of total costs accounted for by unpaid care would have been even higher had we used a valuation such as national average wage or (taking a replacement cost approach) costs to social care providers of paying home carers for the time. We did not find that unpaid care costs were associated with socioeconomic status, contrary to previous findings [43]. In terms of dementia subtypes and variations in cost, and contrary to the study by Costa et al. [44], we found unpaid care costs higher for Parkinson's-type dementia than for Alzheimer's disease participants.

Our study benefited from a large sample, drawn from across Great Britain, with sufficient numbers of people with less common dementia subtypes to allow comparisons. Limitations include reliance on self-report data with attendant difficulties of reporting biases such as forward and backward telescoping [45–47], particularly in a sample with cognitive impairment (albeit mild to moderate) and for participants with no participating carer. Self-reported carer costs were estimated from bands of carer time; there are more detailed methods of tracking carer time (e.g., time diaries), but they impose heavier respondent burdens. To avoid additional carer effort, information was not collected on their own use of health or social care services. Data were limited to snapshots of retrospective service use during 3 months to minimize inaccuracy of recall [45,47]; analyses based on linked health records over longer retrospective periods are planned.

Compared to having a spousal carer, having a nonspousal carer was associated with a greater likelihood of someone with dementia receiving unpaid care; and the absence of a carer was associated with lower likelihood of receiving unpaid care. These differences could be due in part to differences in cognitive functioning. Although the baseline MMSE scores we observed were not contemporaneous with the period over which costs were reported, nonetheless it is possible that having no carer was associated with higher levels of cognitive functioning and consequently less need for care. Likewise the high prevalence of comorbidity (three-quarters had at least one comorbid condition [22]) may be associated with higher use of services and unpaid care. This could not be investigated with only baseline data

because of potential simultaneity of comorbidity incidence and costs but will be examined with data from multiple cohort sweeps. Most nonspousal carers were adult children, who might be more likely to report providing care than spousal carers. Lack of clarity about the person to whom participants with no participating carer were referring when answering unpaid care questions may have resulted in lower reporting of care by this group (Supplementary Material 1). We subsequently revised the unpaid care questions in later data collections to clarify roles played by participating and other unpaid carers.

5. Conclusions

Estimates of paid and unpaid care costs of IDEAL participants varied by dementia subtype, carer status, and living arrangement. Hospital services accounted for the largest part of paid care costs; unpaid care accounted for three-quarters of total costs. Dementia can increase use of paid and unpaid care for older people with other health conditions [14], and carers do not always get the support they need or would like [48]: the condition requires particular attention from policy makers in funding and planning support for people with dementia, families, and friends. Unpaid carers shoulder most of the costs of supporting people with mild-to-moderate dementia: policy makers should give further consideration to improving financial and instrumental support for carers.

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article; all authors contributed to the critical revision of the article and approved the final version to be published.

Supplementary Data

Supplementary data related to this article can be found at https://doi.org/10.1016/j.trci.2019.09.012.

RESEARCH IN CONTEXT

1. Systematic review: We sought person-level studies examining use and costs of paid and unpaid care for people with dementia living in countries of the United Kingdom. Identified studies had one or more limitations: limited geographical coverage, small samples, samples with a single dementia subtype, or unconfirmed dementia diagnoses.

2. Interpretation: In our cross-sectional study, unpaid care accounted for three-quarters of participants' 3-month total care costs. Parkinson's-type dementia was associated with higher costs than other dementias. Costs for participants with no carer were lower than costs of those with a spousal carer. Unpaid care costs were lower in female than male participants with dementia. The role of unpaid carers is a key driver of care costs; carer gender may influence the supply and costs of care.

3. Future directions: We will test associations between costs and dementia subtype, sex, and carer type alongside indicators of need in planned longitudinal analyses.

References

[1] Prince M, Wimo A, Guerchet M, Ali G-C, Wu DY-T, Prina M, et al. World Alzheimer Report 2015. The global impact of dementia: an analysis of prevalence, incidence, cost and trends. London: Alzheimer's Disease International (ADI); 2015.

[2] Prince M, Knapp M, Guerchet M, McCrone P, Prina M, Comas-Herrera A, et al. Dementia UK: Update. 2nd ed. London: Alzheimer's Society; 2014.

[3] Clare L, Wu Y-T, Jones IR, Victor CR, Nelis SM, Martyr A, et al. A comprehensive model of factors associated with subjective perceptions of "living well" with dementia: findings from the IDEAL study. Alzheimer Dis Associated Disord 2019;33:36–41.

[4] Clare L, Wu Y-T, Quinn C, Jones IR, Victor CR, Nelis SM, et al. A comprehensive model of factors associated with capability to "live well" for family caregivers of people living with mild-to-moderate dementia: findings from the IDEAL study. Alzheimer Dis Associated Disord 2019;33:29–35.

[5] Wimo A, Reed CC, Dodel R, Belger M, Jones RW, Happich M, et al. The GERAS Study: a prospective observational study of costs and resource use in community dwellers with Alzheimer's disease in three European countries—study design and baseline findings. J Alzheimer Dis 2013;36:385–99.

[6] Schaller S, Mauskopf J, Kriza C, Wahlster P, Kolominsky-Rabas PL. The main cost drivers in dementia: a systematic review. Int J Geriatr Psychiatry 2015;30:111–29.

[7] Livingston G, Sommerlad A, Orgeta V, Costafreda SG, Huntley J, Ames D, et al. Dementia prevention, intervention, and care. Lancet 2017;390:2673–734.

[8] Alzheimer's Association. 2018 Alzheimer's disease facts and figures. Alzheimers Dement 2018;14:367–429.

[9] Jones RW, Romeo R, Trigg R, Knapp M, Sato A, King D, et al. Dependence in Alzheimer's disease and service use costs, quality of life, and caregiver burden: The DADE study. Alzheimers Dement 2015; 11:280–90.

[10] Gustavsson A, Brinck P, Bergvall N, Kolasa K, Wimo A, Winblad B, et al. Predictors of costs of care in Alzheimer's disease: a multinational sample of 1222 patients. Alzheimers Dement 2011;7:318–27.

[11] Gilbert C, Wilcock J, Thune-Boyle I, Iliffe S. A comparison of service use by people with dementia in two samples a decade apart. Dementia 2015;16:96–107.

[12] Dodel R, Belger M, Reed C, Wimo A, Jones RW, Happich M, et al. Determinants of societal costs in Alzheimer's disease: GERAS study baseline results. Alzheimers Dement 2015;11:933–45.

[13] Gage H, Cheynel J, Williams P, Mitchell K, Stinton C, Katz J, et al. Service utilisation and family support of people with dementia: a cohort study in England. Int J Geriatr Psychiatry 2014;30:166–77.

[14] Bennett HQ, Norton S, Bunn F, Robinson L, Rait G, Goodman C, et al. The impact of dementia on service use by individuals with a comorbid health condition: a comparison of two cross-sectional analyses conducted approximately 10 years apart. BMC Med 2018; 16:114.

[15] Knapp M, Chua KC, Broadbent M, Chang CK, Fernandez JL, Milea D, et al. Predictors of care home and hospital admissions and their costs for older people with Alzheimer's disease: findings from a large London case register. BMJ Open 2016;6:e013591.

[16] National Institute for Health and Care Excellence. Dementia: Assessment, Management and Support for People Living with Dementia and their Carers. NICE Guideline 97. Methods, Evidence and Recommendations. London: National Institute for Health and Care Excellence; 2017. p. 418.

[17] Department of Health, London. Prime Minister's challenge on dementia: delivering major improvements in dementia care and research by 2015. 2012. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf. Accessed December 5, 2018

[18] Clare L, Nelis SM, Quinn C, Martyr A, Henderson C, Hindle JV, et al. Improving the experience of dementia and enhancing active life—living well with dementia: study protocol for the IDEAL study. Health Qual Life Outcomes 2014;12:164.

[19] Silarova B, Nelis SM, Ashworth RM, Ballard C, Bienkiewicz M, Henderson C, et al. Protocol for the IDEAL-2 longitudinal study: following the experiences of people with dementia and their primary carers to understand what contributes to living well with dementia and enhances active life. BMC Public Health 2018;18:1214.

[20] National Institute for Health Research. Available at: https://www.joindementiaresearch.nihr.ac.uk/content/researchers. 2019. Accessed March 2, 2018.

[21] Beecham JK, Knapp MRJ. Costing psychiatric interventions. In: Thornicroft G, Brewin C, Wing JK, eds. Measuring Mental Health Needs. 2nd ed. London: Gaskell; 2001. p. 220–4.

[22] Nelis SM, Wu YT, Matthews FE, Martyr A, Quinn C, Rippon I, et al. The impact of comorbidity on the quality of life of people with dementia: findings from the IDEAL study. Age Ageing 2019; 48:361–7.

[23] Wu YT, Clare L, Hindle JV, Nelis SM, Martyr A, Matthews FE, et al. Dementia subtype and living well: results from the Improving the

experience of Dementia and Enhancing Active Life (IDEAL) study. BMC Med 2018;16:140.

[24] Wu YT, Clare L, Jones IR, Martyr A, Nelis SM, Quinn C, et al. Inequalities in living well with dementia—the impact of deprivation on well-being, quality of life and life satisfaction: results from the improving the experience of dementia and enhancing active life study. Int J Geriatr Psychiatry 2018;33:1736–42.

[25] Martyr A, Nelis SM, Quinn C, Rusted JM, Morris RG, Clare L, et al. The relationship between perceived functional difficulties and the ability to live well with mild-to-moderate dementia: findings from the IDEAL programme. Int J Geriatr Psychiatry 2019;34:1251–61.

[26] Office for National Statistics. The National Statistics Socio-economic Classification: (Rebased on the SOC2010) User Manual. Standard Occupational Classification 2010, Vol. 3. Basingstoke: Palgrave Macmillan; 2010.

[27] Curtis L, Burns A. Unit Costs of Health and Social Care 2015. Canterbury: Personal Social Services Research Unit; 2015.

[28] Department of Health. National Schedule of Reference Costs 2014-15. London: Department of Health; 2015.

[29] Health and Social Care Information Centre. Prescription Cost Analysis England 2014. Health and Social Care Information Centre; 2015.

[30] Curtis L. Unit Costs of Health and Social Care 2012. Canterbury: Personal Social Services Research Unit; 2012.

[31] Koopmanschap MA, van Exel JN, van den Berg B, Brouwer WB. An overview of methods and applications to value informal care in economic evaluations of healthcare. Pharmacoeconomics 2008; 26:269–80.

[32] Office for National Statistics. Annual Survey of Hours and Earnings: 2014 Provisional Results. Statistical Bulletin. London: Office for National Statistics; 2014.

[33] StataCorp. STATA Multiple-Imputation Reference Manual: Release 15. College Station: StataCorp LP; 2017.

[34] StataCorp. Stata: Release 15. Statistical Software. College Station: StataCorp LP; 2017.

[35] McCullagh P, Nelder JA. Generalized Linear Models. London: Chapman and Hall; 1983.

[36] Belotti F, Deb P, Manning WG, Norton EC. twopm: Two-part models. Stata J 2015;15:3–20.

[37] Li KH, Meng XL, Raghunathan TE, Rubin DB. Significance levels from repeated P-values with multiply-imputed data. Stat Sinica 1991;1:65–92.

[38] Rubin DB. Multiple Imputation for Nonresponse in Surveys. Chichester: Wiley; 1987.

[39] Del Bono E, Sala E, Hancock R. Older carers in the UK: are there really gender differences? New analysis of the individual sample of anonymised records from the 2001 UK Census. Health Soc Care Community 2009;17:267–73.

[40] Lenox-Smith A, Reed C, Lebrec J, Belger M, Jones RW. Resource utilisation, costs and clinical outcomes in non-institutionalised patients with Alzheimer's disease: 18-month UK results from the GERAS observational study. BMC Geriatr 2016;16:195.

[41] Bakker C, de Vugt ME, van Vliet D, Verhey FR, Pijnenburg YA, Vernooij-Dassen MJ, et al. The use of formal and informal care in early onset dementia: results from the NeedYD study. Am J Geriatr Psychiatry 2013;21:37–45.

[42] Wittenberg R, Knapp M, Hu B, Comas-Herrera A, King D, Rehill A, et al. The costs of dementia in England. Int J Geriatr Psychiatry 2019; 34:1095–103.

[43] Hojman DA, Duarte F, Ruiz-Tagle J, Budnich M, Delgado C, Slachevsky A. The cost of dementia in an unequal country: the case of Chile. PLoS One 2017;12:e0172204.

[44] Costa N, Ferlicoq L, Derumeaux-Burel H, Rapp T, Garnault V, Gillette-Guyonnet S, et al. Comparison of informal care time and costs in different age-related dementias: a review. Biomed Res Int 2013; 2013:852368.

[45] Bhandari A, Wagner T. Self-reported utilization of health care services: improving measurement and accuracy. Med Care Res Rev 2006;63:217–35.

[46] Evans CJ, Crawford B. Data collection methods in prospective economic evaluations: how accurate are the results? Value Health 2000; 3:277–86.

[47] Thorn JC, Coast J, Cohen D, Hollingworth W, Knapp M, Noble SM, et al. Resource-use measurement based on patient recall: issues and challenges for economic evaluation. Appl Health Econ Health Pol 2013;11:155–61.

[48] Carter D, Rigby A. Turning Up the Volume: Unheard Voices of People with Dementia. London: Alzheimer's Society; 2017.