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

Authors

Catherine Henderson, PhD[1], Martin Knapp, PhD[1], Sharon M Nelis, PhD [2], Catherine Quinn, PhD [2], Anthony Martyr, PhD [2], Yu-Tzu Wu, PhD [2], Ian R Jones, PhD [3], Christina R. Victor, PhD [4], James A Pickett, PhD [5], John V Hindle, DSc[2,4], Roy W Jones, MBBS[6], Michael D Kopelman, PhD[7], Fiona E. Matthews, PhD[8], Robin G Morris, PhD[7], Jennifer Rusted, PhD[9], Jeanette M Thom, PhD[10] and Linda Clare, ScD[2] on behalf of the IDEAL programme team.

[1.] Care Policy and Evaluation Centre, London School of Economics and Political Science, London, UK
[2.] REACH: The Centre for Research in Ageing and Cognitive Health, University of Exeter, Exeter, UK
[3.] Wales Institute for Social and Economic Research, Data and Methods, Cardiff University, Cardiff, UK
[4.] College of Health and Life Sciences, Brunel University London, UK
[5.] Alzheimer's Society, London, UK
[6.] The Research Institute for the Care of Older People (RICE), Bath, UK
[7.] King's College London Institute of Psychiatry, Psychology and Neuroscience, London, UK
[8.] Institute for Health and Society, Newcastle University, Newcastle upon Tyne, UK
[9.] School of Psychology, University of Sussex, Brighton, UK
[10.] School of Medical Sciences, University of New South Wales, Australia
Corresponding author: Catherine Henderson, Care Policy and Evaluation Centre, London School of Economics and Political Science, Houghton St, London, UK, WC2A 2AE.
Email: c. henderson@lse.ac.uk; Telephone: +44 20 79557247

Abstract

INTRODUCTION:

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

METHODS:

We analysed IDEAL 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 socio-demographic sub-groups.

RESULTS:

Use of services apart from primary and outpatient hospital care was low. Unpaid care accounted for three-quarters of total costs (mean £4008 (SE £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. 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 sub-type, carer status, and living arrangement. Policy-makers should recognise 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.

1. Introduction

In the UK, 850,000 people live with dementia; in parallel with global trends, this number looks set to double in the next twenty 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 world-wide [1]. While 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 socio-demographic 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)* programme [18, 19] (dataset version 2.0), following yearly for up to six 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 (2014–11684) and is registered with the UK Clinical Research Network (16593).

Participants were recruited from 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 to August 2016) using face-to-face interviews with participants. Carers self-completed separate questionnaires. One section, on paid and unpaid care, was administered to both participant and carer, if the latter was available.

Sample size was powered on planned structural equation model analyses of measures of capability of living well and were large enough to permit sub-group analyses for age, sex,

dementia sub-type, 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 summarised below (details in Supplementary File 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 Services 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 Socio-demographic characteristics

We examined associations of baseline costs with socio-demographic characteristics and dementia sub-type. We do not focus on dementia-related needs here (ADL, cognition, behaviour, comorbidities), as these were measured at baseline and therefore up to 3 months *after* costs were incurred (explored elsewhere in IDEAL [22-25]). Participant characteristics examined were: age groups, sex, dementia sub-type, education, National Statistics Socio-Economic Classification 5 variable version (NS-SEC 5) [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 non-spousal (friend/other family)). Separate regressions examined associations of lost working time costs with carer characteristics: age groups, sex, carer status, socio-economic 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 over 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 over 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 sub-totals (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 file 1. Proportions of cases missing service use data ran at 4-5%; 9% of cases were missing data on care provided by carers; 6-8% of cases were missing carer questionnaire data on lost earnings. Imputation by chained equations was carried out in Stata 15 [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 socio-economic status, lost earnings and employment.

2.6 Analyses

Differences in costs for socio-demographic and diagnostic sub-groups were examined through multivariate regressions. Generalised linear models (GLM) [35] were fitted to cost sub-categories and total costs, assuming gamma distribution and log-link function to accommodate anticipated skew in costs 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 non-zero costs (henceforth 'models of receipt'); in the second, GLM 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 MI suite of commands [33] to obtain a p-value across regression estimates from multiply-imputed datasets. A 5% significance level was applied to tests of model coefficients. We estimated average marginal effects (AME; henceforth *estimated means)*, for each level of each factor at observed values of each case. Differences in costs between sub-groups were judged significant if 95% confidence intervals of sub-group estimated means did not overlap. Results of analyses conducted on each complete dataset generated by imputation were combined using Rubin's rules [38].

3. Results

3.1 Sample

While more than half of participants were aged >74, 9% were younger than 65 (Table 2). Mean age was 76.4 (SD 8.6). There were more men (56%) than women. More than half of 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 to 24.50 vs. 23.05, 95% CI 22.83 to 23.25, t = 4.34, p <0.001, N=1474). Carers were younger than participants (69.1 years, SD 11.1); 69% were female. On NS-SEC 5, 43% of carers (and 41% of participants) were in the top category. While 53% of carers aged <65 were in paid employment, this proportion dropped to 12% in the 65-69 age-band and less than 3% in the 70+ age-bands. Most non-spousal 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

Over the prior 3 months, 65% of participants saw a GP, 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 over half had hospital outpatient or day-case treatment; 14% visited an emergency department (A&E). Only 6% had an inpatient admission, staying a week on average. Seventy-one per-cent 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 centre attendance was modest (12%) but day centre users averaged 18 attendances over 3 months or 2.6 times weekly; day centre costs constituted the largest element of social care costs (£133, 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 file 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 over 3 months (i.e. 36 hours per week). Thirty per-cent (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 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 Sub-total and total costs

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

Almost all participants (99%) incurred some costs over 3 months (Supplementary file 2, Figure S2.1). A third had some community social care costs. Sub-total and total costs of paid and unpaid care were summarised by socio-demographic and diagnostic sub-groups (Supplementary file 2, Tables S2.2–S2.3). Mean total costs for participants with Parkinson's dementia (Figure 1) were substantially greater than costs for participants with other dementias. Examining carer data on lost working time (Supplementary file 2, Table S2.4), costs of carers aged <65 were more than six times higher than those aged >74, as might be expected.

Figure 1. Paid care costs and total costs of paid, out-of-pocket and unpaid care (£) of participants with dementia, by diagnostic sub-type

3.4   Model results

Relationships between paid and unpaid care and socio-economic and diagnostic factors were explored in two-part models (Supplementary file 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 sub-type 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, occupational class 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 sub-type was associated with primary and community care, mental health care, hospital care and medication costs.

Examining marginal effects of diagnostic sub-types (Table 3), costs of primary and community health care, social care, and medication were highest for those with Parkinson's dementia compared to other dementias. Mental health costs were higher in under-65s than in other age groups. Social care costs of participants with non-spousal 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 (£852) and 2.2 times those of participants with vascular dementia (£890). Costs of participants with non-spousal 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 non-spousal 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 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 non-spousal 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 under 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 working-age carers, 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 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 non-spousal 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. Estimates for participants without participating carers were £2467, less than half of those of participants with non-spousal 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 GP (65%) and half attended outpatients appointments; use of other individual health and care services was low. Dementia sub-type 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 between spousal, non-spousal and no–carer groups. Total costs for women, adjusting for diagnosis, socio-economic 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 carers sample 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 female and this preponderance may have boosted overall unpaid care costs estimates.

Numerous studies have reported similar proportions of female carers of people with dementia [47].

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 that study's sample (N=249) was smaller than ours and recruited people with lower MMSE scores (3 to 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, 40] 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 [41] 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 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]. While 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 socio-economic status, contrary to previous findings [42]. In terms of dementia sub-types and variations in cost, and contrary to Costa et al. [43], 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 sub-types to allow comparisons. Limitations include reliance on self-report data with attendant difficulties of reporting biases such as forward and backward telescoping [44-46], 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 over 3 months to minimise inaccuracy of recall [44, 46]; analyses based on linked health records over longer retrospective periods are planned.

Having a non-spousal carer was associated with a greater likelihood of someone with dementia receiving unpaid care; 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. While 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 due to potential simultaneity of comorbidity incidence and costs, but will be examined with data from multiple cohort sweeps. The majority of non-spousal 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 (Supplementary file 1). We subsequently revised the unpaid care questions for 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 sub-type, 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

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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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Author Contribution

Authors MK, SMN, CQ, AM, IRJ, CRV, JAP, JVH, RWJ, MDK, RGM, JR, JMT and LC were involved in the original conception and design of the study. CH and MK were responsible for design of the economic data analysis and interpretation of results. CH conducted the

analyses. CH drafted the article; all authors contributed to the critical revision of the article

and approved the final version to be published.

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Figure legends

Figure 1
Note: costs derived from participant with dementia questionnaires. AD: Alzheimer's disease; VaD: vascular dementia; FTD: fronto-temporal 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
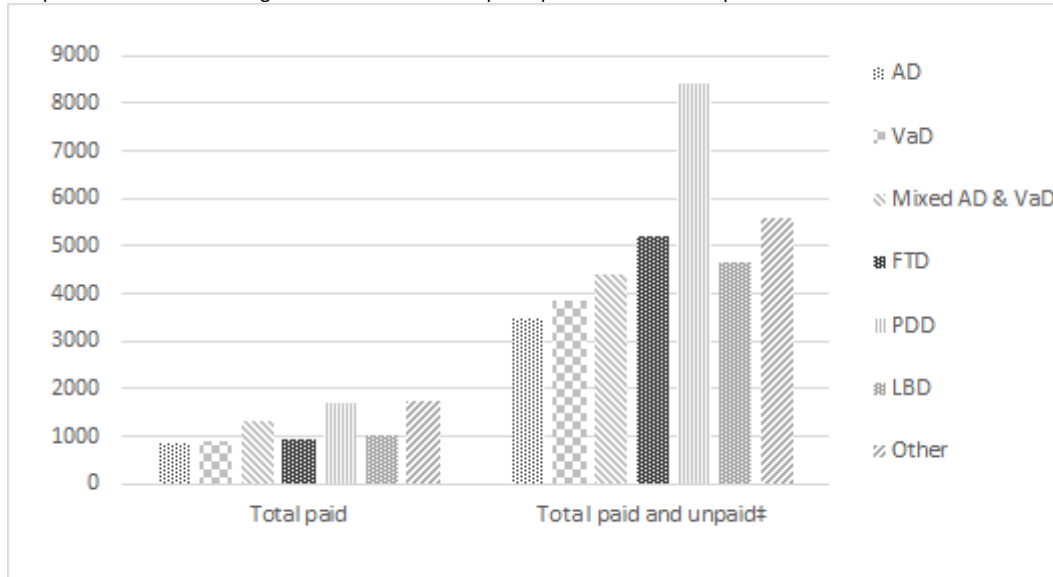
Tables

Table 1. Mean costs (£) of care over prior three months.

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

Total paid and unpaid carer costs‡‡	4008	130	1547

Note: Results of multiply-imputed data (34 complete datasets).

* Includes costs of respite in residential accommodation.

† Costs of dementia and CNS 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 behaviour 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 includes: 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, lost working time costs to other friends and relatives.

Table 2. Demographic and socio-economic characteristics

Participants with dementia (N=1547)

Age band (years)	N	%
<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
Socio-economic classification*	N	%
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
Semi-routine and routine occupations	313	20
Lives alone (self-reported)*	N	%
No	1241	80
Yes	306	20
Income quintiles†	N	%
First quintile (lowest)	431	28
Second quintile	277	18
Third quintile	257	17
Fourth quintile	330	21
Fifth quintile (highest)	252	16
Education	N	%
No qualification	430	28
School certificate age 16	274	18
School certificate age 18	529	34
College-level	314	20
Tenure	N	%
Rents and other forms of tenure	249	16
Owns	1298	84

Carers (N=1283)

Age band (years)	N	%
<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
Socio-economic classification*	N	%
Managerial, administrative and professional occupations	549	43
Intermediate occupations	335	26
Small employers and own account workers	92	7
Lower supervisory and technical occupations	92	7
Semi-routine and routine occupations	216	17
Education*	N	%
No qualification	275	21
School certificate age 16	285	22
School certificate age 18	390	30
College-level	333	26

Notes: Socio-economic classification=National Statistics Socio-Economic Classification 5 levels

* Proportions and numbers of observations estimated from imputed datasets.

† Joint income of the person with dementia and spouse/partner.

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

| | All | | Users | | | | |
| | Intensity | Costs (£) | Observations* | | | Intensity | Costs (£) |
Item	Mean (SE)	Mean (SE)	Min.	Max.	%	Mean (SE)	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)
Physio/OT	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†							
CMH 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)

	All		Users				
	Intensity	Costs (£)	Observations*			Intensity	Costs (£)
Item	Mean (SE)	Mean (SE)	Min.	Max.	%	Mean (SE)	Mean (SE)
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 centre 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)

| | All | | Users | | | | |
| | Intensity | Costs (£) | Observations* | | | Intensity | Costs (£) |
Item	Mean (SE)	Mean (SE)	Min.	Max.	%	Mean (SE)	Mean (SE)
Dementia	0.75 (0.01)	52 (3)	1096	1109	71	1.05 (0.01)	71 (4)

Unpaid care and travel to appointments

Unpaid carer

| | All | | Users | | | | |
	Intensity	Costs (£)	Min.	Max.	%	Intensity	Costs (£)
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

| | All | | Users | | | | |
	Intensity	Costs (£)	Min.	Max.	%	Intensity	Costs (£)
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

| | All | | Users | | | | |
	Intensity	Costs (£)	Min.	Max.	%	Intensity	Costs (£)
Number of trips	1.45 (0.08)	10 (2)	752	765	49	2.95 (0.13)	21 (3)

Notes: People with dementia questionnaire N=1547; carers questionnaire N=1283 unless otherwise indicated. Results of multiply-imputed data (34 complete datasets).
Abbreviations: CNS=Central Nervous System.
* The number of cases with use of each item varied over the 34 complete datasets 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 datasets.
† Items are face-to-face visits unless otherwise stated; items report responses from the participant with dementia questionnaire dataset unless otherwise stated.

‡ Respite in residential homes.

§ Outpatient visits and procedures.

¶ Hours 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 non-zero costs (minimum N=1352, maximum N=1375) was £3087 (SE £119).

** Days lost over the prior three months (variable from the carer questionnaire).

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

Table 4. Marginal means (95% confidence intervals) (£) 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)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	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								
w<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)

Variable	Primary care Mean (95% CI)	Mental health Mean (95% CI)	Social care Mean (95% CI)	Day services Mean (95% CI)	Hospital Mean (95% CI)	Medications Mean (95% CI)	Equipment Mean (95% CI)	Total paid Mean (95% CI)
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)

Variable	Primary care	Mental health	Social care	Day services	Hospital	Medications	Equipment	Total paid
	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)
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

Variable	Primary care	Mental health	Social care	Day services	Hospital	Medications	Equipment	Total paid
	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)
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 cert. 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 cert. 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)

Variable	Primary care Mean (95% CI)	Mental health Mean (95% CI)	Social care Mean (95% CI)	Day services Mean (95% CI)	Hospital Mean (95% CI)	Medications Mean (95% CI)	Equipment Mean (95% CI)	Total paid Mean (95% CI)
Socio-economic 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)
Semi-routine	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								

Variable	Primary care Mean (95% CI)	Mental health Mean (95% CI)	Social care Mean (95% CI)	Day services Mean (95% CI)	Hospital Mean (95% CI)	Medications Mean (95% CI)	Equipment Mean (95% CI)	Total paid Mean (95% CI)
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)
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)

Variable	Primary care	Mental health	Social care	Day services	Hospital	Medications	Equipment	Total paid
	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)
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)

Notes: Results using multiply imputed data (34 complete datasets).

Abbreviations: GLM=generalised linear model; AD=Alzheimer's disease; VaD= vascular dementia; FTD= fronto-temporal dementia; PDD Parkinson's disease dementia; DLB dementia with Lewy bodies; Other= Unspecified/other; School Cert. 16=School certificate age 16; School Cert. 18=School certificate age 18; Managerial= Managerial, administrative and professional occupations; Small employers= Small employers and own account workers; Lower supervisory= Lower supervisory and technical; Semi-routine=Semi-routine and routine.

Table 5. Marginal means (95% confidence intervals) (£) 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)	Mean (95% CI)	Mean (95% CI)	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				
<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)

Variable	Out-of-pocket	Unpaid care time	Lost work time	Total paid and unpaid
Dementia sub-type				
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, 11763)
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)

Variable	Out-of-pocket	Unpaid care time	Lost work time	Total paid and unpaid
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)
Socio-economic 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 empl. & own	46 (33, 59)	2709 (2001, 3417)	25 (5, 46)	3549 (2830, 4268)
Lower super. & tech.	50 (36, 64)	2898 (2138, 3657)	14 (-2, 30)	4028 (3184, 4872)
Semi-routine	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)

Variable	Out-of-pocket	Unpaid care time	Lost work time	Total paid and unpaid
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)

Notes: Results using multiply imputed data (34 complete datasets).

Abbreviations: GLM=generalised linear model; AD=Alzheimer's disease; VaD= vascular dementia; FTD= fronto-temporal dementia; PDD Parkinson's disease dementia; DLB dementia with Lewy bodies; Other= Unspecified/other; School Cert. 16=School certificate age 16; School Cert. 18=School certificate age 18; Managerial= Managerial, administrative and professional occupations; Small empl. & own= Small employers and own account workers; Lower super. & tech.= Lower supervisory and technical; Semi-routine=Semi-routine and routine.