# The use and costs of paid and unpaid care for people with dementia: longitudinal findings from the IDEAL cohort programme

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# ABSTRACT

Background: The drivers of costs of care for people with dementia are not well understood and little is known on the costs of care for those with rarer dementias.

Objective: To characterise use and costs of paid and unpaid care over time in a cohort of people with dementia living in Britain. To explore the relationship between cohort members' demographic and clinical characteristics and service costs.

Methods: We calculated costs of health and social services, unpaid care, and out-of-pocket expenditure for people with mild-to-moderate dementia participating in three waves of the IDEAL cohort (2014-2018). Latent growth curve modelling investigated associations between participants' baseline sociodemographic and diagnostic characteristics and mean weekly service costs.

Results: Data were available on use of paid and unpaid care by 1537 community-dwelling participants with dementia at Wave 1, 1199 at Wave 2, and 910 at Wave 3. In models of paid service costs, being female was associated with lower baseline costs and living alone was associated with higher baseline costs. Dementia subtype and caregiver status were associated with variations in baseline costs and the rate of change in costs, which was additionally influenced by age.

Conclusion: Lewy body and Parkinson's disease dementias were associated with higher service costs at the outset, and Lewy body and frontotemporal dementias with more steeply increasing costs overall, than Alzheimer's disease. Planners of dementia services should consider the needs of people with these relatively rare dementia subtypes as they may require more resources than people with more prevalent subtypes.

*Key Words*

Dementia, health services, social services, unpaid caregivers, frontotemporal dementia, Parkinson's disease dementia, dementia with Lewy bodies

## INTRODUCTION

People living with dementia often have multiple needs for support in their everyday activities, as well as other conditions that require skilled health care. Many people with dementia rely heavily on family and other unpaid caregivers [1]. Taken together, the health, social and unpaid care costs of dementia are already high and are projected to grow considerably over the coming decades as global populations age. For example, more than 650,000 people in England are living with the condition, a number set to reach 1.35 million by 2040 [2]. Recent estimates put the costs of caring for people living with dementia in England at £24.2 billion annually [3]. Projections suggest that, under current funding and service arrangements, the costs of health and social services for dementia will more than double in the next twenty years, accounting for 1.9% of GDP by 2040 [2].

Few studies have explored how those costs change over time for individuals with dementia as their symptoms worsen and their needs for support increase. Thus, little evidence exists on receipt of care services by people with different dementia diagnoses, including low-prevalence diagnoses, yet this is exactly the kind of information needed by health and social care system decision-makers – and indeed by people with dementia and families – to help plan individual and collective responses to changing needs.

In this study, we describe the use and costs of paid and unpaid care over time for a cohort of people in Britain living with dementia; and explore variations in service costs in relation to demographic and clinical characteristics of cohort members.

*Overview of the UK health and social care system*

Health care in the UK is generally provided free at the point of access. The National Health Service (NHS) is largely funded from general taxation as well as hypothecated taxes collected from working people and employers[4]. Funding for adult social care (home-based personal assistance, day care, residential and nursing home care) is raised through central taxation by national governments and local taxation by municipalities (usually known as local authorities or 'councils'). Local authority social services departments across the countries of the UK have legal responsibilities to provide 'social care' to people who meet certain eligibility criteria. These criteria are set nationally but applied according to social services departments' needs- and means-assessments (exceptions to means-testing exist, for instance, low-cost assistive devices and home adaptations are provided free of charge). Arrangements vary between countries of the UK and between individual local authorities. In Scotland and Northern Ireland, councils fund free personal care for older people living at home [5]; and in Wales, councils' weekly charges for home-based social care services are capped [6]. In England, councils are responsible for providing access to information about locally available social care services and for ensuring that services are available to prevent, delay or reduce the care needs of local people [7]. There is no cap for catastrophic social care costs. After years of austerity, the social care system in many parts of the UK is restricted to those in the highest need. Many people fund all or part of their social care. Close to half of English care home residents [8, 9] are 'self-funders'. Social care provision in the UK is marked by local, regional and national inequalities of access[10-12], leaving many older people with unmet needs [13]. Lacking effective treatments for dementia, people with the condition and their caregivers will continue to need substantial social and instrumental care and support. Unless a person with dementia has significant co-existing medical conditions, she is unlikely to qualify for an NHS-funded care package (free of user charges). People with dementia can face substantial or even catastrophic care costs. That people with dementia and their families are penalised for having the 'wrong kind' of health needs has been called a 'dementia tax' [14].

## METHODS

### *Design*

We used Wave 1 to 3 data (collected in 2014–6, 2015–7, and 2016–8 respectively) from the *Improving the experience of Dementia and Enhancing Active Life (IDEAL)* programme [15, 16] (Wave 1 dataset version 4.5; Wave 2 and Wave 3 version 1.5). This cohort study followed people with mild-to-moderate dementia from baseline (hereafter 'participants') and, where available, primary caregivers (relatives/friends providing unpaid support to the participants). The first phase of the study 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).

IDEAL study procedures and baseline characteristics of the sample are detailed elsewhere [15], as are baseline service use and costs analyses [17]. Participants were recruited from across mainland Britain (England, Wales and Scotland). To be eligible at Wave 1, participants had to be living in the community, have a clinical diagnosis of dementia, and score 15 or above on the Mini-Mental State Examination (MMSE) [18]. This MMSE cut-off was chosen so that the sample would represent people with dementia with a broad range of dementia severity over the follow-up period. Thereafter, participants were followed up every year in their place of residence, including care home settings if they had moved during the study period. A median of 12.00 months elapsed between questionnaire administrations. A mean of 12.36 months elapsed between waves 1 and 2, and 11.67 months between waves 2 and 3. At each wave, people living with dementia completed questionnaires in face-to-face interviews; caregivers self-completed their questionnaires. The cohort study was powered to examine structural equation models (SEM) of measures of living well (quality of life, satisfaction with life, and well-being) in key sub-groups: age group, sex, living alone/with others, clinical subtype of dementia, and the relationship between participant and caregiver [15].

### *Measures*

#### Use of paid and unpaid care

At Wave 1, where a caregiver was available, participant and caregiver (dyad) jointly completed questions from the participant questionnaire taken from the Client Services Receipt Inventory (CSRI) [19] on paid care (health and social care, medications, equipment and adaptations) and unpaid care activities. People with dementia without a participating caregiver completed these questions on their own. In the caregiver questionnaire, caregivers additionally completed questions taken from the CSRI on work time lost to unpaid caregivers because of caring responsibilities.

Structuring of resource use and costs questions was modified for subsequent waves. Changes were made to allow simultaneous completion of participant and caregiver questionnaires in a shorter time (because interviews were spread over a maximum of two sessions, rather than three as at Wave 1) and to ensure that participants with dementia were only asked to complete questions on paid and unpaid care if no caregiver was participating [17]. Proxy-completed questions on service use by the person with dementia and provision of unpaid care to the person with dementia were included in the caregiver questionnaires. The dyad completed questions in the participant questionnaire on medication use with a predetermined list of medications (as in Wave 1) because it was easier for the interviewer to record the required information from medication containers or repeat prescriptions (some caregivers were interviewed in other locations without access to these items). Caregivers self-completed questions about working time lost because of providing unpaid care; also, if the participant was not involved at that wave, they completed three brief yes/no questions on medication use by the participant with dementia (use of any prescription medications, and medications specifically for depression or dementia). Lastly, participants without a caregiver were asked at Waves 2 and 3 to report receipt of help from relatives and friends with tasks they found difficult or could not do. Thus, the source of use and costs data diverged between first and subsequent waves as most of these questions moved from the participant to the caregiver questionnaires.

### *Participant characteristics*

Key sub-groups of participant demographic and diagnostic characteristics were examined: age, sex, living status, diagnostic subtype, and caregiver status. Dementia subtypes were Alzheimer's disease (AD), vascular dementia (VaD), mixed (AD and VaD), frontotemporal dementia (FTD), Parkinson's disease dementia (PDD), dementia with Lewy bodies (DLB) and a category combining people with unspecified and other dementias. A binary variable for living alone/with others at Wave 1 was derived from a categorical variable of living arrangements verified against other sources [20]; at subsequent waves the living alone/with others variable was based on the participant’s self-reported status. A variable for caregiver status was defined as: no participating caregiver, spousal caregiver (i.e. spouse or partner participating in the study) or non-spousal caregiver (i.e. friend or other family member participating in the study). Participant age was treated as a continuous variable.

*Costing methods*

Methods for calculating costs at Wave 1 [17] were adapted for subsequent Waves. As at Wave 1, we used nationally applicable unit costs to calculate costs of community health and social care contacts and equipment and adaptations [21]. Prices are in 2014/15 British pounds sterling throughout (the first year of the IDEAL study). We calculated hospital costs by applying average costs per service category (inpatient stays, outpatient and emergency department visits), drawing on the National Health Service (NHS) Reference Costs [22]. We used the average cost of outpatient visits across consultant and non-consultant follow-up contacts (all adult specialties) to cost outpatient visits; we applied the average cost of an inpatient bed-day over all non-elective adult specialties to each reported day to calculate inpatient costs. We calculated medication costs applying NHS Prescription Costs Analysis unit costs [23]. We valued unpaid care by caregivers at opportunity cost (UK minimum wage [24]) [25, 26] and valued lost working time by caregivers and other relatives/friends at opportunity cost (national average wage) using Annual Survey of Hours and Earnings data [27].

Sub-total and total costs of services, unpaid care, out-of-pocket expenditure and lost working time were estimated using data from both questionnaire datasets. Cost items were aggregated to the category and total level, but not pooled across participant or caregiver datasets at this point. After multiple imputation, participant and caregiver questionnaire-derived service costs and out-of-pocket costs were added together to give sub-total and total costs across the participating sample, as the service use questions in both questionnaires covered identical services. Unpaid care costs and total societal costs (paid, out-of-pocket and unpaid care) were calculated separately by source: (i) for people with dementia completing the study without a caregiver and (ii) for people with a caregiver in the study (in dyads).

*Missing data and data imputation*

Missingness in individual service use items was reasonably low (between 1% and 6%), whether participant- or informant-completed. Cases that were missing data on unpaid care provided by caregivers (participant questionnaires) ran at 9% at Wave 1; at subsequent waves, 2% and 3% of data were missing in participant questionnaires and 6% and 2% in caregiver questionnaires, respectively. However, the cumulative impact of missing items on calculation of component and total costs was significant: the proportion of missing data ranged from 30% to 40% across waves. Multiple imputation by chained equations was conducted in Stata 16 [28]. The imputation modelling strategy used for baseline data [17] was adapted for the longitudinal analyses (see Supplementary file S1). Modelling assumed that missing responses of cases participating at each wave were missing at random (in other words, that the probability of missingness was conditional on the values of fully observed data rather than those of unobserved data) [29-31]. Missingness due to participant drop-out from the study (i.e., where all data for the Wave were missing for participants with or without a caregiver) was approached by applying inverse probability weights at second and third waves. Multivariate models of drop-out were constructed based on initial univariate analyses, examining significant associations with sociodemographic and needs-related characteristics and service use; the models included all independent variables to be used in analyses of service costs (see Supplementary file S1).

*Analyses*

Descriptive statistics

We summarised the multiply-imputed and inverse-probability weighted costs derived from both participant and caregiver questionnaire data (paid care costs and out-of-pocket costs), costs calculated only from caregiver questionnaire data (lost working time, unpaid care provided by the caregiver and by other relatives/friends at Waves 2 and 3) and from participant questionnaire data (unpaid care received from all relatives/friends at Waves 2 and 3). Costs were summarised in terms of their means and standard errors.

Inferential statistics

A generalised linear latent growth model [32] was fitted by maximum likelihood estimation to the complete costs datasets generated by the multiple imputation process, using the *gsem* programme in Stata 16. The maximum likelihood function for estimating Generalised SEM (GSEM) assumes conditional normality across observed and latent variables. Estimates are made on the basis of all observations available for each equation [33]. Thus, all non-missing responses at each wave were retained in the analysis. The latent growth curve approach enables the examination of not only the variation in participants' baseline levels of cost, but also variations in their trajectories over time. First, an unconditional growth model was fitted and then a conditional model, with baseline demographic sub-groups as covariates: age, sex, living status, diagnostic subtype, and caregiver status.

The conditional growth model allows the extent to which these characteristics explain the variance in baseline (initial level) costs and the variance in the rate of change (slope) over subsequent waves [32, 34] to be quantified. Overall weights (mean 1.346, SD 0.592, range 0 - 6.38) were applied. GSEM with gamma family and log link were selected as best fitting (see Supplementary file, S1.3). In this multiplicative model, costs is the dependent variable, and the exponentiated model coefficients can be interpreted as the ratio of each subgroup's mean costs to the reference category mean in the case of categorical variables, and the percentage change in cost for a unit increase/decrease in that covariate in the case of continuous variables [35, 36].

Average marginal effects of each demographic sub-group were estimated for each wave. Model estimates and marginal effects generated from each multiply-imputed complete dataset were combined following Rubin [37]. Tests of restrictions were applied across multiply-imputed datasets and the p-values pooled [28, 38]. A standard significance level of 5% was applied to all tests.

## RESULTS

### *Sample*

In Wave 1, 1537 participants and 1277 dyads completed questionnaires; completion rates decreased in subsequent waves for reasons summarised in Figure 1. Eight dyads that did not complete baseline questionnaires but participated at later timepoints were excluded from the longitudinal analyses. A total of 1199 people completed either a participant or a carer questionnaire at Wave 2; the total was 910 at Wave 3. Table S1.2 illustrates the source of responses to questions on paid and unpaid care and the transitions in responders between waves. For instance, at Wave 1, 1,277 dyads jointly completed questions in the Participant questionnaire on participants' use of paid and unpaid care.  Of those dyads, 941 (74%) participated at Wave 2; however at this wave caregivers reported on participant service use in the Caregiver questionnaire. At Wave 3, 692 dyads participated (caregivers again reporting on participant service use), almost all of whom (97%, N=672) had participated as dyads at Wave 2. Only a small number of people participating as dyads switched between waves to only the participant or only the carer participating. Switches from participant-only to caregiver-only participation were very rare.

Participant and caregiver sample composition showed relatively little change over time (Table 1). The sample of people with dementia that continued to participate in the study at Wave 3 was slightly younger than that at Wave 1. There were more male than female participants (approximately 56% across Waves) whereas most caregivers were female spouses or partners. The majority of carers were not in paid employment; 71% (N=674) were in retirement at Wave 1.

On average, study participants had mild dementia as assessed on the MMSE at each of the three waves. However, while half the sample scored between 21 and 26 on the MMSE (mild dementia) at Wave 1, by Wave 3 the spread of scores was wider, with half the sample falling between 17 (moderate) and 25 (mild) on the measure. Participants without a caregiver had higher MMSE scores than dyadic participants (median scores, waves 1-3: participants without a caregiver: 24, 24 and 23; dyadic participants:  23, 22 and 21).

### *Use and costs of individual resource items*

#### Paid care services, medications, assistive equipment and adaptations

Extent of service use and mean intensity of use at each wave (calculated from unimputed data) are presented separately by source: participants without a caregiver in the study and participant-caregiver dyads (Tables 2 and 3). Participants without a caregiver self-reported service use at each wave. Dyads jointly reported use at Wave 1; and caregivers ‘informant-reported’ use at subsequent waves.

Service use by participants without a caregiver: Proportions of participants reporting making GP office visits were 61%, 54% and 49% across Waves 1 to 3, respectively (Table 2). Having at least one inpatient stay was reported by 7% , 10% and 4% of participants at the first, second and third waves, respectively. Forty-two percent of the sample reported outpatient hospital service use at Wave 1; 33% and 22% reported using these services at Waves 2 and 3, respectively. The proportion receiving home care was fairly consistent over the three waves (18%, 22% and 21%, respectively), as was the proportion using day centres over the three waves (9%, 11% and 13%, respectively). Very few care home admissions (temporary or permanent) were reported by participants without a carer in the study in any wave.

At Wave 1, just over half of participants (23/43 or 53%) reported that they or their families were paying for all their homecare. At Waves 2 and 3, 63% (N=22/35) and 48% (N=11/23) of participants with no caregivers reported paying all home care costs. Proportions of missing data were lower at the first than subsequent waves.

<u>Service use by participants in participant-carer dyads</u>: The proportion of participants making GP office visits was 66%, 70% and 62%, respectively, across the three waves, and thus somewhat higher than that in the sample of participants without a participating caregiver. Inpatient stays were reported to be 5% at Wave 1, and 9% at second and third waves; outpatient hospital services were used by half (51%) at Wave 1 but less than a third (31% and 30%) of dyadic participants at second and third waves, respectively. The proportion of participants receiving home care was 10%, 16% and 20% respectively, across the three waves, while the proportion of participants using day centres ranged between 13% at Wave 1 and 20% at Wave 3. While only 1% of caregivers reported residential or nursing home stays (either on a respite or permanent basis) by the participant at the first wave, more reported stays at the second and third waves (6% and 10%, respectively). Proportions of caregivers reporting that participants or their families were paying all costs of home care at

first, second and third waves were 53% (N=61/115), 53% (N=77/145) and 56% (N=83/149), consistent with use reported in the Wave 1 participant questionnaires.

### Unpaid care and lost working time

At Wave 1, most dyads completing participant questionnaires reported high levels of assistance with activities such as personal care, practical household tasks, finances, medications, appointments, and supervision, amounting to approximately 39 hours weekly across 1009 recipients of care. Almost all caregivers (95%) reported providing assistance at Waves 2 and 3, of about 48 hours (N=787) and 56 hours (N=628) weekly, respectively. Participants without a participating caregiver were asked a single question about receipt of assistance from any relatives or friends in the second and third waves: 53% (N=100) reported assistance amounting to approximately 20 hours a week at Wave 2 and a slightly lower proportion at Wave 3, 48% (N=66), reported approximately 18 hours a week of assistance. Few caregivers reported giving up employment for caring responsibilities over the previous 3 months at any wave (Table 3), but over the three waves 6% to 7% reported reducing hours of employment. Caregivers reported that 8% to 9% of other relatives/friends had cut down on paid work (Table 3).

### Paid and unpaid care costs

Categories and totals of paid care and out-of-pocket costs, and costs of unpaid care and caregivers' lost working time, are presented with the source of the data used for their calculation in Table 4 (results without inverse probability weighting at second and third waves were similar; these are presented for comparison in Table S1.3). At each wave, the mean 3-month costs of unpaid care provided by the main caregiver greatly exceeded any category of service costs, costs of unpaid care provided by other relatives/friends or out-of-pocket expenditure on travel and equipment. Health care and medication costs remained relatively stable over the three waves. In contrast, the costs of respite and permanent stays in care and nursing home increased sharply, while the costs of community-based social services and day-care services showed rises, albeit less markedly. Despite the relatively small proportion of the sample using care homes (as permanent or temporary residents), these costs constituted a quarter of Wave 3 service costs.

Wave 2 total service costs were 29% higher than those at Wave 1 (the upper 95% confidence limit of the mean at Wave 1 did not overlap the lower limit of the mean at Wave 2). Service costs at Wave 3 were 61% greater than those at Wave 1 (95% confidence intervals of the means did not overlap). Wave 3 total unpaid care costs were 1.5 times higher than at Wave 1. The total costs of paid, out-of-pocket and time in unpaid care for participants with dementia who had no caregiver involved in the study were less than half of those of people with a participating caregiver at Wave 1 and this proportion decreased subsequently (Table 4).

### Model results

Relationships between total health and social care costs and socio-economic and diagnostic groups were explored in latent growth curve models. Table 5 gives mean weekly costs over time estimated by unconditional and conditional models. Model covariates were significant on a joint test of significance ($F(22,187\ 220) = 8.07$, $p< 0.001$).

There were differences in the baseline level of costs between certain conditional model covariates: the sexes, dementia subtypes, living arrangement status and caregiver status. Baseline service costs of female participants were 15% lower than those of male participants, while service costs of participants living alone were 35% higher than those living with others. Costs of participants with mixed dementia and DLB had costs half again higher than AD, and costs of people with PDD were three times those of people with AD.

Three characteristics – age in years, having a participating non-spousal caregiver (other family or friend) and two diagnostic subtypes - were associated with changes in the rate of costs over time. The rate of increase in weekly costs of participants was greater for participants with FTD and with DLB than for participants with AD between waves. An additional year of age was associated with an increase of 0.8% in the rate of weekly costs. Total costs rose more steeply for participants with non-spousal caregivers than for those with spousal caregivers. However, variances of both intercept and slope in the conditional model were significant while the covariance between intercept and slope growth factors was not. This indicates the presence of considerable heterogeneity in levels and trajectories of cost; for instance, there could be some individuals with low baseline costs that increased over time and some with high baseline costs that decreased over time [39].

Marginal means of sub-groups (Figure 2, Table S1.4) were estimated from the conditional model to illustrate the impact of characteristics on variations in the level and slope of service costs; between-group differences that were significant at the 5% level are reported in Table S1.5. Weekly costs of paid care for participants with PDD grew from £167 at the first wave to £268 at the second and nearly doubled to £513 by the third wave. Participants with

AD had the lowest costs of the diagnostic sub-groups across the three waves. At Wave 2, costs of care for participants with DLB were £98 and £92 more per week than those with AD or VaD, while the costs of their care at Wave 3 were £308 and £301 more per week than AD or VaD. Care costs of female participants at Wave 1 were £12 per week lower than those of male participants; however, at subsequent waves, there was a smaller difference between groups (of £10 and £5 respectively).

Participants without a caregiver in the study had lower care costs than those with a participating family/friend caregiver at each wave; the cost difference between these groups more than doubled between the second and third Wave. Costs grew in step with increasing age: for a participant at the mean age of the sample of 76 years, weekly total service costs could be expected to more than double between Wave 1 and Wave 3. For a participant aged 56 years (not in the table), weekly service costs would be £61 (SE £6) at Wave 1, £69 (SE £7) at Wave 2 and £93 (SE £15) at Wave 3; whereas for a participant aged 86, weekly costs would rise from £77 (SE £5) at the first Wave to £110 (SE £7) and £189 (SE £21) at second and third Waves, respectively. The overall sample estimated marginal mean costs were similar at Waves 1 and 2 to the observed sample means; however, at Wave 3, the estimated mean was £36 higher than the observed mean of £120 per week.

## DISCUSSION

Use and costs of paid care and unpaid care were examined over the first three waves of a cohort of people with dementia and their caregivers living in Britain. The cohort study involved a large sample of people with a variety of clinical subtypes of dementia. Initial levels of use of social services such as home care and day-care were low but increased over subsequent waves. Approximately half of participants using home care received no public funding and bore the full cost of that care. The costs of unpaid care were more than three times that of paid care at all three waves. Controlling for other socio-demographic characteristics, initial service costs of people with mixed dementia and some rarer forms of dementia, DLB and PDD, were found to be higher than those of people with AD. The costs of people living with FTD and DLB rose more steeply over the period than did costs of people with AD.

Differences were observed in trajectories of some components of observed service costs: costs of care home utilization rose steeply over time, which might be expected as the impacts of dementia became more severe [40]. Costs of paid services (unadjusted for socio-demographic characteristics) rose by 61% between the first and third waves. The impact of socio-demographic and diagnostic characteristics on paid costs were modelled. Initial levels of cost varied between sub-groups defined by dementia subtype, living status, caregiver status, and sex. Costs of services for people with mixed dementia, DLB and PDD were higher than those of people with AD. Of note, while at Wave 1 people living alone had higher costs than those living with others, the rate of change in costs over time did not vary between these groups. The stability in the rate of change may be partly related to other characteristics of this group not adjusted for in the analysis. It is possible that significant change in the rate of costs would not be seen in this group over the two-year time window as this group tend to have fewer functional and cognitive difficulties [20] so remain more independent for longer. The average cost of paid services across the cohort showed little change over time, once demographic and diagnostic factors were controlled for. However, the rate of change of costs did vary between dementia subtypes, caregiver types and ages.

FTD and DLB were associated with substantial rises in weekly costs over time compared to AD. Drivers of these rises may be related to several issues. Both conditions are associated with specific behavioural symptoms (hallucinations in DLB [41] and apathy, disinhibition and obsessions in FTD [42]) that might require mental health interventions or early institutionalisation (although the evidence on DLB and early care home admissions is contradictory [41]). DLB is associated with more rapid cognitive decline than AD [43]. FTD in some cases causes severe disability due to neurological syndromes [42].

Of longitudinal observational studies of people with dementia, only the multinational GERAS study of costs of AD has involved a substantial UK cohort (526 people) [40, 44, 45]. Belger, et al. [40] found that health care costs rose modestly but total costs including social services nearly doubled over a five-year period. Two-year results from IDEAL similarly suggest that social services costs (unadjusted for socio-demographic factors) rose more steeply than health service costs over the three waves.

The study's findings on difference in service costs between dementia subtypes will be useful given that the costs associated with these subtypes are not well documented. Information on use and costs of care of people living with DLB is limited compared to the volume of research on use and costs of care of people with AD [43, 46]. A cohort study of a south London population [46] reported that hospitalisation days and costs for people with DLB were higher than for people with AD. The costs of social care for people with DLB were significantly higher than for people with AD in a Norwegian registry study of 109 people with mild dementia [47]. IDEAL participants with PDD and DLB have been found to have lower scores for quality of life, satisfaction with life and well-being than participants with other subtypes, and thus may require greater medical and rehabilitative support [48].

In modelling service costs, it was assumed that these followed a single underlying distribution, but the observed distribution could also be the result of a mixture of distributions. The GLM with a gamma family distribution appeared to fit less well to the third wave data as evidenced by marginal mean estimates nearly a third higher than the mean of the observed data. The slope growth factor estimated by the model suggests that mean total service costs, adjusting for demographic covariates, remained relatively stable over the two-year follow-up. However, the significant variance in the intercept and slope of costs suggests that groups of participants may exist within distinct cost trajectories [49].

In terms of the limitations of this study, the analyses focused on the association of policy-relevant demographic and diagnostic variables with service costs and did not examine the relationship between needs-related characteristics, particularly function in activities of daily living (ADL) and costs [50]. Unpaid care accounts for the greater part of societal costs of care for people living with dementia [51]. Relationships between unpaid care provision for people with dementia, their characteristics and needs [52, 53], carer characteristics and kin relationships [54, 55], and availability of paid care services [10] warrant further investigation drawing on the IDEAL cohort data.

Interpretation of change in service costs over time was complicated because of changes in the questionnaire administration methods for participant-caregiver dyads. Service use questions for dyads continuing to participate at Wave 2 were completed by the caregiver, rather than completed by the researchers in a joint interview with the dyad as in Wave 1. In baseline interviews, the answers to these questions would be negotiated between dyad members and so cannot be said to be purely self- or proxy-reported. Joint discussion might have assisted both participant and caregiver to recollect services used.

The extent to which people can accurately report on services they have used depends on sociodemographic factors, the salience of the services, the frequency of the services and the length of the recall period [56-59]. There is a considerable literature on the accuracy of self-report data compared to medical records or claims data [60]. Evidence on the extent of agreement between the sources, and on which factors most contribute to disagreement, is mixed [61]. Under-reporting of service use (relative to medical records) appears more common than over-reporting [61, 62]. There is little doubt that reporting between people with dementia, caregivers and paid carers' ratings of outcomes such as quality of life can be discrepant[63-66]. People with dementia consistently rate such outcomes higher than do proxies. Surprisingly few studies, however, have compared self- and proxy-reports of service use, either against each other or against administrative records. Wehby, et al. [67] compared the concordance of self- and proxy-reported service use (physician visits, inpatient admissions and outpatient surgery) with Medicare claims data in a US cohort of older people. While proxy-report and self-report showed similar concordance with the claims data, non-spousal proxy report was more concordant with claims data than was report by spousal proxies. Non-spousal proxy-report was associated with less under-reporting of physician visits than self-report. Using the same data sources, Wolinsky, et al. [61] examined demographic factors influencing concordance between claims data and self-reported disease history and service use (factors included three respondent types: self-report, self-report with assistance and proxy-report). Neither proxy nor self-report with assistance were associated with lower concordance with claims data but both were associated with over-reporting of items. Proxies were less likely to under-report items than other respondent types. Being married was associated with higher concordance. Sheehan, et al. [68] found that use of hospital admissions and emergency department visits reported by people with stroke or their caregivers were reliable against Medicare claims records; however reports by both respondent types were less accurate for more routine services (rehabilitation, home health). In a study of caregivers of stroke patients [69], proxy report agreement with medical claims records on outpatient and primary care visits was better than report on inpatient admissions and emergency department visits. Caregivers underreported outpatient and primary care visits, while overreporting hospital admissions. In short, from the limited literature available it seems there is no reason to expect that the switch from dyadic to caregiver-only report would consistently change reporting of service use in one particular direction. There is however evidence that participants and caregivers tend to inaccurately report or under-report services of 'low salience' (for instance, intermittently received services such as GP visits). Concerns that participants without a caregiver in the study gave inaccurate answers because of their memory problems should be tempered by further considerations. These participants had generally milder dementia than dyadic participants; given the evidence on issues with proxy reporting, their responses were not necessarily much less accurate than would have been their proxies; and this sizeable group would otherwise have been excluded altogether from the cost analyses.

Drop-out by people with dementia because of ill-health and death in the months prior to follow-up waves could have been associated with increased use of health and care services and thus not observed in the data. Mortality-related attrition from the sample accounted for a relatively small proportion of the Wave 2 sample (3.1%) but a more sizeable proportion of the Wave 3 sample (including deaths from Wave 2, 7.8%). Inverse probability weights were derived from models including characteristics related to ill health and mortality (e.g. function, comorbidities) and therefore weighted up similar cases remaining in the sample (and it should be noted that weighting had relatively little impact on the cost estimates). The study team are progressing efforts to link the questionnaire data to administrative health service records, in order to address issues of missing data and discontinuous coverage of service use in the IDEAL dataset. This a challenging task (see Lugg-Widger, et al. [70] for a discussion of the issues). National statistics agencies in the UK have not, historically, maintained registers of all the types of health services covered by our participant questionnaires (e.g. community health, primary health care). Consequently such data can be not only patchy but also require substantial time and effort to access [71]. England, the most populous country of the UK, does not maintain a national registry of social service use. Thus efforts to link the IDEAL dataset to administrative records have been confined to requesting linkage to a limited set of national health records, mostly related to secondary care. A recent assessment of these issues concluded that self-report questionnaire methods will routinely be chosen over electronic health records as a safer way for researchers to collect service use information in the UK [71].

### *Conclusions*

In the absence of disease-modifying treatments and given the very long time interval between preventive action and reductions in incidence and prevalence, people with dementia will continue to rely on paid and unpaid care for support to ‘live well’. Societal reliance on unpaid care has implications for caregivers too in terms of stress, burden and poor mental health, particularly when their needs for information and practical assistance are not met by formal services [72-75]. Health and care planners and providers should look beyond a one-size-fits-all approach to services for dementia, as people with less prevalent subtypes such as frontotemporal dementia, Parkinson’s disease dementia and dementia with Lewy bodies, may require substantially more support than people living with Alzheimer’s dementia.

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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.

## DATA ACCESS STATEMENTS

IDEAL data were deposited with the UK data archive in April 2020 and will be available to access from April 2023. Details of how the data can be accessed after that date can be found here: http://reshare.ukdataservice.ac.uk/854293/

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TABLES

Table 1. Characteristics of participants and caregivers completing questionnaires over Waves 1 to 3

| Characteristics | Wave 1<br>N=1537 | Wave 2<br>N=1199* | Wave 3<br>N=910* |
|---|---|---|---|
| *Participants* | | | |
| Mean age (SD); Median; IQR | 76.4 (8.5); 77.0; 71.0-83.0 | 76.1 (8.4); 77.0; 71.0-82.0 | 75.5 (8.5); 76.0; 70.0-82.0 |
| Age groups N (%) | | | |
| <65 | 134 (8.7%) | 103 (8.6%) | 86 (9.5%) |
| 65-69 | 177 (11.5%) | 148 (12.3%) | 127 (14.0%) |
| 70-74 | 257 (16.7%) | 208 (17.3%) | 166 (18.2%) |
| 75-79 | 367 (23.9%) | 292 (24.4%) | 211 (23.2%) |
| 80+ | 602 (39.2%) | 448 (37.4%) | 320 (35.2%) |
| Sex N (%) | | | |
| Female | 672 (43.7%) | 517 (43.1%) | 403 (44.3%) |
| Dementia subtypes N (%) | | | |
| Alzheimer's disease | 851 (55.4%) | 673 (56.1%) | 522 (57.4%) |
| Vascular dementia | 170 (11.1%) | 121 (10.1%) | 92 (10.1%) |
| Mixed (Alzheimer's and vascular) | 324 (21.1%) | 261 (21.8%) | 196 (21.5%) |
| Frontotemporal dementia | 54 (3.5%) | 41 (3.4%) | 33 (3.6%) |
| Parkinson's disease dementia | 44 (2.9%) | 35 (2.9%) | 19 (2.1%) |
| Dementia with Lewy bodies | 53 (3.4%) | 36 (3.0%) | 22 (2.4%) |
| Unspecified/Other | 41 (2.7%) | 32 (2.7%) | 26 (2.9%) |
| Lives alone† | 285 (18.6%) | 208 (17.7%) | 141(16.6%) |
| Caregiver status N (%) | | | |
| Spouse/partner | 1041 (67.7%) | 795 (67.7%) | 580 (68.6%) |
| Family/friend | 236 (15.4%) | 165 (14.0%) | 112 (13.2%) |
| No caregiver involved | 260 (16.9%) | 215 (18.3%) | 154 (18.2%) |
| MMSE Mean (SD); Median; IQR | 23.2 (3.6); 23.0; 21.0-26.0 | 21.6 (5.1); 22.0; 18.0-25.0 | 20.5 (6.2); 22.0; 17.0-25.0 |
| *Caregivers* | N=1277 | N=983 | N=756 |

| | | | |
|---|---|---|---|
| Mean age (SD); Median; IQR | 69.2 (11.1); 71.0; 63.0-77.0 | 70.1 (10.7); 72.0; 64.0-78.0 | 70.7 (10.6); 72.0; 65.0-78.0 |
| Age group N (%)‡ | | | |
| <65 | 364 (28.5%) | 263 (26.7%) | 176 (23.3%) |
| 65-69 | 209 (16.4%) | 147 (15.0%) | 122 (16.1%) |
| 70-74 | 266 (20.8%) | 212 (21.6%) | 169 (22.4%) |
| 75-79 | 223 (17.5%) | 179 (18.2%) | 134 (17.7%) |
| 80+ | 215 (16.8%) | 182 (18.5%) | 155 (20.5%) |
| Sex N (%) | | | |
| Female | 883 (69.1%) | 675 (68.8%) | 518 (68.5%) |
| Caregiver status N (%) | | | |
| Spouse/partner | 1033 (80.9%) | 794 (80.8%) | 580 (76.7%) |
| Family/friend | 244 (19.1%) | 165 (16.8%) | 112 (14.8%) |
| No participant involved | 0 (0.0%) | 24 (2.4%) | 64 (8.5%) |
| In paid employment | 233 (18.2%) | 144 (14.7%) | 112 (14.9%) |

Notes: Table presents data on characteristics of the sample that completed questionnaire sections on paid and unpaid care in either the participant or the caregiver questionnaires. The number of people with dementia whose paid and unpaid care was reported may exceed the number of people with dementia that completed participant questionnaires at that wave. SD=standard deviation; IQR=interquartile range.

* Data from 8 participants who did not complete Wave 1 questionnaires but completed questionnaires at subsequent waves were excluded from all analyses.

† Imputed data (M=40); N=1175 at Wave 2 and N=846 at Wave 3

‡ Imputed data (M=40)

Table 2. Data on self-reported use of paid and unpaid care by participants with dementia without a caregiver in the study

| | | Wave 1 N=260 | | | Wave 2 N=216 | | | Wave 3 N=154 | |
|---|---|---|---|---|---|---|---|---|---|
| | All | | Users | All | | Users | All | | Users |
| | Obs. | Intensity | Obs. | Obs. | Intensity | Obs. | Obs. | Intensity | Obs. |
| Item | N | Mean (SE) | N (%) | N | Mean (SE) | N (%) | N | Mean (SE) | N (%) |
| ***Paid care*** | | | | | | | | | |
| *Primary Health** | | | | | | | | | |
| GP - office | 240 | 1.32 (0.11) | 147 (61) | 182 | 1.11 (0.11) | 98 (54) | 132 | 0.91 (0.12) | 65 (49) |
| GP - home | 242 | 0.14 (0.04) | 18 (7) | 183 | 0.12 (0.04) | 13 (7) | 135 | 0.08 (0.03) | 8 (6) |
| GP - telephone | 241 | 0.35 (0.07) | 44 (18) | 183 | 0.3 (0.06) | 32 (18) | 132 | 0.3 (0.07) | 22 (17) |
| Practice nurse | 238 | 0.65 (0.07) | 89 (37) | 184 | 0.77 (0.11) | 77 (42) | 132 | 0.44 (0.06) | 49 (37) |
| District nurse | 241 | 0.59 (0.36) | 19 (8) | 185 | 0.39 (0.12) | 25 (14) | 133 | 2.31 (1.52) | 13 (10) |
| Physio/OT | 242 | 0.18 (0.05) | 23 (10) | 188 | 0.24 (0.05) | 24 (13) | 136 | 0.58 (0.27) | 13 (10) |
| Specialist nurse | 241 | 0.07 (0.04) | 7 (3) | 185 | 0.07 (0.03) | 8 (4) | 135 | 0.04 (0.04) | … |
| *Comm. Mental Health** | | | | | | | | | |
| Nurse | 240 | 0.36 (0.08) | 43 (18) | 187 | 0.3 (0.07) | 24 (13) | 133 | 0.19 (0.07) | 11 (8) |
| Psychiatrist | 242 | 0.16 (0.03) | 32 (13) | 187 | 0.11 (0.03) | 16 (9) | 137 | 0.04 (0.02) | 6 (4) |
| Psychologist | 242 | 0.06 (0.03) | 8 (3) | 187 | 0.03 (0.01) | … | 137 | 0.05 (0.03) | … |
| *Social care** | | | | | | | | | |
| Social work | 242 | 0.18 (0.06) | 13 (5) | 187 | 0.15 (0.07) | 11 (6) | 133 | 0.08 (0.03) | 8 (6) |
| Home care | 244 | 13.58 (2.85) | 43 (18) | 190 | 18.84 (4.06) | 42 (22) | 136 | 14.46 (3.17) | 28 (21) |
| Meals on wheels | 243 | 2.57 (0.83) | 15 (6) | 189 | 4.35 (1.29) | 15 (8) | 136 | 3.02 (1.28) | 9 (7) |
| Cleaner | 242 | 2.87 (0.36) | 67 (28) | 191 | 3.28 (0.61) | 54 (28) | 136 | 2.87 (0.45) | 39 (29) |
| Laundry | 238 | 0.72 (0.23) | 13 (6) | 189 | ··· | ··· | 136 | ··· | ··· |
| Sitting | 242 | ··· | ··· | 190 | ··· | ··· | 137 | ··· | ··· |
| Caregiver supp | 236 | 0.27 (0.12) | 6 (3) | 188 | ··· | ··· | 137 | ··· | ··· |
| Equipment | 239 | 2.26 (0.16) | 161 (67) | 184 | 2.33 (0.19) | 125 (68) | 135 | 2.3 (0.21) | 93 (69) |
| Residential home days† | 243 | ··· | ··· | 192 | ··· | ··· | 138 | ··· | ··· |
| Nursing home days† | 240 | ··· | ··· | 187 | ··· | ··· | 133 | ··· | ··· |

|  | Wave 1<br>N=260 |  |  | Wave 2<br>N=216 |  |  | Wave 3<br>N=154 |  |  |
|---|---|---|---|---|---|---|---|---|---|
|  | All |  | Users | All |  | Users | All |  | Users |
|  | Obs. | Intensity | Obs. | Obs. | Intensity | Obs. | Obs. | Intensity | Obs. |
| Item | N | Mean (SE) | N (%) | N | Mean (SE) | N (%) | N | Mean (SE) | N (%) |
| Day Centre day | 242 | 1.38 (0.37) | 21 (9) | 189 | 2.54 (0.69) | 21 (11) | 137 | 1.85 (0.56) | 18 (13) |
| Lunch club visit | 243 | 1.81 (0.51) | 24 (10) | 190 | 1.1 (0.38) | 16 (8) | 137 | 0.75 (0.24) | 11 (8) |
| *Hospital care*[‡] |  |  |  |  |  |  |  |  |  |
| ED visits | 244 | 0.15 (0.04) | 24 (10) | 189 | 0.2 (0.05) | 27 (14) | 139 | 0.09 (0.03) | 10 (7) |
| 1st admission | 244 | 0.22 (0.07) | 18 (7) | 189 | 0.34 (0.13) | 15 (10) | 137 | 0.11 (0.06) | 6 (4) |
| Outpatients[§] | 245 | 1.13 (0.19) | 103 (42) | 187 | 1 (0.24) | 61 (33) | 138 | 0.5 (0.09) | 36 (26) |
| *Medications* |  |  |  |  |  |  |  |  |  |
| CNS | 239 | 0.24 (0.03) | 53 (22) | 175 | 0.29 (0.04) | 43 (25) | 128 | 0.36 (0.05) | 45 (35) |
| Dementia | 239 | 0.68 (0.03) | 159 (67) | 175 | 0.66 (0.04) | 113 (65) | 128 | 0.66 (0.05) | 83 (65) |
| ***Unpaid care & travel*** |  |  |  |  |  |  |  |  |  |
| *Unpaid caregiver* |  |  |  |  |  |  |  |  |  |
| Hours help provided | 175 | 145.4 (26.92) | 120 (69) | - | - | - | - | - | - |
| *Other relatives/friends* |  |  |  |  |  |  |  |  |  |
| Hours help receipt | 209 | 10.52 (2.17) | 41 (20) | - | - | - | - | - | - |
| Days lost work | 210 | 0.13 (0.05) | 10 (5) | - | - | - | - | - | - |
| *Any relatives/friends* |  |  |  |  |  |  |  |  |  |
| Hours help[¶] | - | - | - | 190 | 131.52 (26.05) | 100 (53) | 137 | 112.8 (27.43) | 66 (48) |
| *Travel to appointments* |  |  |  |  |  |  |  |  |  |
| Number trips | 241 | 1.07 (0.14) | 106 (44) | 190 | 0.77 (0.24) | 42 (22) | 896 | 0.33 (0.02) | 324 (36) |

Notes: Primary Health=Primary and community health care. OT = Occupational Therapist. Comm. =Community. The symbol '…' denotes numbers occurring in 5 or fewer cases. ED = Emergency department. CNS=Central Nervous System. The symbol '-' denotes that the question was not asked in the questionnaire in that wave.

* Items are face-to-face visits unless otherwise stated; items report responses from the participant with dementia questionnaire dataset .

† Respite and permanent stays in residential homes.

‡ As many as 3 admissions were reported at Wave 1 but numbers reporting a second or third admission occurred in 5 or fewer cases; as many as 5 admissions were reported at Wave 2 but numbers reporting a second, third, fourth or fifth admission occurred in 5 or fewer cases; no third admissions were reported at Wave 3. Admissions 2 to 5 have not been included in the table.

§ Outpatient visits and procedures.

¶ Question asked of participants without a caregiver involved in the study at Waves 2 and 3 as “have relatives or friends regularly helped you with tasks which you had difficulty with, or could not do?” Hours and costs estimates exclude respondents reporting ‘other’ numbers of hours caring per week, N=8 at Wave 2 and in 5 or fewer cases at Wave 3.

Table 3. Data on use of paid and unpaid care  by participants in participant-carer dyads

| | Wave 1<br>N=1277 | | | Wave 2<br>N=983 | | | Wave 3<br>N=756 | | |
|---|---|---|---|---|---|---|---|---|---|
| | All | | Users | All | | Users | All | | Users |
| | Obs. | Intensity | Obs. | Obs. | Intensity | Obs. | Obs. | Intensity | Obs. |
| Item | N | Mean (SE) | N (%) | N | Mean (SE) | N (%) | N | Mean (SE) | N (%) |
| ***Paid care*** | | | | | | | | | |
| *Primary Health†* | | | | | | | | | |
| GP - office | 1234 | 1.37 (0.05) | 808 (66) | 952 | 1.42 (0.05) | 665 (70) | 727 | 1.28 (0.06) | 453 (62) |
| GP - home | 1235 | 0.08 (0.01) | 60 (5) | 965 | 0.19 (0.02) | 96 (10) | 742 | 0.27 (0.04) | 98 (13) |
| GP - telephone | 1229 | 0.31 (0.03) | 214 (17) | 944 | 0.35 (0.04) | 166 (18) | 736 | 0.31 (0.03) | 123 (17) |
| Practice nurse | 1222 | 0.99 (0.05) | 604 (49) | 950 | 1.04 (0.06) | 509 (54) | 726 | 0.95 (0.06) | 344 (47) |
| District nurse | 1222 | 0.56 (0.14) | 103 (8) | 942 | 0.64 (0.16) | 130 (14) | 721 | 0.78 (0.29) | 128 (18) |
| Physio/OT | 1232 | 0.32 (0.04) | 142 (12) | 938 | 0.36 (0.05) | 119 (13) | 729 | 0.34 (0.05) | 88 (12) |
| Specialist nurse | 1231 | 0.15 (0.02) | 110 (9) | 946 | 0.12 (0.03) | 50 (5) | 730 | 0.09 (0.02) | 40 (6) |
| *Comm. Mental Health†* | | | | | | | | | |
| Nurse | 1226 | 0.29 (0.03) | 194 (16) | 942 | 0.21 (0.02) | 110 (12) | 730 | 0.21 (0.03) | 87 (12) |
| Psychiatrist | 1223 | 0.19 (0.01) | 194 (16) | 939 | 0.1 (0.02) | 64 (7) | 731 | 0.09 (0.01) | 48 (7) |
| Psychologist | 1226 | 0.09 (0.02) | 41 (3) | 936 | 0.03 (0.02) | 12 (1) | 728 | 0.03 (0.01) | 14 (2) |
| *Social care†* | | | | | | | | | |
| Social work | 1223 | 0.08 (0.02) | 55 (5) | 933 | 0.2 (0.02) | 95 (10) | 719 | 0.24 (0.03) | 92 (13) |
| Home care | 1240 | 6.38 (0.82) | 122 (10) | 957 | 10.26 (1.25) | 150 (16) | 745 | 15.89 (2.01) | 152 (20) |
| Meals on wheels | 1245 | 0.23 (0.12) | 8 (1) | 950 | 1.21 (0.27) | 35 (4) | 741 | 1.54 (0.5) | 23 (3) |
| Cleaner | 1236 | 2.55 (0.2) | 275 (22) | 959 | 3.06 (0.27) | 252 (26) | 739 | 3.41 (0.31) | 203 (28) |
| Laundry service | 1239 | 0.27 (0.06) | 30 (2) | 964 | 0.03 (0.02) | 6 (1) | 741 | … | … |
| Sitting service | 1245 | 0.25 (0.06) | 31 (3) | 955 | 0.64 (0.13) | 56 (6) | 741 | 0.86 (0.15) | 63 (9) |
| Caregiver support‡ | 1225 | 0.25 (0.06) | 36 (3) | 948 | 0.31 (0.07) | 36 (4) | 731 | 0.3 (0.07) | 31 (4) |
| Equipment | 1209 | 2.22 (0.07) | 805 (67) | 928 | 2.37 (0.09) | 626 (68) | 713 | 2.83 (0.11) | 527 (74) |
| Residential home days§ | 1249 | 0.1 (0.03) | 16 (1) | 973 | 0.5 (0.16) | 48 (5) | 743 | 2.5 (0.51) | 65 (9) |
| Nursing home days§ | - | - | - | 960 | 0.43 (0.18) | 21 (2) | 740 | 0.36 (0.18) | 22 (3) |

| | Wave 1<br>N=1277 | | | Wave 2<br>N=983 | | | Wave 3<br>N=756 | | |
|---|---|---|---|---|---|---|---|---|---|
| | All | | Users | All | | Users | All | | Users |
| | Obs. | Intensity | Obs. | Obs. | Intensity | Obs. | Obs. | Intensity | Obs. |
| Item | N | Mean (SE) | N (%) | N | Mean (SE) | N (%) | N | Mean (SE) | N (%) |
| Day centre days | 1248 | 2.36 (0.23) | 163 (13) | 975 | 2.88 (0.26) | 162 (17) | 748 | 3.93 (0.38) | 146 (20) |
| Lunch club visits | 1245 | 1.17 (0.16) | 111 (9) | 971 | 0.98 (0.18) | 93 (10) | 746 | 0.78 (0.14) | 66 (9) |
| *Hospital care* | | | | | | | | | |
| ED visits | 1223 | 0.13 (0.02) | 120 (10) | 960 | 0.19 (0.02) | 131 (14) | 743 | 0.22 (0.02) | 116 (16) |
| Admission 1 days | 1223 | 0.31 (0.09) | 65 (5) | 957 | 0.33 (0.06) | 89 (9) | 742 | 0.63 (0.15) | 64 (9) |
| Admission 2 days | 1223 | 0.02 (0.01) | 9 (1) | 957 | 0.15 (0.07) | 21 (2) | 742 | 0.06 (0.02) | 13 (2) |
| Admission 3 days | 1223 | … | … | 957 | ··· | ··· | 742 | ··· | ··· |
| Outpatients¶ | 1241 | 1.51 (0.08) | 657 (53) | 962 | 0.83 (0.08) | 301 (31) | 748 | 0.67 (0.05) | 221 (30) |
| *Medications* | | | | | | | | | |
| CNS | 1229 | 0.28 (0.02) | 289 (24) | 961 | 0.02 (0) | 15 (2) | 734 | 0.05 (0.01) | 39 (5) |
| Dementia | 1229 | 0.76 (0.02) | 889 (72) | 961 | 0.01 (0) | 8 (1) | 732 | 0.03 (0.01) | 18 (3) |
| ***Unpaid care & travel*** | | | | | | | | | |
| *Unpaid caregiver* | | | | | | | | | |
| Hours helping** | 1099 | 470.6 (19.08) | 1009 (92) | 832 | 587.42 (22.71) | 787 (95) | 659 | 688.63 (26.98) | 628 (95) |
| Work weeks lost†† | 1189 | 0.08 (0.02) | 12 (1) | 907 | ··· | ··· | 706 | ··· | ··· |
| Hours cut down‡‡ | 1198 | 10.74 (1.52) | 75 (6) | 914 | 11.01 (1.72) | 60 (7) | 718 | 11.24 (1.94) | 47 (7) |
| *Other friends/relatives* | - | - | - | | | | | | |
| Hours helping | 1228 | 32.3 (4.69) | 315 (26) | 961 | 34.21 (3.92) | 280 (29) | 742 | 36.08 (4.37) | 215 (29) |
| Days lost work | 1225 | 0.23 (0.03) | 88 (7) | 961 | 0.34 (0.08) | 76 (8) | 742 | 0.28 (0.05) | 65 (9) |
| *Travel to appointments* | | | | | | | | | |
| Number of trips | 1234 | 1.5 (0.09) | 620 (50) | 965 | 0.94 (0.11) | 282 (29) | 744 | 0.98 (0.12) | 184 (25) |

Notes: Primary Health=Primary and community health care. The symbol '···' denotes numbers occurring in 5 or fewer cases. OT = Occupational Therapist. Comm. = Community. ED = Emergency department. CNS=Central Nervous System. The symbol '-' denotes that the question was not asked in the questionnaire in that wave.

† Items are face-to-face visits unless otherwise stated; items report responses from the participant with dementia questionnaire dataset at Wave 1 and from the carer questionnaire dataset at Waves 2 and Wave 3.

‡ A small number of respondents at Wave 1 (N=7), Wave 2 (n=16) and Wave 3 (n=15) gave implausibly high numbers of visits by 'caregiver support workers'. The descriptor was intended to define support workers for the caregiver to give caregiver short breaks of 2.5 hours, which are much longer than home care visits would typically last. Where caregivers reported more than three visits a week by caregiver support workers it was assumed that respondents intended these to represent a second set of care (not caregiver) support workers, and the visits recoded as home care visits and valued accordingly.

§ Respite and permanent stays in residential homes.

¶ Outpatient visits and procedures.

** Hours estimates reported exclude 78 caregivers reporting 'other' numbers of hours caring per week.

†† Days lost over the prior three months.

‡‡ All hours cut down are assumed to have occurred over the prior three months.

Table 4. Mean weighted costs (£, 2014-15) of care during the prior three months over Waves 1 to 3

| | Wave 1 | | | Wave 2 | | | Wave 3 | | |
|---|---|---|---|---|---|---|---|---|---|
| Cost categories (£) | Source | Mean (95% CI) | N | Source | Mean (95% CI) | N | Source | Mean (95% CI) | N |
| Sub-total and total costs | | | | | | | | | |
| *Health and social care* | | | | | | | | | |
| Primary & comm. health | P | 141 (128,154) | 1537 | P,C | 151 (137,164) | 1199 | P,C | 154 (131,177) | 891 |
| Community mental health | P | 66 (58,75) | 1537 | P,C | 35 (27,44) | 1199 | P,C | 30 (23,37) | 893 |
| Community social care* | P | 152 (130,174) | 1537 | P,C | 225 (188,263) | 1199 | P,C | 269 (225,313) | 897 |
| Day care services | P | 143 (119,167) | 1537 | P,C | 176 (146,206) | 1199 | P,C | 230 (188,271) | 901 |
| Hospital services | P | 345 (273,417) | 1537 | P,C | 372 (274,470) | 1199 | P,C | 367 (258,477) | 894,897 |
| Care home stays | P | 9 (4,15) | 1537 | P,C | 163 (93,234) | 1199 | P,C | 395 (265,525) | 896 |
| Total medication† | P | 57 (51,63) | 1537 | P,C | 58 (50,65) | 1199 | P,C | 52 (45,60) | 908 |
| Equipment (SSD & NHS)‡ | P | 15 (13,17) | 1537 | P,C | 16 (14,19) | 1199 | P,C | 18 (15,21) | 898 |
| Total services & med.§ | P | 929 (842,1015) | 1537 | P,C | 1197 (1057,1337) | 1199 | P,C | 1496 (1300,1691) | 875,881 |
| *Out-of-pocket costs to the person, relatives & friends* | | | | | | | | | |
| Equipment (self or family) | P | 39 (36,42) | 1537 | P,C | 37 (34,41) | 1199 | P,C | 38 (34,43) | 898 |
| Condition-related travel¶ | P | 9 (7,12) | 1537 | P,C | 6 (2,9) | 1199 | P,C | 8 (3,12) | 898 |
| Total out-of-pocket | P | 48 (44,53) | 1537 | P,C | 43 (38,48) | 1199 | P,C | 46 (40,53) | 894 |
| *Costs of unpaid care & lost working time* | | | | | | | | | |
| Unpaid care from main carer# | P | 3083 (2850,3316) | 1277 | C | 3947 (3662,4232) | 983 | C | 4708 (4357,5060) | 750 |
| Unpaid care from friends/relatives** | P | 235 (168,302) | 1277 | C | 268 (211,326) | 983 | C | 266 (203,330) | 753 |
| Unpaid care, all carers †† | P | 3318 (3068,3568) | 1277 | C | 4215 (3918,4513) | 983 | C | 4981 (4619,5342) | 749 |
| Care from any friends & relatives§§ | - | - | - | P | 1168 (630,1706) | 216 | P | 910 (458,1363) | 148 |
| Lost work time (carers)¶¶ | C | 137 (100,174) | 1277 | C | 105 (71,139) | 1194 | C | 78 (47,109) | 907 |
| Lost work time | P | 22 (16,27) | 1277 | C | 37 (21,53) | 983 | C | 28 (19,36) | 753 |

|  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|
| (friends/relatives) ## |  |  |  |  |  |  |  |  |  |
| *Total costs* |  |  |  |  |  |  |  |  |  |
| Total, participants without a carer*** | P | 1926 (1536,2317) | 260 | P | 2154 (1566,2742) | 216 | P | 1623 (1135,2112) | 141 |
| Total, proxy-reported††† | P | 4301 (4020,4582) | 1277 | C | 5516 (5166,5867) | 983 | C | 6708 (6272,7144) | 730,736 |

Notes: Results of multiply imputed data (40 complete datasets). N reports inverse-probability weighted observations from each complete dataset – where observations differed between complete datasets, the range of observations is reported. Comm.=community; SSD=social services departments; med=medications; carers=caregivers; P=Participant with dementia; C=Caregiver.

* Includes costs of respite stays and permanent residence.

† 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 caregiver or participant-only if no caregiver was involved.

# Costs of hours of unpaid care by unpaid caregiver. Costs valued at national minimum wage; hours estimated from Wave 1 Participant questionnaires completed in interviews of complete dyads and from Waves 2 and 3 Caregiver questionnaires.

** Costs of hours of unpaid care by other friends and relatives. Costs valued at national minimum wage; hours estimated from Wave 1 Participant questionnaires completed in interviews of dyads of participants and caregivers and from Waves 2 and 3 Caregiver questionnaires.

†† Costs of hours of unpaid care by unpaid caregiver and by other friends and relatives. Costs valued at national minimum wage; hours estimated from Wave 1 Participant questionnaires completed in interviews of complete dyads and from Waves 2 and 3 Caregiver questionnaires. Mean costs of hours of unpaid care estimated for 260 participants without caregivers at Wave 1: £979 (95% CI £633, £1325).

§§ Costs of hours of unpaid care by any friends and relatives. Costs valued at national minimum wage; costs estimated from interviews with participants without a caregiver in the study completing Waves 2 and 3 Participant questionnaires.

¶¶ Costs of lost working time by unpaid caregiver valued at national average wage based on Wave 1 participant questionnaires and Waves 2 and 3 Caregiver questionnaires.

## Costs of lost working time by other friends and relatives valued at national average wage based on Wave 1 participant questionnaires and Waves 2 and 3 Caregiver questionnaires.

*** Costs estimated from interviews with participants without a caregiver in the study completing Participant questionnaires.

Excludes costs of lost working time to avoid double-counting with costs of time spent in unpaid care.

††† Costs estimated from Wave 1 Participant questionnaires completed in interviews of dyads of participants and caregivers and from Waves 2 and 3 Caregiver questionnaires. Excludes costs of lost working time to avoid double-counting with costs of time spent in unpaid care.

Table 5. Total service costs latent growth curve models (£, 2014-15)

| | Unconditional model | | Conditional model | |
|---|---|---|---|---|
| | Exp ($\beta$) (95% CI) | p | Exp ($\beta$) (95% CI) | p |
| *Intercept* | | | | |
| Female | | | 0.847 (0.728,0.986) | 0.032 |
| Lives alone | | | 1.347 (1.043,1.740) | 0.023 |
| Age (centered)[†] | | | 1.007 (0.999,1.016) | 0.102 |
| VaD[‡] | | | 1.106 (0.867,1.413) | 0.417 |
| Mixed[‡] | | | 1.478 (1.214,1.800) | 0.000 |
| FTD[‡] | | | 1.159 (0.769,1.745) | 0.481 |
| PDD[‡] | | | 2.820 (1.997,3.984) | 0.000 |
| DLB[‡] | | | 1.466 (1.054,2.041) | 0.023 |
| Unspecified/Other[‡] | | | 2.065 (1.287,3.313) | 0.003 |
| Family/friend[§] | | | 1.397 (1.073,1.818) | 0.013 |
| No caregiver involved[§] | | | 0.915 (0.707,1.184) | 0.499 |
| Latent intercept GF | 51.149 (47.328,55.278) | 0.000 | 42.458 (37.485,48.090) | 0.000 |
| *Slope* | | | | |
| Female | | | 1.070 (0.945,1.211) | 0.288 |
| Lives alone | | | 0.969 (0.778,1.208) | 0.782 |
| Age (centered)[†] | | | 1.008 (1.002,1.015) | 0.013 |
| VaD[‡] | | | 0.973 (0.809,1.171) | 0.775 |
| Mixed[‡] | | | 0.902 (0.760,1.070) | 0.237 |
| FTD[‡] | | | 1.353 (1.023,1.789) | 0.034 |
| PDD[‡] | | | 1.205 (0.846,1.717) | 0.301 |
| DLB[‡] | | | 1.533 (1.088,2.159) | 0.015 |
| Unspecified/Other[‡] | | | 1.149 (0.895,1.476) | 0.277 |
| Family/friend[§] | | | 1.255 (1.014,1.554) | 0.037 |
| No caregiver involved[§] | | | 0.876 (0.692,1.110) | 0.274 |
| Latent slope GF | 1.106 (1.034,1.183) | 0.003 | 1.070 (0.958,1.196) | 0.229 |
| Residual SD T1 | 0.988 (0.932,1.046) | 0.670 | 0.986 (0.931,1.044) | 0.631 |
| Residual SD T2 | 0.997 (0.942,1.056) | 0.930 | 1.001 (0.945,1.060) | 0.976 |
| Residual SD T3 | 0.960 (0.882,1.044) | 0.339 | 0.963 (0.888,1.045) | 0.365 |
| *Random effects* | | | | |
| Intercept variance | 1.949 (1.651,2.301) | 0.000 | 1.749 (1.511,2.024) | 0.000 |
| Slope variance | 1.191 (1.060,1.339) | 0.003 | 1.161 (1.040,1.296) | 0.008 |
| Intercept-Slope covariance | 1.101 (0.979,1.239) | 0.082 | 1.068 (0.960,1.188) | 0.226 |
| *N*[¶] | 1479 | | 1479 | |

Exponentiated coefficients; inverse probability weights applied

Notes: VaD= vascular dementia; FTD= frontotemporal dementia; PDD Parkinson’s disease dementia; DLB dementia with Lewy bodies; Other= Unspecified/other; GF=growth factor, SD=standard deviation.

† Centred at the sample mean of 76 years

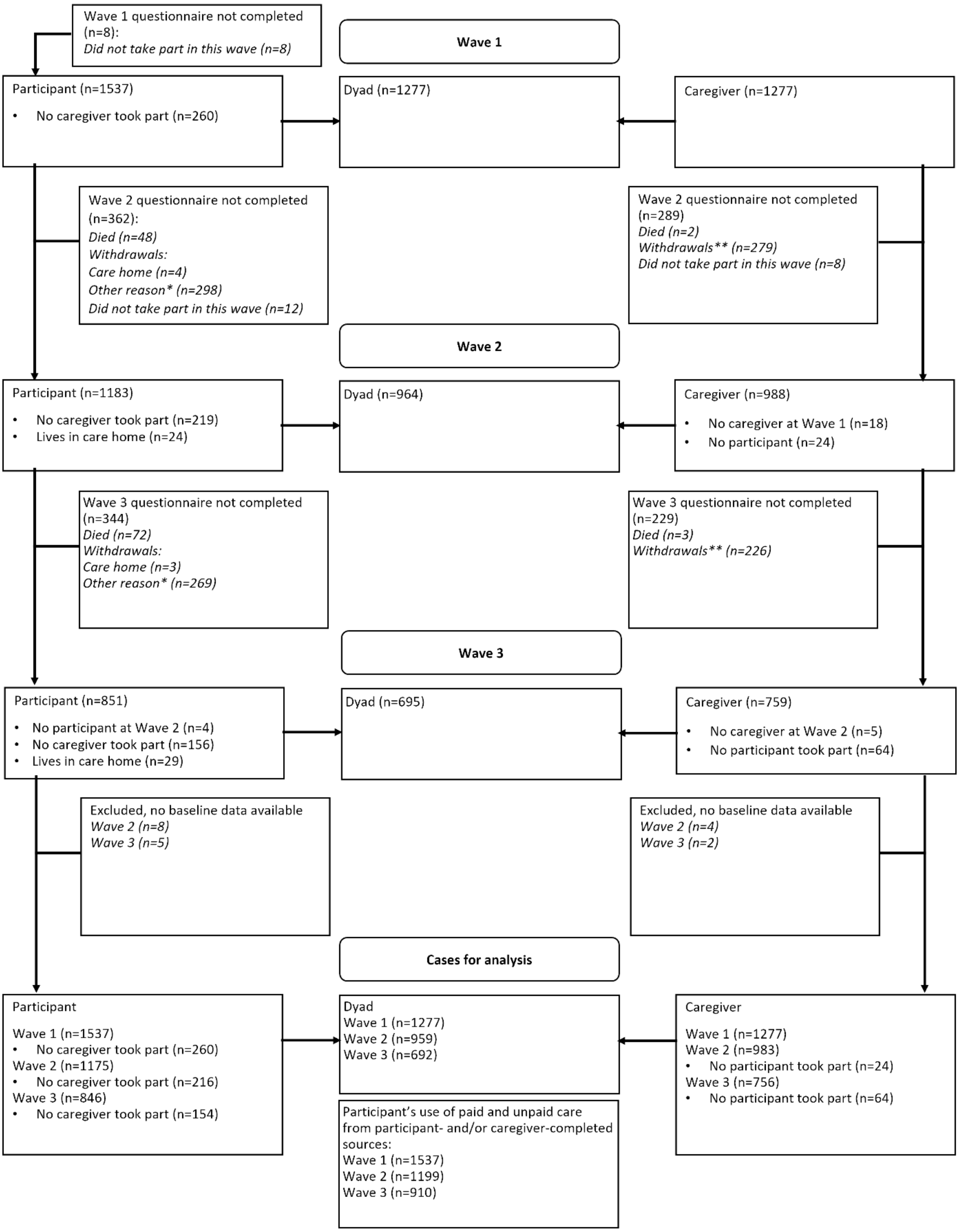
‡ Reference category: AD

§ Reference category: Spousal caregivers

¶ Wave 1 equation: weighted N=1479, Wave 2 equation: weighted N=1199, Wave 3 equation: weighted N= 872-882, numbers of observations varying between complete datasets.

## FIGURES

Figure 1. Questionnaire completion by participants and caregivers and by dyads, Waves 1-3



*Reasons for participant attrition other than death and entry to a care home: withdrew for health reasons, had other commitments, no longer interested, too challenging or distressing, moved out of area, no longer eligible, lost to follow-up

**Reasons for caregiver attrition other than death: participant had died, participant had moved to a care home, participant had withdrawn for other reasons

Figure 2. Trajectories of total paid service costs (95% confidence intervals) (£, 2014-15) in sub-groups, marginal means from conditional latent growth curve model