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The cost of care homes for people with dementia in England: a modelling approach

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Objectives: To examine the cost of care for people with dementia in institutional care settings, to understand the major cost drivers and to highlight opportunities for service development.

Methods: Data on 277 residents with dementia in 16 UK residential or nursing homes were collected. We estimated care and support costs and fitted models to the data. Sensitivity analyses were also conducted.

Results: Care home residents cost £792 weekly: 95% of the costs accounted for by direct fees. Hospital contacts contributed the largest proportion of the additional costs. Having an established diagnosis of dementia ($b=0.070$; $p<0.05$) was associated with higher costs. No association was found between cost and needs ($b=-0.002$; $p=0.818$).

Conclusion: The absence of an association between cost and needs emphasizes the importance of a more needs-based costing system which could result in clinical and economic advantages. © 2016 The Authors. International Journal of Geriatric Psychiatry Published by John Wiley & Sons Ltd

Key words: Alzheimer; dementia; costs; care home; nursing home; cognition; behavioural symptoms; associations; needs

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Introduction

Cost considerations are relevant when providing long-stay services for people with dementia, particularly given the sociodemographic and psychosocial developments impacting on where and by who care is provided. Currently, the majority of the 850 000 people living with dementia in the UK live in the community (Prince *et al.*, 2014; Knapp *et al.*, 2007). However, the nature of the condition means that worsening cognitive and physical functions and the presence of behavioural and psychiatric symptoms may make it difficult for individuals to stay in their own home, which contribute to increasing concern

by family carers, who often experience high levels of distress, depression (Murray *et al.*, 1999; Coen *et al.*, 2002), isolation from their social networks (Leinonen *et al.*, 2001) and additional out-of-pocket expenses to support the care recipient financially (Moore *et al.*, 2001). For some carers, one or more of these may trigger the need to provide formal supportive domiciliary arrangements for the care recipient (Collins *et al.*, 1994), which can cost an average of £7000 on top of the estimated £14 000 in unpaid care provided by family members (Prince *et al.*, 2014). For other carers, alternatives to domiciliary care such as care home provision may be sought, especially in the event of a crisis. However, care

home placements for people with dementia are costly; the average UK care home fee costs a minimum of £525 a week, although it can be higher, depending on the region and the type of room (Curtis and Burns, 2015). This compares with an average fee paid by councils in England of £512 per week (Laing and Buisson, 2015), representing a minimum shortfall in payments to providers by councils of £13 per week. To explain the high costs, providers in England cite increased payroll and non-payroll costs brought about by increases in inflation and an increase in the national living wage to at least £7.20 per hour.

These pressures place further challenges on already cash-strapped local authorities to pay for costly placements. Local authorities may cover some or all of the cost of care in some circumstances, but the help it provides depends on what the individual's needs are, the money they have at their disposal and the level and type of care and support required. Before consideration could be given to the level of cost to be covered by local authorities, there needs to be a closer look at the total costs of care for care home residents and what the characteristics associated with these costs are.

A recent systematic review highlighted the limited literature on what drives costs for people living with dementia in institutional settings (Schaller *et al.*, 2015). The objectives of the current study were to examine the cost of care for people with dementia in institutional care settings, to determine the extent to which there were variations in their costs, whether these were associated with not only personal characteristics but also cognitive ability, dependency, antipsychotic or psychotropic medication use and neuropsychiatric symptoms and to highlight opportunities for service development.

Methods

Sample

The study took place in England in South London, North London and Oxford. The data reported here were extracted from baseline data of a factorial intervention study of Person-Centred Care, Social Intervention, Exercise and Antipsychotic Review (the Well-Being and Health for People with Dementia Programme; Whitaker *et al.*, 2014).

Entry into the study was according to the following process: (i) Potential participants were identified by the managers of the participating care homes who approached residents or their personal consultee to be sent study information by the research team; (ii) the research team discussed the study in further detail

with the resident or personal consultee either on the telephone or at a face-to-face meeting, depending on the preference of the individual; (iii) a trained researcher identified and screened study participants for eligibility; (iv) informed consent was obtained from study participants who were eligible, or if they were not capable of providing informed consent, their personal consultee provided consent on their behalf. Residents for whom consent was not obtained were excluded from the trial; and (v) care home residents were included if they met the diagnostic criteria for dementia—a score of '1' or greater on the Clinical Dementia Rating Scale (Hughes *et al.*, 1982) and score of '4' or greater on the Functional Assessment Staging (Reisberg *et al.*, 1982). Therefore, all participants in the study had mild-to-severe dementia.

Data on 277 residents with dementia in 16 UK care homes were collected.

Study participants were resident either in care homes without nursing support (also called residential care homes) or care homes with nursing support (also called nursing homes).

The study was approved by the Oxfordshire Research Ethics Service Committee C (REC number 11/SC/0066).

Cost estimation

The resident fees included care cost, accommodation costs, ancillary costs and operator's profit and were collected from the care homes. Where data on resident fees were missing, they were imputed based on the average for participants in that care home. Weekly fees were extrapolated to a 3-monthly figure.

Services accessed by the study participants were recorded using the Client Service Receipt Inventory, used in previous studies of care home residents with dementia (Livingston *et al.*, 2013; Knapp *et al.*, 2013). The measure included any services used by the study participants in the last 3 months from services external to the care setting, such as hospital services, community health or emergency services, social care, community mental health services and voluntary services—classified as 'other' services in this study. It was administered retrospectively covering the previous 3-month period.

Services and support costs provided by organizations external to the care home were calculated by multiplying the frequency and intensity of resources used, collected from the Client Service Receipt Inventory by appropriate unit costs. Unit costs (2011/2012 price level) were obtained from a widely used published compendium (Curtis, 2012). Total care costs were estimated by summing care home fees

and the costs of services provided by organizations external to the care homes.

Hypothesis

Following a review of the evidence base on the factors associated with total care costs, discussions with old-age psychiatrists and other researchers on the team, it was hypothesized that the care home fees, non-accommodation and total care costs would be associated with residents' demographic characteristics (age, gender, ethnicity, marital status, first language and next of kin), months in home care, psychiatric and non-psychiatric health problems (diagnosis of dementia, diagnosis of mental health problems, physical problems, sensory problems, mood (Cornell Depression Scale; Alexopoulos *et al.*, 1988), behavioural and other neuropsychiatric symptoms (not including agitation) including apathy and psychosis Neuropsychiatric Inventory—Nursing Home Version (Lange *et al.*, 2004), a diagnosis of agitation Cohen–Mansfield Agitation Inventory (Cohen–Mansfield, 1986), learning disabilities, respiratory complaints, nervous system complaints, cardiovascular complaints, gastrointestinal complaints, other complaints, medication use (antipsychotics use and psychotropic medication use), quality of life for people with dementia (DEMQOL; Smith *et al.*, 2005) and unmet needs covering aspects including accommodation, household skills, food, daytime activities, physical health, psychological distress, memory, money and relationships (using the Camberwell Assessment of Need in the Elderly (Reynolds *et al.*, 2000).

Multivariate models

Mean and standard deviations of 3-monthly costs by resident characteristics (categorized by the median value) were calculated for care home residents who received nursing support and those who did not. Generalized linear modelling was used to account for the distribution of the cost data (Curtis, 2012; Dunn *et al.*, 2003). Total cost of care was used as the dependent variable, and explanatory variables were age, gender, ethnicity, marital status, first language, months in home care, next of kin, diagnosis of mental health problems, physical problems, sensory problems, learning disabilities, respiratory complaints, nervous system complaints, cardiovascular complaints, gastrointestinal complaints, antipsychotics use, psychotropic medication use, diagnosis of dementia, DEMQOL and needs.

Three models were fitted: a full model which used total costs for both types of care home as the dependent variable of and controlled for all explanatory variables and two models using total costs for each type of care home and controlling for the same variables as in the full model. For each of these models, the modified Park test was used to determine the best family distribution (Gaussian, Gamma, Poisson or inverse Gaussian) to use in the model (Manning and Mullahy, 2001).

Sensitivity analysis

We performed two one-way sensitivity analyses by varying the dependent variable. For each of the three models, we controlled for all clinical and demographic variables in addition to the main independent variables; in the first sensitivity analysis, we changed the dependent variable to hospital costs only, and in the second, care home fees were excluded from total costs. Hospital services are an expensive component of healthcare costs; we explored the impact some variables would have on hospital costs only. In the second sensitivity analysis, we removed care home fees from the total costs and reran the models to explore whether care home fees overshadow the costs of external service provision.

All multivariate analyses were performed on STATA (StataCorp, 2011).

Results

Demographic characteristics

Demographic and clinical characteristics and the associated costs for 277 residents living in either residential or nursing homes are summarized in Table 1. The residents were predominantly female (73%), over 87 years old (55%), white (87%) with English as their first language (90%) and did not have a partner (77%) but had a next of kin (96%). Because of the wide inclusion criteria, the residents in the study were at all stages of Alzheimer's dementia; however, most residents who participated in this study had mild-to-moderate dementia (65%). The average Cornell Depression Scale score was 5.0 (SD=4.4), and the mean score on the Cohen–Mansfield Agitation Inventory for agitation was 48.3 (SD=17.2). On DEMQOL—proxy and DEMQOL—patient, the means were 104.2 (12.4) and 89.3 (16.3) respectively. Sixty-one percent of the residents used psychotropic medication to treat neuropsychiatric symptoms.

Table 1 Care home resident characteristics

Age	Number of residents (%)	Mean costs, £ (SD)
≤87	125 (45)	9625 (2356)
>87	152 (55)	9410 (2017)
Gender		
Female	203 (73)	9418 (2014)
Male	74 (27)	9752 (2565)
Ethnicity		
White	241 (87)	9529 (2067)
Non-white	34 (12)	9381 (2906)
Partner		
Yes	53 (19)	10037 (2651)
No	214 (77)	9356 (2047)
First language		
English	250 (90)	9229 (1886)
Other	25 (9)	9540 (2211)
Months in home care		
≤21 months	166 (60)	9861 (2484)
>21 months	105 (38)	8953 (1431)
Next of kin		
Yes	267 (96)	9550 (2196)
No	7 (3)	8055 (1078)
Having sensory problems		
Yes	168 (61)	9343 (2074)
No	91 (33)	9418 (1854)
Having learning disabilities		
Yes	3 (1)	9343 (2074)
No	254 (92)	8240 (948)
Having respiratory complaints		
Yes	74 (27)	9368 (1665)
No	181 (65)	9364 (2141)
Having nervous system complaints		
Yes	19 (7)	8943 (2017)
No	239 (86)	9402 (1999)
Gastrointestinal complaints		
Yes	81 (29)	9446 (1711)
No	174 (63)	9335 (2141)
Cardio-vascular complaints		
Yes	71 (26)	9854 (2432)
No	183 (66)	9178 (1801)
Other complaints		
Yes	163 (59)	9315 (2093)
No	95 (34)	9458 (1836)
Use of antipsychotics		
Yes	49 (17)	9553 (1832)
No	228 (82)	9498 (2245)
Use of psychotropics		
Yes	180 (65)	9681 (2380)
No	97 (35)	9186 (1697)
Cohen–Mansfield Agitation Inventory (CMAI) for agitation score		
≤43	139 (50)	9425 (2027)
>43	138 (50)	9591 (2319)
Cornell depression score		
≤4	145 (52)	9294 (1867)
>4	9 (3)	9631 (1527)
Camberwell Assessment of Need in the Elderly (CANE)		
≤14	139 (50)	9472 (1830)
>14	138 (50)	9544 (2481)
Health-related quality of life for people with dementia (DEMQOL)—patient		
≤93	50 (18)	9762 (2533)
>93	227 (82)	9452 (2091)
Health-related quality of life for people with dementia (DEMQOL)—proxy score		
≤106	136 (49)	9590 (2163)
>106	141 (51)	9498 (2191)

Care home costs

The care home fees averaged £9031 (range: £5343 to £14300) over 3 months. The average total costs were £9508, equivalent to £792 per week (Table 2). As expected, care home fees made up the majority (95%) of the costs. Of the services provided by external care providers, hospital services were the most expensive category. Average hospital costs of £238 (range: £112 to £14040 for those who used hospital services) contributed 3% towards the total costs and 50% of the total costs when care home fees were excluded. Primary and secondary care costs contributed 2% of the total costs.

The residents in nursing homes had higher costs in all categories of care and support except for hospital costs which were higher for the residents in nursing homes without nursing support (Figure 1).

Models

Three models were fitted to the data on the residents in care homes, one model for all care home residents in the sample, another for the residents in nursing homes and a third for those in residential care homes. In all three models, a generalized linear model with a log link function was used. The modified Park test showed that the gamma family was the most appropriate to use with this model (coefficient of 2), and the log link function was used because of the non-normal distribution of costs.

In the full model, which did not differentiate between the types of care home, a shorter time since admission to the care home ($b = -0.002$; $p < 0.001$) and having a next of kin ($b = -0.003$; $p < 0.001$) were associated with lower costs, and having an established diagnosis of dementia ($b = 0.070$;

$p < 0.05$) was associated with higher costs (Table 3). Of note, there were no significant associations with the severity of neuropsychiatric symptoms, antipsychotic use and the use of other psychotropic medications or the level of need.

In nursing home residents, a shorter time since admission continued to be associated with higher costs. In addition, the ethnicity of residents was also associated with cost, with higher costs for non-white residents (Table 4). In residential care homes, next of kin had the only significant relationship ($b = 0.062$; $p < 0.05$), but the directionality was different to the model with all care home residents. There were no other significant associations in the residential care home cost model (Table 5).

Sensitivity analysis

For the first sensitivity analysis, we replaced the total cost variable with hospital costs only as the dependent variable. In nursing home residents, significant associations ($b = 3.360$, $p < 0.0001$) were found between hospital costs and psychotropic medication. We did not find any significant association in the full sample with hospitalization costs and any of the clinical and sociodemographic variables in bivariate and multivariate analyses.

In the second sensitivity analysis, we replaced the total cost variable with non-residential costs (all costs not including care home fees) as the dependent variable. Not having English as first language ($b = -0.896$; $p = 0.002$), less time since residents were admitted to the care home ($b = -0.009$; $p = 0.052$), having sensory problems ($b = 0.464$; $p = 0.035$) and more needs identified ($b = 0.103$; $p = 0.035$) were significantly associated with higher costs.

Table 2 Three-monthly care homes costs (£)

	All residents (n = 277)		Nursing care home residents (n = 122)		Residential care home residents (n = 155)	
	No using (%)	Mean cost (SD) (£)	No using (%)	Mean cost (SD) (£)	No using (%)	Mean cost (SD) (£)
Care home fees	277 (100)	9031 (1722)	122 (100)	9607 (2171)	155 (100)	8577 (1068)
Hospital services	52 (19)	238 (1239)	28 (23)	167 (868)	24 (16)	294 (1467)
Primary care and community health	206 (74)	155 (208)	90 (74)	177 (220)	116 (75)	138 (196)
Community mental health services	25 (9)	10 (48)	16 (14)	15 (65)	9 (6)	6 (26)
Social care	4 (1)	2 (32)	0 (0)	0 (0)	4 (3)	4 (42)
Other services ^a	79 (29)	13 (44)	44 (36)	12 (31)	35 (23)	14 (52)
Medications	185 (67)	59 (126)	86 (71)	63 (127)	99 (64)	56 (126)
Total costs	277 (100)	9508 (2167)	122 (100)	10041 (2437)	155 (100)	9089 (1846)

^aIncludes optician, dentist and hygienist.

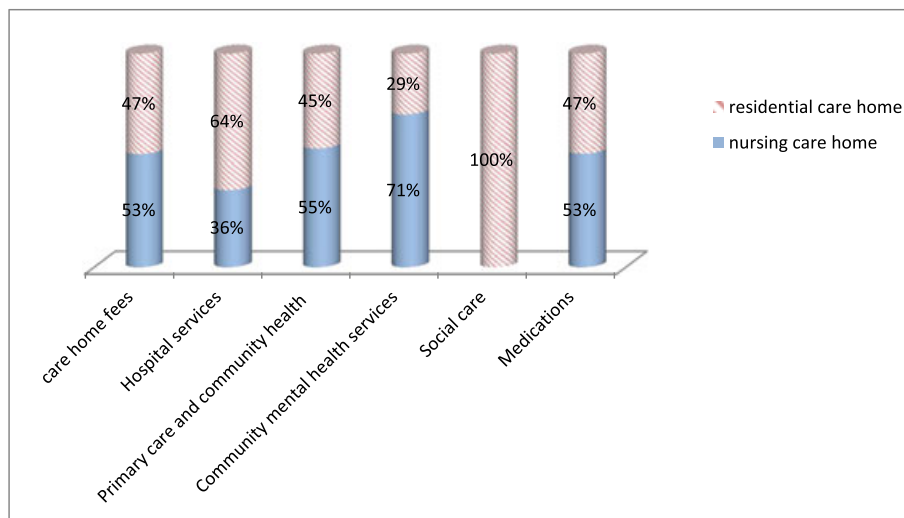


Figure 1 Three-monthly costs by care home.

Discussion

In this study, we calculated the total cost of care for residents living in care homes in an English cohort, incorporating a wide range of health and social care services and care home fees. The total averaged a little over £790 per week, which when extrapolated across all care home residents with dementia in the UK would cost £12.8 billion annually. Although the likely cost nationally for people with dementia in care homes exceeds £12 billion, there is an important caveat on this estimate as there may have been care home residents who may have been self-funders. A recent report puts the UK average of self-funders at 43% and found large regional variations, with more than half (55%) of all care home residents in the South East of England paying the full cost of their care fees, compared with 22% in the northeast (Mort and Aparasu, 2002). Nevertheless, £7 billion represents a substantial cost to the public purse and a sizeable proportion of the national spend on dementia in the UK.

The costs of services outside the residential or nursing home setting are lower than expected, but we would speculate that this was perhaps not due to the lack of need for these services but could be due to ongoing issues with lack of support from health sector services to care home residents (Gage *et al.*, 2012; Met Life Mature Market Institute, 2012; Royal College of Nursing, 2011). Within this context, of particular importance, costs were significantly higher for people with established dementia, even though all individuals within the study cohort all had dementia and the severity of dementia was not significantly associated with cost. This raises the

potentially serious concern that there may be hidden factors disincentivizing the diagnosis of dementia in people living within care home environments and/or that the needs of these individuals are not being met.

We found that hospital costs were 1.76 times higher for people in care homes without nursing support than those in nursing homes. This finding is probably explained by the greater nursing expertise and the associated skills in nursing home settings that may enable a greater proportion of medical events to be managed within the care setting without recourse to expensive hospital services (Konetzka *et al.*, 2008). The results do, however, also highlight a specific opportunity to improve outreach services and training of staff in care homes where there is no nursing support, to reduce unnecessary hospital admissions.

In the base model, neither neuropsychiatric symptoms nor the use of psychotropic drugs was associated with increased overall cost. However, in further sensitivity analyses, the use of psychotropic medicines was associated with hospital costs in nursing home residents. Whilst it may be surprising that the impact of psychotropic drug use on costs was not more substantial, these agents are known to be associated with increased risk of falls, fractures and delirium in older people with dementia (Frijters and Achterberg, 2007), and the more specific association with hospital costs is consistent with what would be expected clinically but has not previously been established.

The base model also showed a significant association between a shorter period of time in the care

Table 3 Base model: generalized linear models of total costs for all residents

Variables	Coefficient	Standard error	p-value
Constant	9.234	32.68	<0.0001
Age	-0.003	0.002	0.204
Gender: male (=1)	0.005	0.032	0.878
Ethnicity: non-white (=1)	0.020	0.037	0.575
Partner: yes (=1)	0.005	0.009	0.551
Fist language (English = 1)	-0.059	0.042	0.163
Months in care home	-0.002	0.000	<0.001
Next of kin: yes (1)	-0.003	0.056	<0.001
Neuropsychiatric symptoms: yes (1)	-0.000	0.002	0.778
Learning disabilities: yes (1)	-0.105	0.072	0.143
Respiratory complaints: yes (1)	0.009	0.010	0.382
Nervous system complaints: yes (1)	-0.047	0.030	0.111
Gastrointestinal complaints: yes (1)	-0.002	0.009	0.852
Cardio-vascular meds: yes (1)	0.068	0.042	0.111
Other complaints: yes (1)	-0.014	0.031	0.652
Antipsychotic use: yes (1)	0.019	0.035	0.592
Psychotropic medication use: yes (1)	0.021	0.033	0.527
Established dementia diagnosis: yes (1)	0.0702	0.283	<0.05
DEMQL proxy score	-0.001	0.000	0.442
CANE	-0.002	0.007	0.818
CSDD	0.006	0.004	0.187
CMAI	-0.000	0.001	0.747
Akaike information criterion (AIC)	20.48		
Bayesian information criterion (BIC)	-1073.704		
n = 223			

CANE, Camberwell Assessment of Need in the Elderly; CMAI, Cohen-Mansfield Agitation Inventory; CSDD, Cornell Depression Scale; DEMQL, quality of life for people with dementia.

home and higher costs. At first consideration, the opposite association may be expected, as severity of dementia and level of need will increase over time. However, people are often admitted to care homes at a time of crisis and many individuals find it difficult to adjust to care home environments. Specific interventions and additional support for newly admitted residents may be important opportunities for commissioners and researchers to improve outcomes for individuals and potentially to also improve cost-efficiency.

The absence of a clear association between needs and severity of dementia respectively and cost is a serious concern and suggests that the current

Table 4 Generalized linear models of total costs for residents in care homes with nursing support

Variables	Coefficient	Standard error	p-value
Constant	9.736	0.463	<0.000
Age	-0.004	0.003	0.163
Gender: male (=1)	0.017	0.051	0.757
Ethnicity : non-white (=1)	0.172	0.061	<0.01
Partner: yes (=1)	0.024	0.015	0.103
Fist language (English = 1)	-0.048	0.062	0.442
Months in care home	-0.003	0.001	<0.01
Neuropsychiatric symptoms: yes (1)	0.001	0.0026	0.719
Next of kin: yes (1)	-0.012	0.095	0.899
Sensory problems: yes (1)	-0.059	0.054	0.273
Learning disabilities: yes (1)	-0.124	0.112	0.271
Respiratory complaints: yes (1)	0.056	0.048	0.249
Nervous system complaints: yes (1)	-0.018	0.0749	0.815
Gastrointestinal complaints: yes (1)	-0.065	0.050	0.196
Cardio-vascular meds: yes (1)	0.031	0.051	0.538
Other complaints: yes (1)	-0.057	0.056	0.308
Antipsychotic use: yes (1)	-0.020	0.058	0.735
Psychotropic medication use: yes (1)	-0.018	0.054	0.733
Mild dementia	0.011	0.069	0.873
Moderate dementia	0.013	0.059	0.829
Severe dementia	0.044	0.071	0.530
DEMQL proxy score	-0.002	0.002	0.498
CANE	-0.015	0.011	0.169
CSDD	-0.003	0.0077	0.676
CMAI	0.001	0.002	0.774
Akaike Information criterion (AIC)	20.88		
Bayesian Information criterion (BIC)	-309.72		
n = 93			

CANE, Camberwell Assessment of Need in the Elderly; CMAI, Cohen-Mansfield Agitation Inventory; CSDD, Cornell Depression Scale; DEMQL, quality of life for people with dementia.

model is not needs driven. An alternative costing model used in the Netherlands has a 10-level payment scale based specifically on level of need (Life, 2007); we would consider including a basic cost which would cover the accommodation element. As the accommodation costs per se do not vary between individuals, this approach enables additional specific care and therapy requirements to be addressed. There may be opportunities to examine different approaches to enable more flexible provision of care to better address the needs of individuals requiring higher levels of support.

In the sensitivity analysis, when care home fees were excluding the from the analysis, not having English as first language and having sensory problems were significantly associated with higher costs,

Table 5 Generalized linear models of total costs for residents in care homes without nursing support

Variables	Coefficient	Standard error	p-value
Constant	9.993	0.111	<0.001
Age	0.002	0.002	0.916
Gender: male (=1)	-0.002	0.043	0.938
Ethnicity : non-white (=1)	0.036	0.040	0.442
Partner: yes (=1)	0.007	0.010	0.452
Fist language (English = 1)	-0.033	0.053	0.531
Months in care home	-0.001	0.000	0.168
Next of kin: yes (1)	0.062	0.070	<0.05
Neuropsychiatric symptoms: yes (1)	-0.002	0.002	0.310
Sensory problems: yes (1)	0.048	0.031	0.132
Learning disabilities: yes (1)	-0.083	0.089	0.349
Respiratory complaints: yes (1)	-0.002	0.033	0.942
Nervous system complaints: yes (1)	-0.029	0.093	0.751
Gastrointestinal complaints: yes (1)	0.083	0.042	0.340
Cardio-vascular meds: yes (1)	0.119	0.059	0.289
Other complaints: yes (1)	0.044	0.037	0.256
Antipsychotic use: yes (1)	0.041	0.039	0.293
Psychotropic medication use: yes (1)	0.043	0.036	0.237
Mild dementia:	-0.009	0.087	0.914
Moderate dementia	-0.016	0.093	0.863
Severe dementia	0.029	0.099	0.774
DEMQOL proxy	0.001	0.001	0.541
CANE	0.001	0.008	0.219
CSDD	0.006	0.004	0.166
CMAI	0.000	0.001	0.987
Akaike Information criterion (AIC)	20.57		
Bayesian Information criterion (BIC)	-539.9159		
n = 133			

CANE, Camberwell Assessment of Need in the Elderly; CMAI, Cohen-Mansfield Agitation Inventory; CSDD, Cornell Depression Scale; DEMQOL, quality of life for people with dementia.

providing further opportunities for specific interventions and service delivery to improve outcomes for individuals without incurring additional cost. Interestingly, the level of needs was also significantly associated with cost in the sensitivity analysis excluding care home fees, and this may provide a better model to evaluate cost-effectiveness for clinical trials in residential care and nursing home settings.

Strengths and limitations

This study has limitations. First, these findings are based on a cross-sectional analysis of care home

provision and service use and reflect what exists and the cost of current care home provision rather than how long-run costs respond to residents with dementia with various needs in different types of care home setting. Second, the study considers UK care homes which have been traditionally subdivided into residential and nursing subtypes but does not explore the relationships by service providers, that is, whether care homes are owned and managed by the local authority, private or voluntary sector. Some evidence exists among institutional care for people with mental health problems by providing sectors but not specifically for those with dementia (Laing, 2013). An extension to these analyses would be to explore in more detail variations in costs depending on the service provider and to test for possible collinearity, as this can interfere with determining the precise effect of each predictor, although it would not affect the overall fit of the model or result in bad predictions. Previous research has shown that the most prevalent resident and staff problem in nursing home dementia care is neuropsychiatric symptoms, and the high prevalence of these symptoms is associated with increased pressures on care home resources (Chisholm *et al.*, 1997; Zuidema *et al.*, 2007). The primary source for the data did not include any care home-specific resource costs in the costing; it is therefore not surprising that we did not find any significant associations between costs and neuropsychiatric symptoms.

We also did not set out to explore the goodness of fit of any of the models or how much of the variation in costs could be explained by the characteristics of residents with dementia as previous robustly conducted research has focused on (Bostick *et al.*, 2006; Wolstenholme *et al.*, 2002), but we did explore an area which has not received much attention: whether the cost of care provided by external agencies from health, social care and the voluntary sector to residents with dementia receiving nursing care and those without are responding positively or indeed negatively to cognitive ability health complaints, medication use, neuropsychiatric symptoms and personal characteristics, which is another strength of the study.

A further strength of the current study is that the total costs of services and support to care home residents cover not only the weekly fees but also the cost of contact made with professionals outside the care home to meet their health and social care needs. The cost of services provided outside the care home has not received attention in the literature. Further research is required in this area.

Conflict of interest

None declared.

Key points

- The costs of care home provision for people with dementia are high, with impacts on health and social care agencies.
- The absence of a clear association between needs and severity of dementia respectively and costs is a serious concern and suggests that the current care model is not needs driven.
- Hospital costs are almost twice times higher for residents in care homes without nursing support than those in nursing homes. Opportunities to improve outreach services and staff training to reduce unnecessary hospital admissions should be explored.

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References

Alexopoulos GS, Abrams RC, Young RC, Shamoian CA. 1988. Cornell Scale for Depression in Dementia. *Biol Psychiatry* 23(3): 271–284.
 Bostick JE, Rantz MJ, Flesner MK, Riggs CJ. 2006. Systematic review of studies of staffing and quality in nursing homes. *J Am Med Dir Assoc* 7(6): 366–376.

Chisholm D, Knapp MR, Astin J, Lelliott P, Audini B. 1997. The mental health residential care study: predicting costs from resident characteristics. *Br J Psychiatry* 170(1): 37–42.
 Coen RF, O'Boyle CA, Coakley D, Lawlor BA. 2002. Individual quality of life factors distinguishing low-burden and high-burden caregivers of dementia patients. *Dement Geriatr Cogn Disord* 13(3): 164–170.
 Cohen-Mansfield J. 1986. Agitated behaviors in the elderly: II. Preliminary results in the cognitively deteriorated. *J Am Geriatr Soc* 34(10): 722–727.
 Collins C, King S, Kokinakis C, et al. 1994. Community service issues before nursing home placement of persons with dementia. *West J Nurs Res* 16(1): 40–56.
 Curtis, L.A., 2012. Unit costs of health and social care 2012.
 Curtis L., and Burns A., 2015. Unit costs of health and social care 2015.
 Dunn G, Mirandola M, Amaddeo F, Tansella M. 2003. Describing, explaining or predicting mental health care costs: a guide to regression models. *Br J Psychiatry* 183(5): 398–404.
 Frijters DH, Achterberg WP. 2007. The ZZZP Questionnaire. Reliability of a new resource utilization measure. *Tijdschr Gerontol Geriatr* 38(4): 165–172.
 Gage H, Dickinson A, Victor C, et al. 2012. Integrated working between residential care homes and primary care: a survey of care homes in England. *BMC Geriatr* 12(1): 1.
 Hughes CP, Berg L, Danziger WL, Coben LA, Martin R. 1982. A new clinical scale for the staging of dementia. *Br J Psychiatry* 140(6): 566–572.
 Knapp, M., Prince, M., Albanese E., Banerjee, S., Dhanasiri, S., Fernandez, J., et al. 2007. Dementia UK (a report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK produced by King's College London and London School of Economics). Alzheimer's Society: London.
 Knapp, M., King, D., Romeo, R., Schehl, B., Barber, J., Griffin, M., Rapaport, P., Livingston, D., Mummery, C., Walker, Z. and Hoe, J., 2013. Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people with dementia (the START (Strategies for Relatives) study): a pragmatic randomised controlled trial.
 Konezka RT, Spector W, Limcangco MR. 2008. Reducing hospitalizations from long-term care settings. *Med Care Res Rev* 65(1): 40–66.
 Laing, W., 2013. Care of Elderly People UK Market Survey 2012/13, Laing Buisson, January 15, 2013. Retrieved March 16, 2015.
 Laing & Buisson (2015). Care home costs continue to rise ahead of local authority fee settlements, Laing Buisson, January 21, 2015 <http://www.laingbuisson.co.uk/MediaCentre/PressReleases/FairPriceforCare-6th.aspx> Retrieved October 10, 2015.
 Lange RT, Hopp GA, Kang N. 2004. Psychometric properties and factor structure of the Neuropsychiatric Inventory Nursing Home version in an elderly neuropsychiatric population. *Int J Geriatr Psychiatry* 19(5): 440–448.
 Leinonen E, Korpišammal L, Pulkkinen LM, Pukuri T. 2001. The comparison of burden between caregiving spouses of depressive and demented patients. *Int J Geriatr Psychiatry* 16(4): 387–393.
 Life MH. 2007. *Quality of Life in Care Homes. A Review of the Literature*. Help the Aged: London.
 Livingston G, Barber J, Rapaport P, et al. 2013. Clinical effectiveness of a manual based coping strategy programme (START, Strategies for Relatives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial. *Br Med J* 347: f6276. 1–14. ISSN 0959-8138.
 Manning WG, Mullahy J. 2001. Estimating log models: to transform or not to transform? *J Health Econ* 20(4): 461–494.
 Met Life Mature Market Institute, 2012. Market survey of long-term care costs: the 2012 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs. Metropolitan Life Insurance Company: New York.
 Moore MJ, Zhu CW, Clipp EC. 2001. Informal costs of dementia care estimates from the National Longitudinal Caregiver Study. *J Gerontol B Psychol Sci Soc Sci* 56(4): S219–S228.
 Mort JR, Aparasu RR. 2002. Prescribing of psychotropics in the elderly. *CNS Drugs* 16(2): 99–109.
 Murray J, Schneider J, Banerjee S, Mann A. 1999. EURO CARE: a cross-national study of co-resident spouse carers for people with Alzheimer's disease: a qualitative analysis of the experience of caregiving. *Int J Geriatr Psychiatry* 14: 662–667.
 Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., Adelaja, B., Hu, B., King, D. and Rehill, A., 2014. Dementia UK: update. Alzheimer's Society: London.
 Reisberg B, Ferris SH, de Leon MJ, Crook T. 1982. The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychiatry* 139(9): 1136–1139.
 Reynolds T, Thornicroft G, Abas M, et al. 2000. Camberwell Assessment of Need for the Elderly (CANE). *Br J Psychiatry* 176(5): 444–452.
 Royal College of Nursing, 2011. Persistent challenges to providing quality care. London.
 Schaller S, Mauskopf J, Kriza C, Wahlster P, Kolominsky-Rabas PL. 2015. The main cost drivers in dementia: a systematic review. *Int J Geriatr Psychiatry* 30(2): 111–129.
 Smith SC, Lamping DL, Banerjee S, et al. 2005. Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL)

- and an evaluation of current methodology. *Health Technol Assess (Winchester, England)* **9**(10): 1–93.
- StataCorp, 2011. Stata statistical software: release 12.0. College Station, TX: Stata Corporation.
- Whitaker R, Fossey J, Ballard C, *et al.* 2014. Improving Well-being and Health for People with Dementia (WHELD): study protocol for a randomised controlled trial. *Trials* **15**(1): 284.
- Wolstenholme JL, Fenn P, Gray AM, *et al.* 2002. Estimating the relationship between disease progression and cost of care in dementia. *Br J Psychiatry* **181**(1): 36–42.
- Zuidema S, Koopmans R, Verhey F. 2007. Prevalence and predictors of neuropsychiatric symptoms in cognitively impaired nursing home patients. *J Geriatr Psychiatry Neurol* **20**(1): 41–49.