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Article (Submitted version) (Pre-refereed)

Original citation:
Knapp, Martin and Iemmi, Valentina and Romeo, Renee (2012) Dementia care costs and outcomes: a systematic review. International journal of geriatric psychiatry, Online. ISSN 0885-6230
DOI: 10.1002/gps.3864o

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Dementia Care Costs and Outcomes: A Systematic Review

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Running Head: Costs and outcomes – review

Key words: Systematic review; dementia; economic evaluation; costs; cost-effectiveness

Key points

- There is more cost-effectiveness evidence on pharmacological therapies than other interventions. Acetylcholinesterase inhibitors for mild-to-moderate disease and memantine for moderate-to-severe disease were found to be cost-effective.
- Regarding non-pharmacological treatments, cognitive stimulation therapy, tailored activity programme and occupational therapy were found to be more cost-effective than usual care.
There was some evidence to suggest that respite care in day settings and psychosocial interventions for carers could be cost-effective, as could coordinated care management.

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Sponsor(s): Alzheimer’s Society

Structured abstract

Objective:
We reviewed evidence on the cost-effectiveness of prevention, care and treatment strategies in relation to dementia.

Methods:
We performed a systematic review of available literature on economic evaluations of dementia care, searching key databases and websites in medicine, social care and economics. Literature reviews were privileged, and other study designs included only to fill gaps in the evidence base. Narrative analysis was used to synthesise the results.

Results:
We identified 56 literature reviews and 29 single studies offering economic evidence on dementia care. There is more cost-effectiveness evidence on pharmacological therapies than other interventions. Acetylcholinesterase
inhibitors for mild-to-moderate disease and memantine for moderate-to-severe disease were found to be cost-effective. Regarding non-pharmacological treatments, cognitive stimulation therapy, tailored activity programme and occupational therapy were found to be more cost-effective than usual care. There was some evidence to suggest that respite care in day settings and psychosocial interventions for carers could be cost-effective. Coordinated care management and personal budgets held by carers have also demonstrated cost-effectiveness in some studies.

**Conclusion:**

Five barriers to achieving better value for money in dementia care were identified: the scarcity and low methodological quality of available studies; the difficulty of generalising from available evidence; the narrowness of cost measures; a reluctance to implement evidence; and the poor coordination of health and social care provision and financing.
Introduction

Anticipated upward trends in the number of people with dementia will lead to substantial increases in health and social care spending unless provision is altered or there are major breakthroughs in prevention or disease course (Comas-Herrera et al., 2007). Coupled with an anticipated downward trend in the availability of (unpaid) carer support – and in a context of macroeconomic austerity – governments and health and social care funding bodies are looking for ways to maintain – better still to improve – the quality and coverage of care without increasing levels of spending. What, then, is known about the cost-effectiveness of prevention, care and treatment strategies in relation to dementia? We performed a systematic review of available literature, privileging literature reviews.

Methods

A systematic literature review was performed searching key databases and websites in medicine, social care and economics. Electronic searches were conducted in February 2011 of numerous databases: PubMed/Medline, Embase, PsycINFO, EconLit, the Cochrane Library (Cochrane Reviews), and the Centre for Reviews and Dissemination (Database of Abstracts of Reviews and Effects, NHS Economic Evaluation Database, Health Technology Assessment). We looked at these websites: the database of the National Institute for Health and Clinical Excellence (NICE), the Social Care Institute for Excellence (SCIE), the National Audit Office, the Royal College of
Psychiatrists, the Royal College of General Practitioners, the Alzheimer’s Society, the King’s Fund, Carers UK, the Mental Health Foundation, Age UK, and the Bradford Dementia Group.

Key words used for the search were ‘dementia’, ‘Alzheimer’s disease’, ‘vascular dementia’ combined with ‘cost’, ‘hospital’ and ‘home care’. Specific types of dementia beyond Alzheimer’s disease were searched for: ‘dementia with Lewy bodies’, ‘dementia in Parkinson’s disease’, ‘dementia in human immunodeficiency virus (HIV) disease’. Rare types of dementia linked to metabolic or neurological disorders were not specifically searched for but were not excluded, such as ‘dementia in Pick’s disease’, ‘dementia in Huntington’s disease’, ‘dementia in Creutzfeldt-Jakob disease’, ‘dementia in other specified diseases classified elsewhere’, and ‘unspecified dementia’.

Searches were limited to items published from 2005 onwards for databases, and from 2000 onwards for websites. We searched for papers with title and abstract available in English; and full-text in English, French, Spanish or Italian. The inclusion criteria were studies focused on evaluating interventions for people with dementia or their carers which reported evidence on service use or costs, conducted in high-income countries. All study designs were considered: quantitative, qualitative, mixed methods, economic evaluations, systematic interventions targeted on people with mild cognitive impairment (MCI) which did not lead to a dementia diagnosis. We first screened titles and abstracts for relevance (according to the inclusion criteria) and then obtained the full text of included articles.
Narrative analysis was used to synthesise the results. All eligible papers were included. We grouped the papers into four categories:

- pharmacological interventions;
- non-pharmacological interventions for individuals with dementia;
- interventions for carers of individuals with dementia; and
- organisation of care and support.

Literature reviews were privileged, and other study designs included only to fill gaps in the evidence base. Details of the search strategy are available on request from the authors.

Results

After removal of duplicates, 2305 references were identified. Then, the screening by title and summary led to 329 potentially relevant references. Finally, the screening by full-text resulted in 56 included in the final literature review. 29 single studies were considered in order to fill the gap in the evidence presented in the 56 literature review. Figure 1 illustrates the study selection process. Meta-analysis was not performed due to the heterogeneity of the studies.

Pharmacological interventions
The majority of the economic evidence was on pharmacological interventions aimed at alleviating behavioural, cognitive and functional symptoms. A particular interest in the literature is the possibility of slowing down the progression of the disease. From an economic standpoint, this has the potential to reduce carer burden, lessen the rate of hospitalization and delay long-term admission into institutional care, where costs often increase dramatically (Fillit, 2005; Fillit and Hill, 2005). The majority of cost-effectiveness-studies found in our review focused on drugs for Alzheimer’s disease.

Acetylcholinesterase Inhibitors (AChEI) and memantine

Most of the literature reviews concerned acetylcholinesterase inhibitors (AChEI) and memantine. NICE (2011) recently updated its technology appraisal guidance on the use of acetylcholinesterase inhibitors and memantine for Alzheimer’s disease (National Institute for Health and Clinical Excellence, 2006, 2009). Published economic evaluations since 2004 were systematically reviewed by NICE, and results presented by severity of disease. For mild-to-moderate Alzheimer’s disease, it was concluded that AChEI (donepezil, rivastigmine and galantamine) were cost-effective treatments from a health and social care perspective. Memantine represented a cost-effective use of resources only as second choice, when people with mild-to-moderate Alzheimer’s disease were intolerant to or have contraindications to the use of AChEI. In fact, memantine generated fewer quality-adjusted life years (QALYs) at a higher cost. For moderate-to-severe
Alzheimer’s disease, memantine appeared to be the most cost-effective treatment.

Notwithstanding the high quality of the NICE review, these results have a number of limitations. The number of cost-effectiveness studies was relatively small (twelve for AChEI, six for memantine). Second, most of these studies were funded and/or conducted by the manufacturers of the medications, with the attendant potential conflicts of interests. Third, the adaptation of the Assessment of Health Economics in Alzheimer’s Disease (AHEAD) model used by the NICE analysts was contested by the original developers of the model because of the limited amount of data available (Getsios et al., 2007). Though the model was based on old data (1988-1999) and collected on a small sample, it was argued by NICE to be using the best available data.

A previous literature review of AChEI and memantine (Cappell et al., 2010) found donepezil and rivastigmine to be cost-effective (from a societal perspective) compared to placebo in mild-to-moderate, and memantine in moderate-to-severe Alzheimer’s disease. The authors of this well-conducted independent review concluded that this result was largely due to a reduction in dependency and an increase in the proportion of carer time free of caregiving.

Earlier reviews reached slightly different conclusions. For instance, the literature review underpinning the 2006 NICE guideline was unable to reach a conclusion on the cost-effectiveness of AChEI for mild-to-moderate or
memantine for severe Alzheimer’s disease (Loveman et al., 2006). The literature review by the Belgian Health Care Knowledge Centre (Hulstaert et al., 2009) was similarly cautious due to the quality of available studies. These authors argued that health benefits were often gauged by cognition and not as functional abilities, which they averred were pivotal in the decision to admit someone to institutional care. Hulstaert et al. also highlighted that the difference in outcome and cost measures across studies made it difficult to pool evidence. They also made the well-known point that it is hard to generalise the cost-effectiveness results of a study conducted in one country to the context of another. Finally, they noted the pervasive lack of long-term data. These same weaknesses were highlighted by Geldmacher (2008) in their brief review.

Antipsychotic medications

Antipsychotic medications were recommended in the recent NICE-SCIE guidelines for treating non-cognitive symptoms in Alzheimer’s disease, vascular dementia, mixed dementia or dementia with Lewy Bodies with severe non-cognitive symptoms, but only after an individual risk-benefit assessment due to the possible increased risk of cerebrovascular events (NICE-SCIE, 2011). We found no literature reviews on the cost-effectiveness of antipsychotic drugs in Alzheimer’s disease. A single study based on a Markov model concluded that olanzapine was cost-effective compared to doing nothing for the treatment of agitation and psychosis in community-dwelling individuals with Alzheimer’s disease in the United States (Kirbach et
Conversely, a randomized controlled trial found that second-generation antipsychotics (olanzapine, quetiapine, risperidone) analysed as a group were not cost-effective compared to placebo for treating agitation, psychosis and aggression in community-dwelling individuals with Alzheimer’s disease in the United States (Rosenheck et al., 2007). This well-conducted American study (CATIE-D) found that, while health benefits were equivalent, health costs were significantly lower in the placebo group. However, the short follow-up of 9 months did not allow examination of long-term outcomes or costs (e.g., stemming from side-effects or longer-term delays to institutionalisation).

Non-pharmacological interventions for individuals with dementia

We found little economic evidence on non-pharmacological interventions for individuals with dementia. The evidence can be grouped by intervention type: group-based cognitive stimulation, physical exercises programmes and tailored activity programmes.

*Cognitive stimulation therapy (CST)*

Cognitive stimulation therapy (CST) offers ‘activities involving cognitive processing; usually in a social context and often group-based, with an emphasis on enjoyment of activities’ (NICE-SCIE, 2011, p.49). CST has been shown to be effective as primary prevention for older people with good cognitive functioning and as secondary prevention for older people with mild-
to-moderate dementia (Medical Advisory Secretariat, 2008). Literature reviews by the Ministry of Health and Long-Term Care in Ontario (Medical Advisory Secretariat, 2008) and the Belgian Health Care Knowledge Centre (Hulstaert et al., 2009) identified only one randomized controlled trial evaluating the cost-effectiveness of a CST programme as secondary prevention (Knapp et al., 2006). In this English study, CST was offered to people with mild-to-moderate dementia in group sessions run in care homes and day centres twice a week for eight weeks. The sessions focused on senses, remembering the past, people and objects, and everyday practical issues. The authors concluded that CST had the potential to be more cost-effective than usual care and support through its effects on cognition and quality of life. Costs for people receiving CST were not significantly higher than costs for usual care. However, findings were weakened by the small sample (91 intervention group, 70 control) and the short follow-up period (8 weeks, and so long-term outcomes are not known. Only people with mild-to-moderate dementia living in care homes or attending day centres were included, which makes it hard to generalise the results to other severity levels or settings. In addition, social interaction between group participants could have generated the positive outcomes rather than the CST itself. No economic evaluation was found for CST as primary prevention intervention (Medical Advisory Secretariat, 2008).

Physical exercise programmes
Physical exercise programmes have been shown to be effective as primary prevention measures for older people with good cognitive functioning and as secondary prevention for older people with mild-to-moderate dementia (Medical Advisory Secretariat, 2008; Forbes et al., 2008). They have the potential to delay onset or slow dementia progression. They are recommended in England and Wales as part of a care plan to promote and maintain independence for people with dementia (NICE-SCIE, 2011). No economic evidence was found.

**Tailored activity programme (TAP)**

The tailored activity programme approach (TAP) is a home-based intervention consisting of eight sessions (six home contacts and two telephone contacts) of structured occupational therapy over four months, providing individuals with dementia with activities tailored to their cognitive and functional capabilities, and to train carers in the use of those activities. It is organised around three phases: abilities are evaluated by the occupational therapist; then activities are tailored to the capabilities of the individual with dementia and carers are instructed on strategies; and finally, once the activities have been mastered, occupational therapists help to generalise the strategies to other care activities.

A randomised controlled trial conducted in the United States demonstrated the cost-effectiveness of TAP compared to usual treatment (Gitlin et al., 2010), mainly because TAP was able to reduce carer time inputs. However,
the study was unclear on how carers chose to spend the non-caregiving time
that was ‘released’ or whether there were improvements to carer health.
Moreover, the sample size was small (60 patient-carer pairs, four of whom
dropped out) and there was no collection of data beyond four months.

Occupational therapy

A randomized controlled study in the Netherlands found that occupational
therapy at home for community-dwelling people with mild-to-moderate
dementia was not only cost-effective but also cost-saving when compared to
usual care (Graff *et al.*, 2008). The intervention consisted of ten one-hour
sessions at home, delivered over five weeks. The first stage was the
evaluation of the severity of an individual’s disability and its effects on
activities of daily living (ADLs), and the selection of which ADLs to aim to
improve. The second stage was the modification of the home and
environment, and the teaching of compensatory and environmental strategies.
Carers were also trained to use effective supervision. The study found that
cost savings mainly accrued as a result of reductions in informal care, and
that occupational therapy ‘yielded significant and clinically relevant
improvements in daily functioning in patients and sense of competence in
carers’ (Graff *et al.*, 2008, p.7 online). The study has limitations: like many
studies in this area, it was not possible to make it double-blind, the follow-up
period was short (3 months, and there were questions about
representativeness of study participants.)
**Positron emission tomography (PET)**

A Belgian study, based on a decision tree design, found that F-fluoro-deoxyglucose positron emission tomography (FDG PET) was cost-saving when added to standard diagnostic approaches because it had the potential to delay cognitive decline by allowing the more accurate prescription of medications (Moulin-Romsee *et al.*, 2005).

**Magnetic resonance imaging (MRI) and neuropsychological testing**

Although there is supportive evidence on clinical effectiveness of magnetic resonance imaging (MRI) and neuropsychological testing for individuals with minor cognitive impairment and mild dementia as diagnostic tools (SBU, 2008), no cost-effectiveness evidence was found (Hulstaert *et al.*, 2009).

**Wandering**

A systematic literature review of non-pharmacological interventions to prevent wandering in individuals with dementia in comparison to usual care reported no relevant cost-effectiveness studies (Robinson *et al.*, 2006; Robinson *et al.*, 2007).

**Ginko biloba**
No evidence was found on the cost-effectiveness of Ginko biloba as a primary or secondary preventive intervention (Hulstaert et al., 2009).

Interventions targeted on carers

Given the key role that unpaid family and other carers play in supporting people with dementia, a breakdown in that relationship can often lead to short- or long-term admission into a care home or hospital, both of which generate high costs for funding bodies, the family or the person with dementia themselves. We found economic evidence for only two broad types of intervention: respite care and psycho-educational support.

*Respite care or short-term breaks*

Respite care or short-term breaks may be offered in different forms: day care services, in-home respite services, host-family respite, institutional (overnight) respite services, respite programmes, multi-dimensional carer-support packages and video respite (Arksey et al., 2004). Given this variety it has been hard to draw clear conclusions from the available evidence. A report from the Ministry of Health and Long-term Care in Ontario (Medical Advisory Secretariat, 2008) found only two substantial reviews of the economic literature on respite care: a Cochrane review by Lee and Cameron (2004) and the above-mentioned review by Arksey and colleagues (2004).
In their comprehensive review, Arksey et al. (2004) found economic evidence in support of day care. Within the four studies included in their review, two ‘suggested that day care might be cost-saving’ while the other two ‘suggested that day care might provide greater benefits but at a higher cost as compared to standard care. All four studies suggested that the benefits of day care might be similar or greater than those achieved through standard care’ (p.52). A Canadian study that examined the cost-effectiveness of multi-dimensional carer-support packages in the 1980s concluded that cost per QALY for the support package was quite favourable compared to other health care interventions (Drummond et al., 1991). No economic evidence was found for in-home respite, host-family respite, institutional or overnight respite, respite programmes or video respite.

Psycho-educational support

The Belgian Health Care Knowledge Centre identified only two literature reviews on cost-effectiveness of caregiver support (Hulstaert et al., 2009). The first was produced by the Swedish Council on Technology Assessment in Health Care and based on one short-term study and two long-term economic models of non-pharmaceutical interventions for carers (SBU, 2008). Support was broadly defined as programmes of counselling, education, emotional support, and contact provided to carers. No significant change in cost or outcomes was reported when comparison was made to standard care. The second review was produced by NICE in collaboration with SCIE: it reached no conclusion on the cost-effectiveness of interventions for caregivers of
individuals with dementia in comparison with usual care, because of the scarcity of evidence and the heterogeneity of the five available economic evaluations (NICE-SCIE, 2006).

_Befriending_

Charlesworth _et al._ (2008) evaluated a befriending intervention in which trained befrienders were matched with carers and given one-to-one emotional support in England. Wilson _et al._ (2009) reported the associated cost-effectiveness study. The researchers concluded that the befriending intervention was neither effective nor cost-effective compared to standard care.

_Psychosocial intervention_

A quasi-experimental study of a psychosocial intervention for family carers in Sweden found that counselling sessions and conversation groups resulted in significant delays in nursing home placements for people with dementia, compared to standard care arrangements (Andren and Elmstahl, 2008). A randomised trial was conducted in the United States, evaluating a multi-component intervention that included ‘modules focusing on information, safety, caregiver health and well-being, and behaviour management for the care recipient’ (Nichols _et al._, 2008, p.3 online). Twelve individual sessions were delivered in the caregivers’ home (nine sessions) and through telephone (three sessions), and supplemented by five telephone-administered support-
group sessions of five or six careers. The study highlighted a significant
difference in care-giving hours, each additional hour of care-free time for
carers costing just under $5 per day or an extra $893 over the 6-month
period. However, the authors highlighted the short duration of their study (6
months) compared to the Brodaty and Peters (1991) study in Australia that
demonstrated cost-savings over 39 months from a multi-component
residential training programme for carers.

Organization of care and support

Research on the organisation of care and support which has included
economic evaluation has concentrated on three main areas: direct payments,
care management, and coordinated responses to co-morbidity.

Direct payments

Direct payments transfer social care funding to service users, who then have
the opportunity to spend their budgets on a range of services to meet their
personal (care) needs. Variants of direct payments have been tried in different
countries as individual budgets, self-directed support, personal budgets, and
personal health budgets.

There is no evidence on the economic impacts of direct payments or personal
budgets specifically for people with dementia. The only well-conducted
economic evaluations for older people – one in England and one in Germany
– do not offer especially encouraging support for this organisational arrangement. In Germany, Arntz and Thomsen (2011) concluded that cash payments crowded-out informal care activity, and did not appear to be cost-effective. In England, the evaluation of the individual budgets pilot programme showed that costs were no different compared to standard care arrangements for older people with individual budgets, but outcomes were marginally worse (Glendinning et al., 2006). However, the evaluation period of six months may have been too short to show expected better outcomes over time. Analysis of the impacts of individual budgets on carers of older people suggested better outcomes at equivalent costs, compared to standard care and support arrangements (Glendinning et al., 2009).

*Care management*

One review of cost-effectiveness of community-based care management (case management or coordinated care/case management) for individuals suffering from dementia and their carers was found (Pimouguet et al., 2010). Only three randomized controlled studies conducting an economic analysis of case management programmes for people with dementia were identified by those reviewers. Pimouguet et al. interpreted the evidence as not indicating cost-effectiveness, due to the dearth of studies and heterogeneity of the populations studied, but our reading of the evidence is different. Notwithstanding the scarcity of robust studies, there are a few other well-conducted studies that demonstrate the impact of care management arrangements on delayed institutionalisation, implying economic pay-offs in
the United States (Mittelman et al., 2006; Brodaty et al., 2009), in China (Chien and Lee, 2008) and in Australia and England (Brodaty et al., 2009).

One study evaluated the cost of a coordinated care management intervention for people with dementia living on community settings in the United States (Duru et al., 2009). Patients with dementia were assigned a care manager responsible for assessing problems at home and then to reassess them every six months, developing a care plan, and referring on to primary care and community agencies for specific treatment and care services. While coordinated care management was not cost-saving compared to standard care, it was found to be cost-effective from both payer and social planner perspectives because of improvements in patient and carer outcomes, and in dementia care quality.

Management of co-morbidity

Individuals with dementia have an elevated risk of co-morbid conditions (Duthie et al., 2011), and hence could require more medical or social care. An American study showed the higher costs compared with matched individuals without dementia (Kuo et al., 2008). The most prevalent co-morbidities were psychiatric conditions (depressive, bipolar and delusional disorders), ischemic or unspecified stroke, and hip fractures/dislocations. For example, psychiatric conditions were five times more prevalent among people with Alzheimer’s disease than matched controls, and costs were 1.5 times higher (and even
this was an under-estimate due to the inclusion only of costs recorded in the Medicare database and medical and pharmaceutical claims).

In the UK, it has been suggested that a quarter of acute NHS hospital beds are occupied by people with dementia (Alzheimer's Society, 2009). The dementia hospital research in the UK (DEMHOS) highlighted the main causes of hospitalization in individuals with dementia as falls (14%), broken/fractured hip (12%), urine infection (9%), chest infection (7%) and stroke (7%). Hospital stays were longer for people with dementia than for other patients, with expected higher costs. Another English study carried out for the National Audit Office found that earlier discharge and better management of hip fracture in demented patients could save between £64 million and £102 million a year in England (Henderson et al., 2007; and National Audit Office, 2007).

Discussion

Summary findings

Our literature review synthesised the economic evidence on dementia care. There is more cost-effectiveness evidence on pharmacological therapies than for any other types of intervention, with the largest collection of evidence relating to acetylcholinesterase inhibitors (AChIIE) and memantine. In particular, AChIIE for mild-to-moderate disease and memantine for moderate-to-severe disease were found to be cost-effective. The much smaller body
evidence on non-pharmacological treatments (cognitive stimulation therapy, tailored activity programme and occupational therapy) was harder to interpret.

Evidence on support for family and other unpaid carers was limited and confined to a narrow range of options: day care, psycho-educational interventions and befriending. Similarly, there was little cost-effectiveness evidence on strategies to alter the organisation of care and support: some evidence on direct payments and some on care/case management. Evidence in the latter area suggested long-term cost-effectiveness. The small body of evidence on management of co-morbidity in people with dementia pointed to potentially sizeable savings and cost-effectiveness gains.

No evidence were found on primary prevention of dementia or action to delay its onset, and on end-of-life care for people with dementia except for one study of costs (McCrone, 2009).

Limitations

While database searches covered all countries, websites searches were confined to the United Kingdom. Although we did not expect to find many studies from governmental and non-governmental websites in other countries, we were unable to check. Second, the quality of some literature reviews found was low and none of presented findings was supported by meta-analysis due to the paucity and heterogeneity of available studies. Third, for the same reason we were unable to perform a meta-analysis on included studies.
Barriers to achieving cost-effectiveness

From this review we can identify a number of barriers to achieving better value for money in dementia care. One obvious barrier is the scarcity and low methodological quality of the available studies, making it difficult to draw conclusions with confidence. Among those limitations is the short time frame adopted for measuring most outcomes and costs.

Second, generalisation from the available evidence is hindered by both the heterogeneity of the populations studied (in terms of severity, co-morbidity, care settings) and familiar inter-country differences in organisation, funding and incentives in health and social care systems.

Third, many studies adopt a narrow perspective when measuring cost, looking only at health care. Given the pivotal roles of family and other carers in dementia care, a broader societal perspective is generally needed if decision-makers are to understand the wide range of potential economic impacts, including the opportunity costs of carer inputs and the impacts of caring on their own health and wellbeing.

Fourth, even when robust evidence is available and relevant, there is an apparent reluctance to implement it by adjusting the treatment, care and support offered. For instance, even though cognitive stimulation therapy is supported by fairly good effectiveness and cost-effectiveness evidence, albeit
over relatively short periods, only 10% of the primary care trusts and mental health trusts in England is commissioning or delivering such therapy (data from a FOI request sent to Trusts and passed on to us).

Fifth, while people with dementia usually experience deteriorations in both health and capacity for self-care, and hence need both health and social care support, these services are often delivered by different providers and funded from different budgets, and poor coordination – most damagingly in the form of cost-shifting and ‘problem-dumping’ – will be a source of inefficiency. The need for better coordination is heightened at a time of macroeconomic austerity – with attendant budget cuts – but is arguably harder to achieve in such a context. Some form of self-directed care, for example personal budgets held by carers, might offer a solution to this ‘silo budget’ problem.

**Funding support**

The work described in this paper was part-funded by the Alzheimer’s Society, but all views expressed are those of the authors.

**Conflict of interest**

None

**Acknowledgements**

This paper benefitted from comments from the Alzheimer’s Society.
References


Figure 1: Flow chart of study selection process

N=2731
potentially relevant references identified from electronic databases (N=2686) and websites (N=45);
eligible for screening by title/abstract

N=1976
references excluded after screening by title/abstract

N=329
potentially relevant references;
eligible for screening by full-text

N=258
references excluded after screening by full-text

N=71
references excluded because full-text not found

N=426
references excluded as duplicates

N=56
relevant references;
eligible for data extraction
APPENDIX

Search strategy

PubMed
"Dementia"[Mesh] AND ("Costs and Cost Analysis"[Mesh] OR "Hospitals"[Mesh]) OR "Home Care Services"[Mesh])
Limits: Publication Date from 2005/01/01 to 2011/12/31

Embase (OvidSP)
dementia AND ("cost" OR hospital OR home care)
Limits: Publication Date from 2005 to 2011

PsycINFO (OvidSP)
(exp dementia/) AND ((exp "costs and cost analysis") OR hospitals/ OR home care/)
Limits: Publication Date from 2005 to 2011

EconLit (EBSCO)
(Dementia* OR Alzheimer*) AND (Economic* OR cost OR costs OR costing OR Cost-benefit OR Cost-utility OR Cost-effectiveness OR Expenditure* OR commissioning OR spending OR Budget OR savings OR financ* OR pay-off* OR Payer OR “Third-party payer” OR “health insurance” OR “health insurances” OR “psychiatric insurance” OR “psychiatric insurances” OR “catastrophic health insurance” OR “catastrophic health insurances” OR “high-deductible health plan” OR “high-deductible health plans” OR Medicare OR Medicaid OR Medigap OR Medisave OR Medishield OR Medifund OR Eldershield OR Fee* OR “fee-for-service” OR “fee for service” OR “hospital charge” OR “hospital charges” OR “out-of-pocket” OR “co-payment” OR “copayment” OR “co-insurance” OR “coinsurance” OR “user charge” OR “user charges” OR deductib* OR reimbursement* OR “diagnosis-related group” OR “diagnosis-related groups” OR “diagnosis related group” OR “diagnosis related groups” OR “Medical Savings Account” OR “Medical Savings Accounts” OR “social security” OR “social care” OR “disability claim” OR “disability claims” OR “disability benefit” OR “disability benefits” OR “disability allowance” OR “disability allowances” OR “disability living allowance” OR “disability living allowance” OR “carer’s allowance” OR “carer’s allowances” OR “attendance allowance” OR “attendance allowances” OR “self directed support” OR “self-directed support” OR “direct payment” OR “direct payments” OR “cash payment” OR “cash payments” OR housing OR Institutionalisation* OR Institutionalization* OR “nursing home” OR “nursing homes” OR “skilled nursing unit” OR “skilled nursing units” OR “care home” OR “care home” OR “care homes” OR “rest home” OR “rest homes” OR “convalescent home” OR “convalescent homes” OR “medicalised home” OR “medicalised homes” OR “medicalized home” OR “medicalized homes” OR “home care” OR “homecare” OR “respite care” OR “residential care” OR “community care” OR “community-based care” OR “long term care” OR “long term support” OR “long term support” OR “assisted living” OR Employment* OR Income* OR salary OR salaries OR Wage* OR “career mobility” OR (resource* N3 use*) OR (resource* N3 utili*) OR (resource* N3 consum*) OR (service* N3 use*) OR
The Cochrane Library (Cochrane Reviews)
(MeSH descriptor Dementia explode tree 2) AND (Economic* OR cost OR costs OR costing OR Cost-benefit OR Cost-utility OR Cost-effectiveness OR Expenditure* OR commissioning OR spending OR Budget* OR savings OR financ* OR pay-off* OR Payer OR Medicare OR Medicaid OR Medigap OR Medisave OR Medishield OR Medifund OR Eldershield OR Fee* OR fee-for-service OR out-of-pocket OR co-payment OR copayment OR co-insurance OR coinsurance OR deductibl* OR reimbursement* OR housing OR Institutionalization* OR Institutionnalisation* OR homecare OR Employment* OR Income* OR salary OR salaries OR Wage* OR insurance* OR high-deductible OR (fee for service) OR (hospital charge) OR (hospital charges) OR (user charge) OR (user charges) OR (diagnosis-related group) OR (diagnosis-related groups) OR (diagnosis related group) OR (diagnosis related groups) OR (Medical Savings Account) OR (Medical Savings Accounts) OR (social security) OR (social care) OR (disability claim) OR (disability claims) OR (disability benefit) OR (disability benefits) OR (disability allowance) OR (disability allowances) OR (disability living allowance) OR (disability living allowances) OR (carer's allowance) OR (carer's allowances) OR (attendance allowance) OR (attendance allowances) OR (self-directed support) OR (self-directed support) OR (direct payment) OR (direct payments) OR (cash payment) OR (cash payments) OR (nursing home) OR (nursing homes) OR (skilled nursing unit) OR (skilled nursing units) OR (care home) OR (care homes) OR (rest home) OR (rest homes) OR (convalescent home) OR (convalescent homes) OR (medicalised home) OR (medicalised homes) OR (medicalized home) OR (medicalized homes) OR (home care) OR (respite care) OR (residential care) OR (community care) OR (community-based care) OR (long term care) OR (long-term care) OR (long term support) OR (long-term support) OR (assisted living) OR (career mobility) OR (resource* AND use*) OR (resource* AND utili*) OR (resource* AND consum*) OR (service* AND use*) OR (service* AND utili*) OR (service* AND consum*) OR hospitali* OR (inpatient AND use*) OR (inpatient AND utili*) OR (inpatient AND consum*) OR (in-patient AND use*) OR (in-patient AND utili*) OR (in-patient AND consum*) OR (hospital AND use*) OR (hospital AND utili*) OR (hospital AND consum*) OR (healthcare* AND use*) OR (healthcare* AND utili*) OR (healthcare* AND consum*) OR (health care* AND use*) OR (health care* AND utili*) OR (health care* AND consum*)

Limits: Publication Date from 2005/01/01 to 2011/12/31

Centre for Reviews and Dissemination (DARE, NHS EED, HTA)
(MeSH Dementia EXPLODE 2) AND (Economic* OR cost OR costs OR costing OR Cost-benefit OR Cost-utility OR Cost-effectiveness OR Expenditure* OR commissioning OR spending OR Budget* OR savings OR
financ* OR pay-off* OR Payer OR Medicare OR Medicaid OR Medigap OR Medisave OR Medishield OR Medifund OR Eldershield OR Fee* OR fee-for-service OR out-of-pocket OR co-payment OR copayment OR co-insurance OR coinsurance OR deductible* OR reimbursement* OR housing OR Institutionalization* OR Institutionalisatation* OR homecare OR Employment* OR Income* OR salary OR salaries OR Wage* OR insurance* OR high-deductible OR "fee for service" OR "hospital charge" OR "hospital charges" OR "usercharge" OR "user charges" OR "diagnosis-related group" OR "diagnosis-related groups" OR "diagnosis related group" OR "diagnosis related groups" OR “Medical Savings Account” OR “Medical Savings Accounts” OR “social security” OR “social care” OR “disability claim” OR “disability claims” OR “disability benefit” OR “disability benefits” OR “disability allowance” OR “disability allowances” OR “disability living allowance” OR “disability living allowances” OR “carer’s allowance” OR “carer’s allowances” OR “attendance allowance” OR “attendance allowances” OR “self directed support” OR “self-directed support” OR “direct payment” OR “direct payments” OR “cash payment” OR “cash payments” OR “nursing home” OR “nursing homes” OR “skilled nursing unit” OR “skilled nursing units” OR “care home” OR “care homes” OR “rest home” OR “rest homes” OR “convalescent home” OR “convalescent homes” OR “medicalised home” OR “medicalised homes” OR “medicalized home” OR “medicalized homes” OR “home care” OR “respite care” OR “residential care” OR “community care” OR “community based care” OR “long term care” OR “long-term care” OR “long term support” OR “long-term support” OR “assisted living” OR “career mobility” OR (resource* AND use*) OR (resource* AND utili*) OR (resource* AND consum*) OR (service* AND use*) OR (service* AND utili*) OR (service* AND consum*) OR (hospital* OR (inpatient AND use*) OR (inpatient AND utili*) OR (inpatient AND consum*) OR (in-patient AND use*) OR (in-patient AND utili*) OR (in-patient AND consum*) OR (hospital AND use*) OR (hospital AND utili*) OR (hospital AND consum*) OR (healthcare* AND use*) OR (healthcare* AND utili*) OR (health AND care* AND consum*) OR (health AND care* AND use*) OR (health AND care* AND utili*) OR (health AND care* AND consum*)

Limits: Publication Date from 2005 to 2011

Websites
Google advanced search: dementia OR "Alzheimer's disease" OR "vascular dementia" cost OR hospital OR "home care" site:[website address]

Search results

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<thead>
<tr>
<th>Source</th>
<th>Number of references</th>
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<tr>
<td>PubMed</td>
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<tr>
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<tr>
<td>PsycINFO (OvidSP)</td>
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<tr>
<td>EconLit (EBSCO)</td>
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<td>The Cochrane Library (Cochrane Reviews)</td>
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<tr>
<td>Centre for Reviews and Dissemination (DARE)</td>
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</table>
NHS, EED, HTA
Total (databases) 2686

**Websites**
- National Institute for Clinical Excellence 3
- Social Care Institute for Excellence 1
- National Audit Office 6
- Royal College of Psychiatrists 0
- Royal College of General Practitioners 0
- Alzheimer’s Society 26
- Kings Fund 3
- Carers UK 1
- Mental Health Foundation 3
- Age UK (formerly Age Concern & Help the Aged) 2
- Bradford Dementia Group (at Bradford University) 0

Total (websites) 45

Total before screening 2731