Components, impacts and costs of dementia home support: a research programme including the DESCANT RCT

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Scientific summary

The DESCANT RCT

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Scientific summary

Background

Dementia is a major challenge to public health and care, with high disability and high cost. Recent policy and research has explored ways to address this challenge. With no known cure at present, the immediate priority is to help people to 'live well with dementia'.

Over half of people with dementia live at home. Therefore, helping them to live well means identifying appropriate and effective home support from the NHS and social care. Research into non-pharmacological interventions has identified potentially effective approaches, but these have not been translated into routine home support that could be provided. There is some evidence about different interventions and how these could be combined into models of support. As yet, however, there is little evidence about the effects and costs, let alone the cost-effectiveness, of different forms of support.

The literature identifies evidence gaps where new knowledge is required. The potential benefits of a home-based cognitive support component in early dementia and specialist domiciliary care at later stages are two promising areas of enquiry. It is important for future policy and practice to identify appropriate home support, with components used alone and in combination, and to evaluate their costs and benefits.

Objectives

Our aims were to distinguish different models of home support, classify them, survey their current operation in England, and evaluate their clinical effectiveness and cost-effectiveness. We also aimed to disseminate findings in the form of guidance for managers and commissioners.

Specific objectives

Workstream 1: components

- To investigate the evidence for components of psychosocial interventions for dementia in any setting (overview of systematic reviews) and then assess how to combine these into multicomponent home support approaches (systematic review).
- To measure the presence of different components in existing provision in England through a national survey of NHS and social care.
- To develop an economic model to inform later analyses.

Workstream 2: impact

- To evaluate the clinical effectiveness and cost-effectiveness of memory aids and guidance in their use in early dementia through a pragmatic randomised trial [i.e. the DESCANT (Dementia Early Stage Cognitive Aids New Trial)].
- To estimate the clinical effectiveness and cost-effectiveness of different models of home support in later dementia through a naturalistic observational study.
- To disseminate evidence-based guidance through a toolkit developed in one trust with commissioners, managers and practitioners.

Workstream 3: costs and consequences

- To seek evidence of the transition from informal to formal home support in dementia and the costs of this potential support.
- To examine the preferences of people with dementia and their carers between different home support packages, combining components in different ways.
- To estimate the cost-effectiveness of home support models emerging from the programme to public agencies, people with dementia and carers.

Methods

We divided the programme into three workstreams that were undertaken between 2013 and 2020.

Workstream 1: components

We conducted an evidence synthesis of literature on home support in dementia, undertaking two systematic reviews to provide evidence. First, an overview of systematic reviews to identify components of psychosocial interventions to people with dementia in any setting, including care homes, day care and at home. Second, a systematic review of quantitative and qualitative studies of home support interventions, using the components identified in the overview to discern distinct combined approaches to home support. Both systematic reviews used narrative synthesis in response to the heterogeneity of interventions and outcome measures.

We undertook national surveys of NHS and social care services in England. These assessed the presence of different components of home support in existing services and who provides them. The first investigated provision by specialist NHS services, memory clinics and Community Mental Health Teams, the second investigated provision by social care services.

We developed an economic model to synthesise economic evidence for home support approaches in two stages: (1) a systematic review to identify cost-effectiveness evidence and (2) development of an economic model by choosing an appropriate model and the types of data to use, identifying data shortfalls in identifying home support approaches and, later, comparing benefits with costs.

Workstream 2: impact

Building on our evidence synthesis, surveys and economic modelling, we undertook a multisite pragmatic randomised trial to compare the clinical effectiveness and cost-effectiveness of memory aids delivered by dementia support practitioners to people with early dementia with treatment as usual. We conducted internal feasibility and pilot studies and then a full trial across 10 NHS trusts in England and Wales. Eligible participants were people with early-stage dementia (and their carers) who were aged > 50 years and diagnosed through NHS memory services. The primary outcome was activities of daily living after 6 months, measured by the Bristol Activities of Daily Living Scale. We used multilevel mixed-effect models to analyse the data and mixed methods within-trial interviews to undertake a process evaluation to assess implementation and acceptability.

We also conducted a naturalistic observational study of people with dementia and their carers already receiving home support services. We recruited participants across 10 local authority areas with different intensities of provision, identified from our national survey. Eligible participants were people with later-stage dementia (and their carers) who were aged > 60 years and were screened by health and social care agencies. The primary outcome was activities of daily living after 6 months, also measured by the Bristol Activities of Daily Living Scale. We evaluated the relative effectiveness of care packages with different intensities of provision through linear mixed models, using propensity scores to minimise the effect of confounding. The study included a qualitative analysis that was embedded within the study research interviews.

The resulting toolkit on the programme website disseminated evidence to commissioners and managers through a set of infographics and web-based tools.

Workstream 3: costs and consequences

We consulted panels of experts, carers and staff through simulation exercises and asked them to identify the inputs necessary to support people in different circumstances through case vignettes. These enabled us to analyse the balance of costs between formal paid help and informal care.

We conducted two discrete choice experiments to assess the preferences of people with dementia and their carers between home support packages with different components, with one for early dementia and the other for later dementia. We recruited participants through memory clinics, online and postal questionnaires, and discussion groups. We analysed data by conditional logistic regression to model the strength of preferences for different attributes.

We used cost–utility analysis to model the costs and benefits of these home support packages from our two primary studies: (1) the trial in early dementia and (2) the observational study in later stages. We compared incremental cost-effectiveness ratios with a range of decision-makers' willingness to pay for a quality-adjusted life-year gained. The perspective of the primary analysis was public and carer costs and health benefits to people with dementia and their carers, and we analysed several other perspectives.

Results

Workstream 1: components

We identified 279 reviews and included 36 (13%) in our overview. One hundred and forty-eight (61%) of the 243 excluded reviews were of pharmacological interventions. Of the included reviews, 15 (42%) assessed a range of interventions and 21 assessed specific interventions, of which 18 (86%) were set within nursing or care homes. Synthesis identified 14 components (nine for people with dementia and five for carers). For people with dementia, there was evidence of clinical effectiveness for cognitive support, but less for sensory stimulation, emotional support, behaviour management and daily living assistance. For carers, there was evidence of clinical effectiveness for behaviour management and emotional support. Our second systematic review identified 603 references and included 70 (12%). Fifty-two of the included reviews assessed multicomponent studies for carers and 36 assessed studies for people with dementia, of which 21 (58%) focused on specific interventions. We identified nine home support packages [seven home support packages for carers based on behaviour management, education or advice, or social support (three apparently more effective), and emotional support or respite; and two home support packages based on environmental modifications and care co-ordination for people with dementia].

Our national survey about mental health care received responses from 51 NHS trusts that provide mental health services (i.e. 75% of 68 trusts). The trusts provided data on 120 (79%) of the 151 local authority areas in England. They reported that Community Mental Health Teams and memory services offered information and advice about dementia, access to relaxation and assistance in managing challenging behaviours. In particular, 110 (92%) memory clinics and 108 (90%) Community Mental Health Teams provided advice on using memory aids. Our national survey about social care received responses from 122 (81%) of the 151 local authorities. Respite care (83%) and day care (81%) were the most frequently reported services and specialist home care was reported in 28% of areas. From these surveys, we derived a 'service mix score' to help select sites for the observational study, using 16 indicators (nine indicators about local authorities and seven indicators about the NHS). This score represented the scope for people with dementia to receive a range of different services.

The economic review retrieved 151 articles, of which 14 studies met the inclusion criteria (eight concerning support to people with dementia and six about support to carers). Five studies reported data for cost per quality-adjusted life-year. In four studies, home support interventions 'dominated' usual care. Two interventions were more costly but more beneficial and were favourable when judged against acceptability thresholds. Occupational therapy, home-based exercise and a carers' coping intervention were potentially cost-effective. In developing our economic model, there were insufficient data to estimate complex mathematical models and so we decided to rely on primary data from our trial and observational study to model the costs and effects of home support in early and later dementia, respectively.

Workstream 2: impact

A multicentre, pragmatic randomised trial (i.e. DESCANT) of the manualised intervention developed in workstream 1 was developed to estimate the effectiveness of providing memory aids and guidance to people with early-stage dementia. We recruited and randomised 468 people with dementia and their carers, with 234 pairs in each arm. Attrition at 6 months was as expected and so the total number of participants with analysable data at baseline was 347, slightly lower than our target. Our intervention had no significant effect at the primary end point of 6 months on the activities of daily living of people with dementia. We assessed these activities by Bristol Activities of Daily Living Scale scores, which range from 0 to 60, with higher scores showing greater dependence. After adjustment for differences at baseline, the mean difference was 0.38, slightly but not significantly favouring the comparator group receiving treatment as usual. The 95% confidence interval ran from −0.89 to 1.65 ($p = 0.56$). Adjusted analysis also showed no significant effect on a comprehensive portfolio of secondary outcomes for both people with dementia and their carers. Our process evaluation showed good engagement, with the intervention delivered as planned with packages individually tailored to participants. Qualitative analysis highlighted issues concerning the research interview itself and the recruitment of people with dementia to trials.

In an observational study of later-stage dementia, we recruited 518 people with dementia and their carers, which was well above our target sample size of 400 and allowed for attrition. We interviewed 389 participants after 6 months. The resulting models showed no evidence that more intensive packages of care were more effective than basic care at home. Although participants with more home care visits were more likely, and those receiving higher intensity care less likely, to be living at home at 12 months, it is difficult to infer causation in any observational study.

Workstream 3: costs and consequences

The types of home support suggested most frequently by our expert panels were informal care, personal home care and day care. Across five case vignettes, staff suggested an average of 66 hours per week of support and informal carers an average of 51 hours. Translating these into costs, formal care would cost a mean of £719 and £634 per week, as recommended by staff and informal carers, respectively. Informal care would cost a mean of £632 and £391 per week, as recommended by staff and informal carers, respectively. Therefore, staff recommended informal care costing 88% of formal care, but for informal carers the ratio was only 62%.

Generally, from the discrete choice experiments, the most preferred components of home support in early dementia were support for personal feelings and concerns, information on coping with dementia and packages costing less. However, people with dementia most preferred social and recreational activities, and carers of those in later dementia most valued regular respite care and regular home care.

In early dementia, our DESCANT intervention is unlikely to be cost-effective. In later dementia, more intensive care packages are unlikely to be cost-effective (i.e. they were more costly and less effective than basic care). From a third-sector perspective, intermediate intensity packages were cheaper but less effective, driven mainly by reduced use of carers' groups.

Conclusions

The toolkit co-produced with staff, carers and people with dementia identifies several components with potential to support people with dementia and their carers at home. Although several services are already providing some of these components, there is a need for more evidence of clinical effectiveness and cost-effectiveness. Preferences differ. Cognitive support was judged to be important by people with dementia and carers, but less so by professionals. People with dementia valued advice on memory aids, emotional support, access to community facilities, health promotion, information and relaxation.

Two primary studies, for early- and later-stage dementia, were essentially negative. There was no evidence that use of and guidance on memory aids benefited daily living activities, or that more intensive packages were more effective than basic care. However, home care appears successfully targeted at more vulnerable people and is effective at keeping people at home. Our interventions in both early and later dementia are unlikely to be cost-effective.

Recommendations for future research

There is still a need for research into home support for people with dementia and their carers, and for methodological development. Eliciting the preferences of people with dementia, carers and staff is important, and sensitive outcomes are required to detect subtle effects that people with dementia and their carers value, such as independence and engagement. We need to work on the effectiveness of different recruitment strategies for studies, particularly for those who are hard to reach. Methods of economic evaluation in this area, particularly of social care, are another priority for future development.

Study registration

This trial is registered as ISRCTN12591717. The evidence synthesis is registered as PROSPERO CRD42014008890.

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