

The effectiveness of collaborative care for people with memory problems in primary care: results of the CAREDEM case management modelling and feasibility study

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Scientific summary

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Background

Dementia care in the UK is in urgent need of improvement, with difficulties in delivering services in a timely, integrated, effective or cost-effective manner. Current national guidance on dementia care recommends the provision of co-ordinated health and social care, led by a single health or social care professional (a case manager). Case managers systematically follow up patients under regular supervision and (usually) provide psychological support and practical help. However, there is little reason to promote case management for people with dementia on the current available evidence, and there is a clear lack of UK-based research exploring the clinical effectiveness and cost-effectiveness of a case management approach in dementia care.

Objectives

This feasibility study was designed to explore (1) what skills are needed to be a dementia case manager working in primary care, and by whom, and how these skills are best provided; (2) whether or not case management is acceptable and beneficial to people with dementia and their families; (3) whether or not case management of people with dementia is feasible in UK general practice; and (4) what resources are needed to deliver case management to people with dementia in UK primary care.

Methods

Following a literature review, three work packages were carried out in this study. In work package 1 (WP1) a co-design approach was taken to the development of the intervention, with an intervention design group comprising health and social care professionals, a carer and members of the Alzheimer's Society and Age UK. This group met six times over a year to identify the skills and personal characteristics required for case management and the types of information and advice needed by people with dementia and their family carers. An independent panel of subject area experts from different backgrounds critically reviewed the materials produced by the design group, which included a case management training programme, built around educational needs assessment, training and mentoring, and a manual on case management with information materials to use with people with dementia and their carers. Care protocols used in a US study were adapted for use in a UK setting with people with dementia and their family carers.

In work package (WP2), the case management intervention was tested in four volunteer general practices for its acceptability to key stakeholders (patients, carers and professionals) and its feasibility for use in UK primary care. Two practices (in London and Norfolk) seconded one of their practice nurses to the case management project for one session per week. The other two (in Newcastle) had access to a full-time social worker seconded from local authority adult services. People with dementia were identified from practice Quality and Outcomes Framework (QOF) dementia registers and their eligibility was assessed by case managers in conjunction with practice staff. Inclusion criteria were (1) having a dementia diagnosis confirmed by specialist services; (2) having a carer; (3) not being resident in a care home; and (4) not having regular reviews by specialist services. Eligible patient-carer dyads were invited by either general practitioners or case managers to participate in an evaluation of the case management intervention, and those who expressed an interest were visited by researchers to obtain consent. Baseline data were collected from carers about the person with dementia using the Neuropsychiatric Inventory, the Bristol Activities of Daily Living Scale and the Client Services Receipt Inventory. Carers were asked to complete the 28-item General Health Questionnaire (GHQ-28) and the European Quality of Life-5 Dimensions (EQ-5D)

scale, and the person with dementia was asked to complete the Mini Mental State Examination (MMSE) and the Dementia Quality of Life (DEMQOL) scale; the latter was completed only if the MMSE score was > 10. After 5 months, participants were contacted to establish whether or not they were available and willing to be followed up.

Case managers were asked to document their needs assessment of the dyads and any subsequent action taken, including planned contact with the dyads. An Admiral nurse (specialist community nurse) seconded to the project provided regular mentoring for the case managers, accompanying them on the first needs assessment encounters when possible, visiting the practices as needed and maintaining contact by telephone and e-mail. Case managers met to discuss their experiences close to the midpoint of the study, and preliminary findings from the project were presented to a Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) public and patient involvement (PPI) group for external review and comment.

In the third work package an embedded qualitative study ran alongside WP2 to explore the feasibility and acceptability of study procedures and views on case management. Qualitative interviews were carried out with people with dementia and their carers, the case managers and their mentor and other professionals in their general practices and in local specialist services. Interviews were digitally recorded, transcribed and analysed thematically.

Results

The case management intervention developed in WP1 had high face validity for the expert and review groups and was feasible to use in primary care but a longer induction and preparation period would have been helpful. None of the four practices achieved its recruitment target of 11 dyads over a 6-month period but at least one would have done so if case management tasks had been less demanding of time. Although in the present study patients living in care homes or being regularly reviewed by specialist services were excluded, many professionals considered that these patients had unmet needs and would also have benefited from case management. Inclusion and exclusion criteria were not consistently followed but were often modified by case managers and their colleagues in participating practices. Practice QOF dementia registers contained fewer patients than expected and additional searches of electronic medical records identified people with dementia who were not included on the register but who were being prescribed anticholinesterase inhibitors. Problems were encountered with the use of the DEMQOL scale and the GHQ-28 as outcome measures.

People with dementia and their carers were positive about the intervention, although the direct benefits to them during the short duration of the feasibility study were limited. Although all stakeholders identified a range of potential benefits of case management, only one of the four practices achieved a level of case management activity that would be likely to have an effect on outcomes for people with dementia or their carers. Barriers to effective case management included erosion of case manager time by other clinical tasks in practices in which nurses fulfilled the role; difficulties in identifying and acting on 'low level' unmet needs; a lack of clarity over case management; poor integration with local services; and a lack of embeddedness within the primary care team. There was considerable variation in case activity between case managers and this was not related to the amount of time that they had available for the role. Data capture for research purposes was inconsistent, challenging the evaluation, and there was evidence of research burden for both dyads and case managers.

Conclusions

In line with the purpose of a feasibility study, the experiences of implementing an innovative way of working led to some changes of emphasis between the original plan (as documented in the protocol) and the actual study. Case management as implemented in this study did appear to be compatible with the values, norms and perceived needs of the practices, the case managers and the recipients of case management, although the compatibility was more conceptual than practical. Case managers experienced some lack of clarity about case management and concern was expressed about potential duplication of existing roles. The case managers' difficulties also arose from time constraints and unfamiliarity with dementia, as well as from the demands of the research process.

Implications for practice

In this pilot study we were not able to identify signs that case management produced measurable gains for patients, and the role as conceived and constructed was difficult to implement. The flexibility that was built into the case management role, in order to tailor it to the different disciplines of case managers, the practice settings and the needs of dyads, interfered with the research function. Embedding case manager work in the practices proved difficult. Senior staff in practices made decisions about participation, encouraging their staff to take up the case manager role, but did not necessarily support them in the new role.

Implications for research

Although this study identified significant unmet needs, the CAREDEM model of case management is not suitable for further evaluation in a randomised controlled trial, and further developmental work is needed. The skills and attributes that appear to be needed for potentially effective case management for people with dementia may not be widely available in the existing primary care workforce, and a training programme to enhance skills may need to be longer than that tested in this study. Different approaches to recruiting and training case managers, and to identifying people with dementia who might benefit from case management, are needed. Finally, we note that the research processes themselves can have a detrimental effect on the implementation and evaluation of an innovative way of working, and this should be addressed in future development studies.

Trial registration

This trial is registered as ISRCTN74015152.

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