Introducing case management for people with dementia in primary care: a mixed-methods study

**Abstract**

The increasing prevalence of dementia presents considerable challenges for the NHS, especially given the policy commitment to deliver care as close to home as possible, and to prioritise family carers’ needs. Around 700,000 people in the UK have dementia. The cost of caring for them is estimated at around £2.3 billion a year. Two-thirds of people with dementia live at home, with most of their care provided by family members. It is estimated that family caregiving saves public expenditure around £6.8 billion each year. People with dementia occupy one-quarter of NHS beds at any one time, and are being admitted to acute hospital beds in increasing numbers. The National Audit Office encourages the case management of people with dementia. National Institute for Health and Care Excellence guidance on dementia recommends coordinated health and social care led by a single professional, with systematic follow-up. This community-based, individualistic approach to case management with its ad hoc but regular contact is different from the hospital-based approach in which multidisciplinary teams carry out comprehensive geriatric assessment, which is then followed by case management.

**Introduction**

Dementia case management can reduce hospital and emergency admissions, as well as embarrassment, isolation, relationship strain, stress, and relocation to a care home, although few studies have recorded large effects. There has been no agreed choice of professional background for the case manager role, although nurses’ claim to holistic care makes them appear suitable. The heterogeneity of people in dementia in primary care studies and the lack of subgroup analyses make it difficult to identify the disease stage at which patients and their carers derive most benefit. A systematic review of randomised controlled trials of case management for people with dementia and their carers concluded that evidence for the efficacy of case management remains equivocal.

**Developing a case management intervention**

The CAREDEM study was designed to adopt a successful primary care case management intervention from the US ‘PREVENT’ model for use in England to train primary care staff in this culturally-adapted intervention, and to test its acceptability and feasibility in general practice. The PREVENT study deployed a nurse practitioner and a social worker, using evidence-based protocols. It demonstrated significant improvements for people with dementia (increased depression scores for antidepressive medication, and fewer behavioural and psychological symptoms) and for their family carers (fewer depressive symptoms and higher carer satisfaction). The CAREDEM study followed the Medical Research Council’s guidance on developing complex interventions, and complementary guidelines for nursing service development, and was conducted by a multidisciplinary team supported by lay experts. The cultural adaptation of the PREVENT intervention followed an experience-based design approach, and is described elsewhere. It was underpinned by diffusion science, which describes how uptake of an innovation is determined by its compatibility with the values, norms, and perceived needs of practitioners, ease of use, clear, unambiguous effectiveness or cost-effectiveness, testability in practice, adaptability to fit local circumstances, likely benefits to the user’s social approval, and lack of compulsion. The intervention consisted of training and mentoring based on an educational needs assessment, plus a learning manual that could be shared between case managers and patient-carer dyads.

Face-to-face training of case managers began with an educational needs assessment to tailor learning to individual understanding and competencies, learning preferences, and skill mix. It reflected the complexity of case management as a technique and of dementia itself. It was intended to foster reflection, allow practitioners to plan changes, and help them to tolerate tension and discomfort. The learning manual covered topics including communication with the patient with dementia, managing challenging behaviour, maintaining mobility, managing personal care, coping with sleep disturbance, managing legal and financial matters, and sustaining the physical health of the carer and the person with dementia. The trainer and mentor for the case managers was an experienced Admiral nurse (a dementia specialist nurse) who visited all case managers at their workplaces and was available by telephone or e-mail.

**Methods**

The eastern practice was situated in a large market town and had two satellite surgeries, with 4.5 whole-time equivalent (WTE) GPs serving 14,400 patients, and the practice’s deprivation score was 18.7. The London practice was in an inner-city area, had a registered population of 15,510 served by 8.5 WTE GPs, and spanned two boroughs with deprivation scores of 21.2 and 25.0. The North-east urban practices had list sizes of 28,396 and 6501, WTE GP staffing of 15 and 4.25, and deprivation scores of 27.8 and 29.7, respectively. The processes of practice recruitment are reported elsewhere. Practice nurses undertook the case manager role in the east rural and London inner-city practices, and a second social worker worked full time with the two north-east urban practices. One practice nurse had previous experience of working with people with dementia, while the other had experience of case management. Both practice nurses had one session per week for case management.

**Participants**

Patients with dementia who had a carer willing to participate, who were not receiving sustained psychosocial support after initial diagnosis and information signposting. Case management, including systematic follow-up, provision of brief psychological therapy, and medication management, has the potential to overcome this service fragmentation. This study suggests that case management, whether carried out by experienced practice nurses in dedicated sessional time, or by a seconded social worker devoted exclusively to the project, does not fit easily into practice routines. Further studies are needed to clarify the purpose of case management, to resist the skills and attributes required for case management, to embed delivery of case management in primary care, and to establish when in the illness trajectory case management is likely to have maximum cost-effectiveness.

**How this fits in**

Services for people with dementia and their family carers are fragmented, with many families not receiving sustained psychosocial support after initial diagnosis and information signposting. Case management, including systematic follow-up, provision of brief psychological therapy, and medication management, has the potential to overcome this service fragmentation. This study suggests that case management, whether carried out by experienced practice nurses in dedicated sessional time, or by a seconded social worker devoted exclusively to the project, does not fit easily into practice routines. Further studies are needed to clarify the purpose of case management, to resist the skills and attributes required for case management, to embed delivery of case management in primary care, and to establish when in the illness trajectory case management is likely to have maximum cost-effectiveness.
and Outcomes Framework dementia register and from additional searches of the electronic medical records. Participants were interviewed before case management began and 5 months later. Because this was a moulding study the sample size was decided pragmatically.

Evaluation
Mixed-methodology case studies32 of the introduction of case management in the general practices were carried out. Case studies allow processes and experiences of case management at different time points. The majority of interviews were conducted face to face with individuals. Where this was not feasible, interviews were conducted in a small group, or individually by telephone. Interview transcripts from the case study interviews were transcribed and line-by-line condensed. Three researchers independently reviewed the transcripts to identify potential codes. A code frame was developed for the coding process. All codes were then categorised and put into a code frame that was discussed and agreed by the research team. An agreed code frame was used to code and categorise the transcripts and agree on the final coding and categorisation. Any discrepancies between researchers were discussed and resolved until consensus was reached.

RESULTS
Recruitment
The recruitment target was 11 patient–carer dyads in each practice. A total of 29 dyads were recruited (Figure 1 shows 28 because one carer participated while the person they were caring for declined).14 from the two north-east practices, nine in the eastern practice and six in the London practice. Recruitment was halted at the eastern practice to deal with a backlog of case management work. Figure 1 shows the combined recruitment data from all sites.

Of those patients not living in care homes, 43 (33%; 95% confidence interval [CI] = 29% to 48%) met all the criteria for inclusion in the study and of those prospective participants, 28 (62%; 95% CI = 46% to 76%) consented to the study.

Data sources
Quantitative data collected in the study included numbers of patients with dementia identified, eligible for case management, and agreeing to participate in case management, the number and type of needs identified, and the number of contacts with the person with dementia and/or their carers. Two researchers jointly reviewed case manager documentation for each participant. Documentation included formal data capture forms, case managers’ handover notes, and correspondence sent to GPs to summarise the case management intervention and psychological symptoms), and financial or legal needs (including information on benefits and lasting power of attorney). The frequency with which needs in each of these areas were identified is shown in Table 2.

Table 2. Patient and carer needs identified by case managers

<table>
<thead>
<tr>
<th>Area of unmet need</th>
<th>Patient Carer All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily living</td>
<td>13 7 9 1</td>
</tr>
<tr>
<td>Physical wellbeing and medication</td>
<td>12 10 2 0</td>
</tr>
<tr>
<td>Emotional wellbeing and support</td>
<td>13 2 4 6</td>
</tr>
<tr>
<td>Coping with dementia-related problems</td>
<td>16 4 2 3</td>
</tr>
<tr>
<td>Financial and legal needs</td>
<td>5 2 0 8</td>
</tr>
<tr>
<td>All unmet needs</td>
<td>55 25 18 18</td>
</tr>
</tbody>
</table>

The type of contact varied significantly by case manager (Fisher’s exact test P = 0.001) (Table 1).

Table 1. Type of contact by case manager

<table>
<thead>
<tr>
<th>Case manager</th>
<th>Number of patients</th>
<th>Face to face</th>
<th>Telephone</th>
<th>Letter/ e-mail</th>
<th>Not specified</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>East</td>
<td>9</td>
<td>10</td>
<td>26</td>
<td>0</td>
<td>1</td>
<td>48</td>
</tr>
<tr>
<td>London</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>North-east</td>
<td>9</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>Total</td>
<td>26</td>
<td>16</td>
<td>26</td>
<td>2</td>
<td>19</td>
<td>63</td>
</tr>
</tbody>
</table>

Table 3. Actions recorded by case managers by area of unmet need

<table>
<thead>
<tr>
<th>Area of unmet need</th>
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<td>5 2 0 8</td>
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<td>All unmet needs</td>
<td>55 25 18 18</td>
</tr>
</tbody>
</table>

The perceived benefits of a case manager included acting as first point of contact and also as a ‘safety net’, and creating a one-to-one therapeutic relationship. Some suggested that case managers should also take a more active role in negotiating with local services. Participants valued the ability of case managers to address both health and social care problems. Patients and carers were generally satisfied with the experience of case management and several were clear that they wished the service to remain in place, both for their own benefit and to benefit others. The service created feelings of security for some and a number of practical benefits were reported, including easier access to GP appointments.

Interviews with NHS and social care professionals
Case management was seen as benefiting the person with dementia by providing continuity of care and dealing with problems...
Box 2. Sample discrepancies between researcher and case manager

<table>
<thead>
<tr>
<th>Extract from case manager notes</th>
<th>Researcher coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient declined to present on a visit to her bladder. She stated that she constantly feels that she needs to urinate and can go to the toilet 30–40x per day. This is very disorienting for her and has affected her confidence in going outside.</td>
<td>PWD unmet need relating to physical wellbeing</td>
</tr>
<tr>
<td>This also has an effect on [husband] as [patient] frequently forgets where the toilet is and requires [husband] to take her to it. This means that [husband] feels that he needs to be constantly with her and the result is that she rarely goes out unless it is absolutely necessary.</td>
<td>PWD unmet need relating to emotional wellbeing</td>
</tr>
<tr>
<td>‘[Patient] reports that she generally sleeps straight back to sleep and the nightly disruption [Carer] stated he does not tend to be able to go to sleep and the nightly disruption means that [husband] feels that he needs to be constantly with her and the result is that the husband rarely goes out unless it is absolutely necessary.</td>
<td>PWD unmet need relating to daily routines</td>
</tr>
<tr>
<td>Issues in managing this are also an issue in the care of [patient’s] bladder problems, but as yet nothing has been found. Various medications have been tried and none have seemed to make any difference.</td>
<td>PWD unmet need relating to daily routines</td>
</tr>
<tr>
<td>Carer unmet need ‘coping with dementia-related problems’</td>
<td></td>
</tr>
<tr>
<td>Carer unmet need relating to daily routines</td>
<td></td>
</tr>
<tr>
<td>Action — physical wellbeing addressed by other professional</td>
<td></td>
</tr>
<tr>
<td>Case manager notes</td>
<td></td>
</tr>
<tr>
<td>‘[Patient] generally sleeps straight back to sleep and the nightly disruption means that [husband] feels that he needs to be constantly with her and the result is that the husband rarely goes out unless it is absolutely necessary.</td>
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<td></td>
</tr>
<tr>
<td><img src="image.png" alt="Image" /></td>
<td></td>
</tr>
</tbody>
</table>

**Researcher coding**

- PWD = person with dementia.

earlier. It was also seen as complementary to existing secondary care and social services, neither of which had the capacity to monitor patients and carers, nor to provide support early in the disease.

**Interviews with case managers**

Among the case managers there was strong commitment to the case management approach. The perceived advantages of case management were continuity of care and flexibility in responsiveness to needs. There was frustration that there had been insufficient time to show the potential of case management. The practice nurse case managers had had relatively little time to develop their work with patients and carers, and identified relatively few concrete benefits to participating patients and carers. All case managers reported that some participants had gained financially and that feedback from patients and carers to the case managers had generally been positive.

**DISCUSSION**

Summary

This study explored the realities of primary care-based case management for patients with dementia, in a range of settings using a range of skills. The evaluation triangulated data from patient-carer dyads, other NHS and social care professionals, and the case managers themselves. Case managers had variable levels of contact with patient-carer dyads. The volume of needs identified varied across practices, and there was a difference between researcher assessments and case manager judgements about the level of needs among participants. Contact with relevant specialist services was limited. Case management did appear to be compatible with the values, norms, and perceived needs of the general practices, the case managers, and the recipients of case management. While all three case managers cited time constraints as an obstacle to working with their target patient group, the most successful case manager had only half a day a week available, yet carried a larger case management case load than the full-time case manager. This case manager had previous clinical experience in working with people with dementia. Although the perceived complexity of an innovation can be reduced by practical experience with it, it was not clear that this occurred within the study’s time frame. The study provided a ‘testability space’ for the idea of case management, but the case studies suggest that the role as constructed was difficult to implement for two of the three case managers. This study did not suggest that case management was substantially beneficial for patients or carers.

Adoption of an innovation is increased if potential adopters can adapt the innovation to suit their own needs. Flexibility was built into the case management role, which was tailored to discipline (nurse or social worker), practice, and individual. One of the mentor’s functions was to support that tailoring. However, such flexibility interferes with research, which seeks to standardise measures and processes.

There is no evidence that the case manager role added to the user’s social approval (either from patient and carer feedback) or enhanced practices’ standing within their clinical communities. **Strengths and limitations**

This is the first attempt to embed case management for people with dementia and their families in general practice, and evaluate its impact. Only small numbers of people with dementia and their carers were identified, approached, and recruited to the study, across all four settings. This may have been due to narrow eligibility criteria, and an unjustified assumption that those living in care homes or being followed-up by specialist services were already receiving case management. The small scale of the study means that the conclusions that can be drawn from it must be tentative.

**Comparison with existing literature**

The positive and negative findings of this study are congruent with the view that case managers need broad clinical skills, protected time access to multidisciplinary expertise, and a recognised mandate. The skill base of the case managers in this study was varied, but may not have been wide enough for them to have an impact. Time constraints were cited by all as a barrier to case management. Contact with multidisciplinary teams was limited, although individualised mentoring was at a high level. And the mandate for developing case management came from the practices rather than from the wider NHS and social care community. For the practice nurses, the new occupational role had to be negotiated and sustained in a turbulent work environment.

**Implications for practice and research**

Case management offers potential benefit to patients, their carers, and community-based professionals through continuity of care with a named, trusted individual who can act proactively to prevent a crisis. However, the findings of this modelling study suggest that needs may be overlooked. This study suggests that it is difficult to embed case management within UK general practice. It is too soon to tell whether case management for people with dementia and their carers can be successfully incorporated into routine general practice and such services should not be commissioned currently. Further development work is needed to establish the best approaches to meeting the needs of people with dementia and their carers.

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**Ethical approval**

Ethics committee approval for this study was obtained from NRES Wandsworth (11/LO/1555).

**Provenance**

Freely submitted; externally peer reviewed.

**Competing interests**

The authors have declared no competing interests.

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