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

Aim

To adapt a U.S. model of primary care-based case management for people with dementia and test it in general practice.

Design and setting

Mixed-methodology case studies of case management implementation in four general practices: one rural, one inner-city, and two urban practices. Participants were case managers in the role in the rural and inner-city practices, and were allocated one session per week for case management by their practitioners. A second social worker worked full time for the ten urban practitioners.

Method

Participants were community-dwelling patients with dementia who were living at home with a family carer, and who were not receiving specialist services at the time of recruitment.

Case study methods included analysis of case loads and interviews with patients, carers, local NHS and other stakeholders, and case managers. Measures included numbers of consultations with dementia and their carers, number of unmet needs identified, and actions taken to meet needs. Case manager records were compared with findings from social work patients and carers, and with other stakeholders.

Results

The number of eligible patients was smaller than expected. No practice achieved its recruitment target. Researchers identified more unmet needs than case managers.

The practice nurse/case manager reported lack of time and found research documentation burdensome. Patients and carers were positive about case management as a first point of contact with the practice, as a ‘safety net’, and for creating a one-to-one therapeutic relationship.

Conclusion

Further investigation is required before case management for people with dementia and their carers can be implemented in primary care.

Keywords

care; case management; case studies; dementia; general practice; nursing practice.

INTRODUCTION

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,1 and to prioritise family carers’ needs.2 Around 60,000 people in the UK have dementia.3 The cost of caring for them is estimated at around £23 billion a year.4 Two-thirds of people with dementia live at home, with most of their care provided by family members.5 It is estimated that family caregiving saves public expenditure around £8 billion each year.6 People with dementia occupy one-third of NHS beds at any one time,7 and are being admitted to acute hospital beds in increasing numbers.8

The National Audit Office encourages the use of case managers to reduce avoidable hospital admissions of people with dementia.9 National Institute for Health and Care Excellence guidance on dementia recommends coordinated health and social care led by a single professional,10 with a systematic follow-up.11 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.12

Impact of case management

Dementia case management can reduce hospital and emergency admissions,13 as well as embarrassment, isolation, relationship strain,14 stress,15 and relocation to a care home,16 although few studies have recorded large effects.17 There has been no agreed choice of professional background for the case manager role,18 although nurses’ claim to holistic care makes them appear suitable.19 The heterogeneity of people in dementia case management studies and the lack of subgroup analyses make it difficult to identify the disease stage at which patients and their carers derive most benefit.20 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.21

Developing a case management intervention

The CAREDEM study was designed to develop a successful primary care case management intervention from the US (the 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,22 using evidence-based protocols. It demonstrated significant improvements for people with dementia (increased prescribing of cholinesterase medication, and fewer behavioural and psychological symptoms) and for their family carers (fewer depressive symptoms and higher carer satisfaction).23

The CAREDEM study followed the Medical Research Council’s guidance on developing complex interventions,24 and complementary guidelines for nursing service development,25 and was conducted by a multidisciplinary team supported by lay experts.

The cultural adaptation of the PREVENT intervention followed an experience-based design approach26 and is described elsewhere.27 It was underpinned by diffusion science,28 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 benefit to the user, social approval, and lack of compulsion.29

METHODOLOGY

The CAREDEM 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.30

Face-to-face training of case managers began with an educational needs assessment to tailor learning to individual understanding and competences, learning preferences, and skill mix.31 It reflected the complexity of case management as a technique and of dementia itself.32 It was intended to foster reflection, allow practitioners to plan changes, and help them to tolerate tension and discomfort.33

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.

Settings

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 28.7.

The north-east urban practices had list sizes of 28,396 and 6,501, 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.34 Practice nurses undertook the case manager role in the east rural and London inner-city practices, and a seconded 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 care coordination from specialist services, and who were not living in a care home, were eligible for the study. Patients with dementia were identified from the Quali...
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>10</td>
<td>46</td>
</tr>
<tr>
<td>London</td>
<td>9</td>
<td>2</td>
<td>0</td>
<td>3</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>North-west</td>
<td>9</td>
<td>3</td>
<td>0</td>
<td>6</td>
<td>9</td>
<td>18</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 2. Patient and carer needs identified by case managers

<table>
<thead>
<tr>
<th>Area of unmet need</th>
<th>Patient</th>
<th>Carer</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical and medication</td>
<td>No need</td>
<td>No need</td>
<td>4</td>
</tr>
<tr>
<td>Daily living</td>
<td>8</td>
<td>10</td>
<td>18</td>
</tr>
<tr>
<td>Emotional wellbeing</td>
<td>2</td>
<td>15</td>
<td>17</td>
</tr>
<tr>
<td>Coping with dementia-related problems</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Financial and legal needs</td>
<td>5</td>
<td>20</td>
<td>25</td>
</tr>
<tr>
<td>All needs</td>
<td>20</td>
<td>8</td>
<td>28</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>
<th>Patient</th>
<th>Carer</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial and legal needs</td>
<td>No action recorded</td>
<td>No action recorded</td>
<td>8</td>
</tr>
<tr>
<td>Daily living</td>
<td>13</td>
<td>7</td>
<td>20</td>
</tr>
<tr>
<td>Emotional wellbeing</td>
<td>12</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Coping with dementia-related problems</td>
<td>14</td>
<td>4</td>
<td>18</td>
</tr>
</tbody>
</table>

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 cared for declined). 14 from the two north-eastern 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, 45 (33%), 95% confidence interval (CI) = 29% to 46% met all the criteria for inclusion in the study and of those prospective participants, 28 (62%), 95% CI = 44% to 76% consented to the study.

Case management process

Sixty-three case manager contacts were recorded, 59 of which were with patients and/or carers. Only four contacts with other professionals were recorded: two with GPs, one with an old-age psychiatrist, and one with a member of staff from the Alzheimer’s Society.

The contact type varied significantly by need for carers (P = 0.001) but not for patients (Table 3).

There were discrepancies between the assessment of needs by case managers and the needs expressed by patients (related to physical and emotional wellbeing, and everyday tasks) as illustrated in Box 2.

People with dementia identified from QOF register and supplementary searches (n = 276)

In care homes (n = 118)

Number assessed for eligibility (n = 138)

Excluded (n = 110)

- Needy or carer not contactable (n = 26)
- Unavailable or unable to contact (n = 18)
- Had pre-existing care (n = 41)
- Other, including practice reasons (n = 43)

Declined to participate (n = 17)

Number recruited (28 patients and 29 carers)

Figure 1. Recruitment flow diagram. QOF = Quality and Outcomes Framework.

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 carer. Two researchers jointly reviewed case manager documentation for each participant. Documentation included formal data capture forms, case managers’ freehand notes, and correspondence sent to GPs to summarise the case management and intervention.

To illustrate this process, Figure 1 shows how an extract from case manager notes was coded. The full coding frame is reported elsewhere.22

In-depth interviews were conducted with stakeholders including people with dementia, carers, case managers and their mentor, health and social care professionals in local services, and researchers. Separate interview topic guides were developed for each stakeholder group and were adapted iteratively.

Members of the research team conducted interviews during the study to capture 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.

Interviews with patients and carers

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 their 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...
This is also an author of this paper.

Acknowledgements
The authors have declared no competing interests.

Funding
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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.

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.

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.

Researchers 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 caseload 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 testable ‘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 (other than patient and carer feedback) or enhanced practice’ standing within their clinical communities.

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BOX 2. SAMPLE DISCREPANCIES BETWEEN RESEARCHER AND CASE MANAGER

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Case Manager</th>
</tr>
</thead>
<tbody>
<tr>
<td>PWD unmet need relating to physical wellbeing</td>
<td></td>
</tr>
<tr>
<td>PWD unmet need relating to emotional wellbeing</td>
<td></td>
</tr>
<tr>
<td>PWD unmet need relating to daily routines</td>
<td></td>
</tr>
<tr>
<td>PWD unmet need coping with dementia-related problems</td>
<td></td>
</tr>
<tr>
<td>Carer unmet need coping with dementia-related problems</td>
<td></td>
</tr>
<tr>
<td>Action—physical wellbeing addressed by other professional</td>
<td></td>
</tr>
</tbody>
</table>

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