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Introducing case management for people with dementia in primary care:

a mixed-methods study

Abstract

Background

Case management may be a feasible solution to the problem of service fragmentation for people with dementia.

Aim

To adapt a US 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. Practice nurses undertook the case manager role in the rural and inner-city practices, and were allocated one session per week for case management by their practices. A seconded social worker worked full time for the two urban practices.

Method

Participants were community-dwelling patients with dementia who were living at home with a family carer, and who were not receiving specialist care coordination. 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 patients with dementia and their carers, number of unmet needs identified, and actions taken to meet needs. Case manager records were compared with findings from interviews with 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 managers 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

carers; case management; case studies; dementia; general practice; nursing, practice.

INTRODUCTION

The increasing prevalence of dementia presents considerable challenges for the NHS,¹ especially given the policy commitment to deliver care as close to home as possible,² and to prioritise family carers' needs.³ Around 670 000 people in the UK have dementia.⁴ The cost of caring for them is estimated at around £23 billion a year.⁵ Two-thirds of people with dementia live at home, with most of their care provided by family members.^{5,6} It is estimated that family caregiving saves public expenditure around £8 billion each year.⁵ People with dementia occupy one-quarter of NHS beds at any one time,⁶ and are being admitted to acute hospital beds in increasing numbers.^{7,8}

The National Audit Office encourages the use of case management 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 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 patients 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.¹⁸ 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.²⁰

Developing a case management intervention

The CAREDEM study was designed to adapt a successful primary care case management intervention from the US [the PREVENT model] for use in England to train

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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 revisit 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.

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,¹⁶ 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).

The CAREDEM study followed the Medical Research Council's guidance on developing complex interventions,²¹ and complementary guidelines for nursing service development,²² and was conducted by a multidisciplinary team,²³ supported by lay experts.

The cultural adaptation of the PREVENT intervention followed an experience-based design approach,²⁴ and is described elsewhere.²⁵ It was underpinned by diffusion science,²⁶ 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's social approval, and lack of compulsion.^{27,28}

METHOD

Intervention

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.²³

Face-to-face training of case managers began with an educational needs assessment to tailor learning to individual understanding and competence, learning preferences, and skill mix.²⁹ It reflected the complexity of case management as a technique and of dementia itself.³⁰ It was intended to foster reflection, allow practitioners to plan changes, and help them to tolerate tension and discomfort.³¹

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 sited 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 18.77. 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 21.5 and 27.0. The two 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.³² 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 Quality

Extract from case manager notes	Researcher coding
<p><i>'Things she mentioned without prompts:</i></p> <ul style="list-style-type: none"> • <i>Loss of motivation</i> • <i>Weight loss</i> • <i>'Muzzy' head in the mornings</i> • <i>More muddled</i> • <i>Forgetting more things</i> • <i>That her husband must 'roll his eyes at times with her' although 'he never says anything'</i> • <i>Needing a nap after lunch</i> • <i>Rash/spots abdomen that occur occasionally ?cause; itchy but feels ok with it'</i> 	<p>PWD unmet need relating to coping with dementia-related problems</p> <p>PWD unmet need relating to physical wellbeing</p>
<p><i>'Both undergoing a lot of stress with family member ill'</i></p>	<p>PWD — unmet need emotional wellbeing Carer — unmet need emotional wellbeing</p>

PWD = person with dementia.

Evaluation

Mixed-methodology case studies³³ of the introduction of case management in the general practices were carried out. Case studies allow service developers to focus on the context of a system,³⁴ and enable researchers to understand emerging problems and their practical solutions.^{35,36}

Quantitative and qualitative findings were synthesised by the research team, with input from lay experts, in an iterative process that tested hypotheses against data until consensus was reached.

Sixty-three case manager contacts were

Case manager	Number of patients	Type of contact			Total
		Face to face	Telephone	Letter/ e-mail	
East	9	10	26	0	46
London	6	3	0	2	8
North east (combined)	9	3	0	0	9
Total	24	16	26	2	63

Needs	Patient			Carer		
	No need	Met need	Unmet need	No need	Met need	Unmet need
Daily living	8	10	20	1	0	10
Physical wellbeing and medication	0	5	22	1	2	3
Emotional wellbeing and support	6	2	15	6	2	10
Coping with dementia-related problems	5	2	20	0	2	5
Financial and legal needs	1	4	3	0	2	8
All needs	20	23	80	8	8	36

Area of unmet need	Patient		Carer		All	
	No action recorded	Action recorded	No action recorded	Action recorded	No action recorded	Action recorded
Daily living	13	7	9	1	22	8
Physical wellbeing and medication	12	10	3	0	15	10
Emotional wellbeing and support	13	2	4	6	17	8
Coping with dementia-related problems	16	4	2	3	18	7
Financial and legal	1	2	0	8	1	10
All unmet needs	55	25	18	18	73	43

The number of contacts with patients (either alone or with the carer) ranged from 0 to 8 (mean 1.08), while the number of contacts with carers (either alone or with the patient) ranged from 0 to 6 (mean 1.42). The median number of contacts per patient-carer dyad differed significantly by case manager (independent samples median test $P<0.001$). The eastern practice case manager had 46 contacts with nine dyads, the London case manager had 8 contacts with six dyads, and the social worker case manager in the two north-east practices had 9 contacts with nine dyads.

Case management was seen as benefiting the person with dementia by providing continuity of care and dealing with problems

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graph TD; A[People with dementia identified from QOF register and supplementary searches (n = 276)] --> B[Number assessed for eligibility (n = 138)]; A --> C[In care homes (n = 138)]; B --> D[Number recruited (28 patients and 29 carers)]; B --> E["Excluded (n = 110)  
• Receiving palliative care (n = 4)  
• No carer or carer uncontactable (n = 24)  
• Unavailable or unable to contact (n = 18)  
• Already case managed (n = 4)  
• Other, including practice reasons (n = 43)  
Declined to participate (n = 17)"]
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Flowchart illustrating the recruitment process:

- People with dementia identified from QOF register and supplementary searches ($n = 276$)
- Number assessed for eligibility ($n = 138$)
- Number recruited (28 patients and 29 carers)
- Excluded ($n = 110$):
 - Receiving palliative care ($n = 4$)
 - No carer or carer uncontactable ($n = 24$)
 - Unavailable or unable to contact ($n = 18$)
 - Already case managed ($n = 4$)
 - Other, including practice reasons ($n = 43$)
- Declined to participate ($n = 17$)
- In care homes ($n = 138$)

Box 2. Sample discrepancies between researcher and case manager

Extract from case manager notes

'[Patient's] main problem at present is in relation 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 distressing for her and has affected her confidence in going outside.

'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 he also now rarely goes out unless it is absolutely necessary.

'Investigations are ongoing as to the cause of [patient's] bladder problems, but as of yet nothing has been found. Various medications have been tried, but none have seemed to make any difference. [Patient] has been supplied with incontinence pants from the district nurse and wears them all the time.

'[Patient] reports that she generally sleeps okay, but usually has to get up 3-4x during the night to go to the toilet. This affects [carer's] sleeping also as he has to get up to help her find the toilet and each time can take up to 30 min. [Carer] stated he does not tend to be able to go straight back to sleep and the nightly disruption does mean he is frequently quite tired during the day.'

PWD = person with dementia.

Researcher coding

PWD unmet need relating to physical wellbeing

PWD unmet need relating to emotional wellbeing

PWD unmet need relating to daily routines

PWD unmet need 'coping with dementia-related problems'

Carer unmet need 'coping with dementia-related problems'

Carer unmet need relating to daily routines

Action — physical wellbeing addressed by other professional

Carer unmet need relating to physical wellbeing

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.²⁷ 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 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.³⁷ 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.³⁸

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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