Patient and carer perceptions of case management for long-term conditions

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Abstract

Nurse-led case management programmes have become increasingly popular over the last 15 years. Countries such as the USA, Canada, Sweden and the Netherlands have long running case management programmes in place for frail elderly people. The Department of Health in England has recently introduced a 'community matron' role to provide case management to patients with highly complex long-term conditions; a group that is predominantly comprised of elderly people. Department of Health policy documents do not define the day-to-day role of community matrons but instead describe the objectives and principles of case management for long-term conditions. The aim of this qualitative study was to describe case management from the perspective of patients and carers in order to develop a clearer understanding of how the model is being delivered for patients with long-term conditions. In-depth interviews were conducted with a purposive sample of 72 patients and 52 carers who had experience of case management. Five categories of case management tasks emerged from the data: clinical care, co-ordination of care, education, advocacy and psychosocial support. Psychosocial support was emphasised by both patients and carers, and was viewed as equally important to clinical care. Patient and carer perceptions of case management appear to contrast with descriptions contained in Department of Health guidance, suggesting an 'implementation surplus' in relation to the policy. This particularly appears to be the case for psychosocial support activities, which are not described in official policy documents. The provision of significant psychosocial support by community matrons also appears to differentiate the model from most other case management programmes for frail elderly people described in the literature. The findings emphasise the importance of seeking patient and carer input when designing new case management programmes.

Keywords: case management, long-term conditions, patient perceptions

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Introduction

Nurse-led case management programmes for frail elderly people were first implemented in the early 1990s in the USA (Rogers *et al.* 1991) and Canada (Hall *et al.* 1992). Since this time case management approaches for elderly people have become increasingly popular and can now also be found in Australia (Lim *et al.* 2003, Allen and Fabri 2005), Italy (Bernabei *et al.* 1998), the Netherlands (van Achterberg *et al.* 1996, Willems 1996), Sweden (Hokenstad and Johansson 1996), and the UK (Jiwa *et al.* 2002, Drennan *et al.* 2005, Adam 2006, Lyon *et al.* 2006).

The development of case management for elderly people was linked to pressures to contain healthcare costs, reduce fragmentation of care, prevent exacerbations of illness, reduce hospital admissions, enhance quality of care and generally improve patient outcomes (Taylor 1999). These implementation drivers were initially observed in the USA but were also common in other countries.

One model of case management being delivered in England is the community matron programme. Key components of this programme were initially introduced by the pilot Evercare projects run by United Health Europe (UHG 2004) and subsequently rolled out nationally under the community matron policy. The aim of the policy is 'treating patients sooner, nearer to home and earlier in the course of disease' (Department of Health 2005a, p. 7) and reducing inpatient emergency bed days by 5% to achieve Public Service Agreement targets. An Evercare-based model was considered appropriate for achieving these aims as research conducted in the USA had found Evercare to be effective in reducing hospital admissions and bed days (Kane et al. 2003). However, recent research conducted among the UK pilot sites suggests that the Evercare model has not succeeded in reducing emergency hospital admissions or lengths of stay (Patrick et al. 2006, Gravelle et al. 2007).

Research into case management approaches for long-term conditions and frail elderly people has focused on evaluating the effectiveness of models for improving clinical outcomes, reducing hospital bed use and reducing healthcare costs. In some of this research the model of case management is only briefly described and it is unclear what tasks were conducted by case managers or teams in their day-to-day work (Dalby *et al.* 2000, Hughes *et al.* 2000, Caplan *et al.* 2004). Department of Health guidance has also been somewhat vague in regard to the actual tasks involved in case management.

One Department of Health document states that 'there is no one agreed definition of case management' (Department of Health 2006, p. 4) and another notes that definitions of case management vary across health and social care (NHS Modernisation Agency and Skills for Health 2005). Policy documents do, however, specify that community matrons should provide 'clinical intervention as well as care co-ordination' (Department of Health 2005a, p. 16) to patients with 'very complex and intensive clinical needs' (Department of Health 2006, p. 3).

Department of Health documents recognise that other health and social care professionals provide case management to a range of patient groups. The community matron's role is delineated from these other roles in being that of 'a qualified nurse who can provide advanced nursing and clinical care as well as effective case management' (Department of Health 2006, p. 3). The publication of a core competencies framework for community matrons and case managers (NHS Modernisation Agency and Skills for Health 2005) provided further clarification on official expectations of the community matron role, but did not provide detailed information about how each of the nine domains were to be achieved; this was left to individual programmes to ascertain at local level.

In the wider literature, it is evident that there is considerable variation among case management models for frail elderly people. Challis *et al.* (1990) explained the main components of a long-term care management programme for frail elderly people as including case finding and screening, assessment, care planning, monitoring and review. Other studies have also reported case managers or teams conducting the primary tasks of assessing patients, developing care plans, regularly monitoring patients, co-ordinating care and responding to crisis situations (van Achterberg *et al.* 1996, Bernabei *et al.* 1998, Gagnon *et al.* 1999, Marshall *et al.* 1999, Jiwa *et al.* 2002, Lim *et al.* 2003, Adam 2006).

In disease-specific case management models it is common for the case manager, usually a specialist nurse, to provide direct clinical care to patients. Alternatively, in programmes for community-based elderly people with complex conditions, clinical care is usually provided by the patient's general practitioner (GP) or a relevant specialist (Bernabei et al. 1998, Marshall et al. 1999, Hughes et al. 2000, Jiwa et al. 2002, Drennan et al. 2005). In these models the case manager or team co-ordinates the patient's clinical care by making referrals, arranging appointments, facilitating access to clinics and following-up medical appointments with patient visits. A minority of studies report case managers providing direct clinical care to patients in community-based settings (Gagnon et al. 1999, Guttman 1999, Kane et al. 2001, Schein et al. 2005).

Case management programmes for community-based frail elderly people tend to focus upon co-ordination of care and prevention of exacerbations of illness rather than psychosocial support. However, a small number of studies have included psychosocial support as a central component of the case manager role. An evaluation by Challis et al. (1995) of a care management programme designed to reduce long-stay hospital care among frail elderly people reported the inclusion of psychosocial support, counselling and advice within the model. Similarly, Allen and Fabri (2005) noted that nurse 'relief of psychological symptoms' was a core case manager role. Schein et al. (2005) found that complex relationship building, psychological comfort promotion and coping assistance were three of the four most common interventions provided by nurse case managers. Another model, described by Schaefer and Davis (2004), provided medication and/or behavioural health interventions to patients with chronic illnesses and a comorbidity of depression. This programme delivered case management interventions through a team-based approach with nurses, physicians and behavioural case managers providing medication, cognitive behaviour therapy or problem-solving therapy as appropriate to their professional role.

Disease-specific case management models usually include patient education and advice as core components

of the model of care. In case management models for elderly people with complex conditions, health promotion and disease education do not feature as prominently. A small number of studies have described models of case management which included patient education and health promotion activities (Guttman 1999, Fick *et al.* 2000, Ritchie *et al.* 2002, Schein *et al.* 2005) although these components are not described in detail. One exception is the study by Allen and Fabri (2005) which lists patient and carer education tasks provided by nurses.

Case management models designed to improve health and well-being also vary according to the professional background of case managers, the mode of delivery, the length of the intervention period, the location of services within wider health service structures, collaboration arrangements with other services and the ways in which patients are identified for intervention. Given the wide variation in case management models, there is a need to describe how community matrons are implementing case management for long-term conditions.

Aim

The research aim was to describe community matron case management from the perspective of patients and carers in order to develop a clearer understanding of how the model is being delivered for patients with long-term conditions.

Method

Participants and context

As part of a larger evaluation study, patient and carer perceptions of community matron case management were explored. By investigating the perceptions of patients and carers, new information, which may not have been anticipated by policy-makers, can be gained about the characteristics of the model of care. Seeking early feedback on the acceptability of community matron case management among patients and carers can also help to inform programme development.

The methods and findings of the wider evaluation are described elsewhere (Boaden *et al.* 2006). The patient and carer component recruited a purposive sample of 72 patients and 52 carers who had experience of community matron case management. The research was conducted in six Primary Care Trusts (PCT) which had established case management programmes within the last two years. The researchers liaised with community matron teams in each PCT to identify potential participants. Patients and carers with a good level of cognitive functioning, moderate hearing ability, willingness to

talk at length about their personal experiences of case management and an ability to critically reflect on their care were invited to participate by community matrons. The details of those patients and carers who agreed to take part were passed to the researcher who then telephoned to arrange a convenient time to conduct a confidential interview. Ethical considerations did not allow the direct invitation of research participants.

The participant selection process is likely to have identified a group of younger and healthier patients compared to the larger population receiving community matron case management. It is also possible that the selection process led to patients and carers being reluctant to criticise services, further biasing the findings. However, participants were reassured that interviews were strictly confidential and that any information they provided would not be directly shared with their community matron. The researchers found that patients and carers were not reluctant to criticise services, particularly in relation to service delivery hours that were investigated as part of the larger evaluation (refer to Boaden *et al.* 2006).

The age of participants ranged from 52 years to 99 years with a mean age of 79 years. Interviews lasted for approximately 30 minutes to 1 hour and were conducted in patients' and carers' own homes, residential care homes and nursing homes. The research was approved by a Multi-site Research Ethics Committee and the research governance committees of the six PCTs. Participants were given a study information sheet and provided informed consent and permission for interviews to be tape-recorded. Interviews were structured according to a thematic interview guide which was developed by the research team and piloted prior to the research. The interview guide sought to collect detailed information on patients' patterns of health and illness, the types of care received from community matrons and patients' and carers' attitudes towards this care.

Analysis

Grounded theory methods guided the collection and analysis of data (Glaser and Strauss 1967, Glaser 1992, 1998, Strauss and Corbin 1998). Interviews were transcribed verbatim then transcripts were independently coded and analysed by members of the research team. The researchers kept memos during the initial coding process and then discussed these with the group. Memos guided further theoretical sampling as the interview process proceeded. Themes identified by all researchers, and triangulated across multiple pilot sites, underwent a secondary process of joint advanced coding. This process identified salient themes and concepts related to the care provided by community matrons.

Results

Five main categories of community matron care tasks emerged from the data. These were clinical care, care co-ordination, education, advocacy and psychosocial support. Clinical care tasks frequently described by patients and carers included top-to-toe physical examinations, listening to patients' chests, ordering tests and investigations, checking medications, prescribing medications (in accordance with care plans) organising prescriptions (in liaison with the GP), referring patients to specialist clinics, monitoring blood pressures, giving patients vaccinations and vitamin injections, weighing patients, obtaining blood and urine specimens, providing ad-hoc wound care and conducting initial care assessments for social services. In some circumstances community matrons also provided ad-hoc clinical care to carers, even though they were not formally responsible for these tasks.

Patients and carers were enthusiastic about the thorough physical examinations conducted by community matrons. This aspect of community matron case management contributed to a feeling of 'being cared for' and reassured patients that their long-term conditions were being monitored by a health professional. Patients described how their community matron's examinations gave them confidence that they were in stable health, reduced their anxiety and worry, and helped them to 'feel more secure'.

She checks my blood pressure and so far nothing has come up. So that's where it gives me confidence in my health, because she takes my blood pressure and if it's OK and my heartbeat is OK, em my lungs clear, well I think there can't be a lot matter with me, so therefore she gives me confidence. It's like, [community matron's name] is like taking a pill. (Patient, site 5)

Patients explained how community matron monitoring of their medications has prevented them, 'getting mixed up, or you know, me running out' [Patient, site 5] and avoided complications arising from changes to medications during hospital stays. Community matrons conducted medication reviews to identify whether medications were appropriate and being taken correctly. They also investigated drug interactions and adverse effects of medications in liaison with GPs and pharmacists. One carer described how a community matron's medication review identified the cause of her partner's falls:

He kept having falls, he didn't really know why he was falling but as soon as the case manager come along she immediately started looking through all his medication and asking me various questions and it was realised very quickly through talking to someone else that actually the falls he was having were not falls they were blackouts, and that it's not easy to pick that up

... in the end it was the medication, that was the thing that they found had happened ... no detriment to anyone else, but it hadn't been picked up by the medical people ... That had gone on for maybe two months and that hadn't been picked up, nobody had looked at the medication. and the first thing the case manager did was look at the medication ... (Carer, site 4)

The second category of care identified by informants was care co-ordination. Many care co-ordination tasks were conducted outside patient-community matron interaction, yet informants were cognizant of them as discrete community matron tasks. Community matron care co-ordination consisted of liaison and collaboration with a multitude of individuals and organisations to ensure that necessary healthcare and social care services and goods were provided to patients, and to prevent gaps or duplications in care. Informants praised community matrons for keeping them informed throughout these complex processes. They recognised the uniqueness of community matron case management for tying together disparate elements of care and 'sorting out' any problems. Carers in particular appreciated having 'a reference person' to co-ordinate the patient's care:

She's [community matron] a great link-up between all the services. She has made a difference to the efficiency of getting things done. (Carer, site 4)

The third category of care provided by community matrons comprised of education and advice to patients and carers. This included health promotion, disease education, information and advice about medications and advice about support services (including referrals). Patients and carers perceived that the education and advice provided by community matrons extended beyond the usual forms provided by other healthcare professionals. They regarded this education and advice as comprehensive, relevant and meaningful to their individual situation. Patients and carers frequently commented that they had received deficient information from other health professionals about illnesses, treatments or prognosis:

I never knew the name of it, you know, and yes, she did a lot of explaining ... (Patient, site 1)

Informants described how community matrons established an open dialogue of information sharing, rather than imposing didactic relationships traditionally observed within medical settings. Patients and carers noted how they felt comfortable discussing problems with their community matron and asking for advice. Community matrons 'advise' rather than 'tell' them what to do:

She will advise me, she won't tell me, she'll advise me. She's not the sort of em, she's not domineering, she's such a nice ordinary person to talk to. (Carer, site 1)

The education and advice provided by community matrons helped patients and carers to improve self-care, improve adherence to medications regimens, improve symptom control and to prevent illnesses developing. As one carer noted, 'She has shown [patient] how to use his inhalers properly because according to her he wasn't getting the total benefit he should be getting out of them' (Carer, site 4). Informants stated that their improved knowledge about illnesses and early warning signs of exacerbations provided them with a feeling of reassurance. This prevented both patients and carers panicking unnecessarily:

She explains, she doesn't frighten you but at the same time she puts things into perspective for me, and it stops me panicking, it stops me panicking about things, you know. (Carer, site 1)

The fourth category of care conducted by community matrons involved advocating on the behalf of patients with hospital consultants, GPs, pharmacists and nursing services, and advocating on the behalf of patients and carers with social services. Patients and carers appreciated community matrons advocating on their behalf to increase the quality of care provided. Many examples were given of the positive outcomes of this advocacy, including the community matron who intervened after a consultant 'just fobbed off' a patient, and another community matron who secured physiotherapy sessions for a patient:

I'm doing a course up at the day hospital, where you go in for the day and you get physiotherapy ... [community matron] kept putting in a request on my behalf, and at first it was explained, 'no, it's not necessary', but with her persuading we finally got up there ... (Patient, site 1)

Community matrons also advocated on behalf of the patients and carers with a wide range of organisations to gain access to services and obtain equipment. Patients and carers described community matrons writing letters of support and following up referrals with telephone calls to social workers. This assisted in the rapid installation of showers, stair lifts, safety rails and the quick delivery of basic home care equipment. As one carer noted:

She's helped me get equipment, she has, when I was getting nowhere with the social worker she got onto the social worker. (Carer, site 1)

Patients and carers gave examples of community matrons advocating on their behalf with local authorities to have environmental hazards such as uneven footpaths rectified. Community matrons also liaised with pharmacists to ensure medications were provided to patients in user-friendly formulations and packaging:

I had some trouble at the pharmacy at one time, because they brought out a new style em package like, like a big one, a smooth one, and with my stroke I've not got much feeling in my fingers, so I couldn't get them out, cause they were slippy, and they'd end up on the floor. So em I asked for the old pack back and they said 'no, you can't', you know, they said 'it's either that or you can go somewhere else and get the tablets' ... and I talked to [community matron] and she went in and had a word with the pharmacist about it and they gave me back my old package. (Patient, site 2)

The wide remit of the community matron role means that they can potentially work with any professional group to ensure the health and social care needs of the patient are met. One patient in his 50s described how his community matron has advocated on his behalf with a solicitor to help him gain access to his children:

Honestly, she's done things, not just for my health, she's got me contact with my children, when I didn't have contact before. I had a solicitor on it and she got involved ... She helped me sort it out and I've got full contact now with my children and I wouldn't have had that if it wouldn't have been for my nurse. (Patient, site 4)

The fifth category of community matron care identified by informants was psychosocial support. Patients and carers in all sites talked at length about the psychosocial support provided by their community matron. Analysis of the data revealed that patients and carers regarded this aspect of community matron care as equally important to clinical care. Informants praised their community matron as someone they can 'depend on', someone whose visits they 'look forward to' and someone who 'builds me up'. As one patient stated:

Mentally, you know, it means so much knowing that [community matron] is there for me, if I do need her any time ... So you know, it has made a big, it really has made a big difference to me. (Patient, site 1)

A common sentiment expressed by patients was that community matrons 'make you feel cheerful'. One patient who had been discharged from community matron care reflected, 'I looked forward to her coming and having little chats and everything ... it was nice to have someone to talk to, to be honest ... It stopped me feeling sorry for myself' (Patient, site 2). A patient in another site noted that the support provided by his community matron has helped curtail his suicidal behaviour:

I think if I wouldn't have had [community matron] I don't think I'd be here now. Because I was taking a lot of overdoses and cutting my wrists and all that has stopped now, you know, she's saved my bloody life. (Patient, site 4)

Carers perceived a dual role of their community matron in supporting them in addition to the patient. Carers described feeling that their community matron 'was on my side' as much as the patients. Carers frequently stated that community matrons 'take the pressure off' them, helped to ease their stress and helped them to cope with the practical and emotional demands of caring. One carer noted: 'She [community matron] was heaven sent because it just took so much pressure off' (Carer, site 5). Carers explained how their community matron takes the time to sit with them and ask how they are coping, both physically and emotionally, with their caring role. This helped to 'un-bottle' their tension and improve their ability to cope:

When I know she [community matron] is coming in to see her [patient], then it relaxes me as well ... that's where she's been very helpful, she's helped me to un-bottle and get rid of the tension that I'm feeling. (Carer, site 2)

Carers described feeling isolated and unsupported before community matron intervention. They commonly felt that there was no one they could turn to for advice and that they were reluctant to 'keep bothering the doctor' with 'small problems'. They felt comfortable approaching their community matron with even minor concerns and welcomed the shift in responsibility for making decisions about the patients' care:

It's helped me a lot because I have to decide, do we need help? And, you know, do we need sorting out? ... Because it was always down to me to decide, does he need a doctor and things? You know, I had to work it all out, is he more breathless today? But now I can ring him [community matron] and he'll check him then for me ... (Carer, site 2)

Discussion

Interviews with patients and carers identified five types of care tasks conducted by community matrons in their role as case managers for long-term conditions. These tasks were clinical care, care co-ordination, education, advocacy and psychosocial support. Within the category of clinical care community matrons conducted a wide range of tasks, from blood pressure monitoring to medication reviews. Some clinical care tasks, such as 'listening to chests' and prescribing medications, were located within the medical paradigm and were previously provided by GPs. Other clinical care tasks, such as monitoring blood pressures, fell clearly within the nursing domain and were previously provided by district nurses, practice nurses or community staff nurses for elderly people.

The clinical care tasks conducted by community matron case managers are similar to those of Evercare nurse practitioners, as described by Abdallah (2005) and Kane *et al.* (2001). This is not surprising given the fact that the community matron programme was based upon the US Evercare model. Community matron

clinical care tasks are also similar to those reported by Guttman (1999) in a study of a Canadian case management programme for frail elderly people. However, it appears that community matrons in England are delivering more advanced clinical care compared to the case managers in Guttman's (1999) study.

Patient and carer descriptions of their case managers 'listening to chests', diagnosing illnesses and prescribing medications indicate that community matrons are fulfilling at least some of the criteria which define advanced practice nursing. Despite the absence of formal definitions and standards, most authors agree that advanced practice nurses provide expertise in clinical practice, clinical judgement and decision-making skills (Davies and Hughes 2002, Pearson and Peels 2002, Mantzoukas and Watkinson 2006). Advanced practice nursing is also characterised by 'role extension', which involves taking on skills or areas of practice previously associated with other professional domains (Daly and Carnwell 2003). The research suggests that these characteristics of advanced nursing practice are present within the community matron model of case management.

None of the patients or carers had previous experience of any type of case management and while a small number were initially wary of community matron intervention, all gradually developed a great appreciation of their community matron's role as co-ordinator of the disparate elements of their care. The majority of care co-ordination tasks took place outside community matrons' interaction with patients and carers, yet informants were aware of these tasks as a fundamental component of community matron case management. These findings indicate that community matron case management is succeeding in achieving the objective of 'integrating and co-ordinating the individual journey through all parts of the health and social care system' (NHS Modernisation Agency and Skills for Health 2005, p. 4).

Care co-ordination is typically included as a core feature of case management models for frail elderly people (van Achterberg 1996, Guttman 1999, Jiwa et al. 2002, Lim et al. 2003, Abdallah 2005, Adam 2006). Care co-ordination can reduce duplications of health care, avoid gaps and reduce health and social care service costs. The benefits to patients are multifaceted and can include improved access to services, avoidance of unnecessary investigations and procedures, improved disease management and faster discharge from hospital. Informants in the research appreciated having one designated 'link-up' person co-ordinating their care. Some models of case management provide team-based care co-ordination yet reported similar benefits for care co-ordination (Jiwa et al. 2002, Adam 2006). Further research is required to further explore patient preferences and outcomes in relation to named individual

models of case management compared to team-based models.

In non-disease-specific models of case management, education and advice often tend to be peripheral to the core function of care co-ordination. A small number of previous studies have included patient education as an activity of case management among elderly patients with complex conditions (Guttman 1999, Fick *et al.* 2000, Ritchie *et al.* 2002, Schein *et al.* 2005). However, none provided in-depth descriptions of what these activities entailed and none identified patient education as a core role of case management. Schein *et al.* (2005) reported that only 37 frail elderly persons out of 175 received patient education whereas our informants regarded education and advice as one of the five most important tasks conducted by their community matron.

Informants suggested that their community matron acts as a unique source of education and advice and that they help patients and carers to learn more about long-term conditions and their prognosis, to use medications correctly, to recognise the early warning signs of exacerbations of illness and to reduce anxiety. This finding indicates that community matrons are providing education and advice that extends beyond the Department of Health expectation that community matrons should, 'teach carers and relatives to recognise subtle changes in the patient's condition' (Department of Health 2005a, p. 17).

Patients and carers identified advocacy as another key activity of community matron case management. This finding is similar to Allen and Fabri (2005) and Ritchie et al. (2002) who emphasise the importance of advocacy within case management programmes for vulnerable elderly people. Patients and carers gave examples of community matron advocacy on their behalf with a range of professionals, from consultants through to social workers and home care assistants. This component of community matron care was considered highly beneficial to patients and carers, helping to reduce patient and carer stress involved in negotiating with health and social care services, assisting patients and carers to access services or equipment to maintain or improve quality of life and helping to improve the quality of care received by patients and carers from different organisations.

Similarly to advanced clinical skills, the inclusion of patient education and advocacy within the five core components of community matron case management suggests that community matrons are delivering a model of advanced nursing practice. Mantzoukas and Watkinson (2006) include coaching and mentoring within their seven generic features of advanced nursing practice while Taylor (1999) and Stanton *et al.* (2005) note that advanced practice nurse case management typically includes patient advocacy and education.

Informants identified psychosocial support as a crucially important component of community matron case management. This finding contrasts with Department of Health guidance which does not include psychosocial support as an activity of community matron case management. Few case management programmes for frail elderly people have formally included psychosocial support as a core element of the model of care. However, there is evidence from Schein *et al.* (2005) that psychosocial support in the form of coping assistance can improve patient functional status.

Our informants also suggested that psychosocial support from their community matron helped to promote a feeling of being 'cared for', reduced their stress, improved their mood and improved their ability to cope. Allen and Fabri (2005) similarly reported that nurse 'relief of psychological symptoms' promoted a feeling among patients that they were 'cared for'.

Perhaps the most interesting finding to emerge from the research was the suggestion that community matrons fulfil a dual role of providing care to both patients and carers. Some informants described this dual role as similar to the traditional GP role, commenting that GPs often no longer have the time for this task. Carers viewed community matrons as important sources of advice, practical and emotional support, and as someone to help them cope with the stress of caregiving. Two other studies have reported benefits for carers as a result of case management interventions. Allen and Fabri found that nurse case management assisted carers to feel 'supported, cared for, reassured and to have an increased sense of confidence' (2005, p. 1206) while Hughes et al. (2000) found that support provided to carers reduced care giver burden and improved quality of life.

Conclusion

The findings of the research indicate that community matrons provide five main types of care to patients and carers: clinical care, care co-ordination, education, advocacy and psychosocial support. Each of these tasks was enthusiastically appraised by patients and carers, with psychosocial support being regarded as equally important to clinical care.

The domain of 'supporting self care, self-management and enabling independence' in the Case management competences framework for the care of people with long-term conditions (NHS Modernisation Agency and Skills for Health 2005) suggests that case managers can educate and empower patients and carers to improve their ability to self-care. However, the 'very complex' patients with 'intensive clinical needs' targeted by case management programmes are often too ill or frail to achieve

these aims. The research suggests that rather than expecting case-managed patients to improve dramatically their level of independence and ability to self-care, there is a need for policy and programmes to reflect the realities of the target group. This could be remedied by including 'psychosocial support' as a 10th competency domain of case management.

Our wider research with programme managers and staff indicates that there is debate whether psychosocial support is an appropriate role for highly qualified, clinically skilled and expensive community matrons. Yet our informants suggested that they are often unable to access other sources of confidential, caring and reliable support. For many patients and carers, their community matron was perceived to be the only source of psychosocial support available to them.

While psychosocial support is common in mental health models of case management, it is relatively rare in models designed to improve the health and wellbeing of other groups. Our research emphasises the need for case management programme managers to consider including formalised coping assistance or psychosocial support in models designed for frail elderly people or people with long-term conditions. At the very least, programmes should consult patients and carers about their needs and preferences regarding psychosocial support.

Patient and carer descriptions of community matron psychosocial support and, to a lesser extent, patient education and advocacy, indicate that community matrons are delivering a model of case management that extends beyond Department of Health policy directives. This phenomenon is described by Sheaff (1997) in another healthcare policy context as 'implementation surplus'. Patients and carers highly valued the case management implementation surplus provided by community matrons. Policy-makers need to be aware of this, and any further evidence of patient and carer preferences towards case management, if services are to become truly 'patient-led' (Department of Health 2005b).

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