

End of Life Papers

Centralisation of end of life care coordination: impact on the role of community providers

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Key messages

- Survey and anecdotal evidence suggests that the majority of people would wish to be cared for and die in their own home, which has implications for how health and social care is coordinated and delivered in the community setting.
- Centralised administrative coordination has benefits for the delivery of end of life care, and in particular allows community nurses to spend more time with patients, particularly those with complex needs.
- Centralised coordination also has the potential to adversely affect communication between professionals, and may lead to inequitable or ill-considered allocation of resources across patient groups.
- Centralised coordination should incorporate clinical input, to ensure a more appropriate allocation of resources.

Why this matters to me

End of life care has historically received limited policy or service improvement intervention. As such, there is now much debate regarding the delivery and coordination of quality care. Patients who are nearing the end of life (and their carers) interact with many different health and social care providers, and it is vital that there is a comprehensive and transparent process for coordinating this care.

ABSTRACT

Background The recently published *End of Life Care Strategy*¹ and emerging service improvements have raised the profile of end of life care (EOLC) across health and social care sectors. Policy emphasises providing patients with more choice over where they are cared for at the end of life. Surveys and anecdotal evidence suggest that the majority of people would prefer to be cared for (and die) in their own home. Such care provision evidently requires considered planning across community providers. Some areas have instigated a centralised administrative process for such care planning.

Setting This shift towards centralising the administrative function of care coordination for patients who are nearing the end of life has implications for community care providers.

Question This paper seeks to understand the impact that centralising EOLC care coordination in the community has had on community providers.

Methods This paper draws on findings from case studies of two large primary care trust (PCT) regions in England. One hundred and two semi-structured interviews with service managers, commissioners and providers were conducted across the two case studies, as well as two focus groups (ten participants - acute and community nurses), observation of key local palliative care planning meetings, and documentary analysis of strategic and operational papers.

Results The findings presented demonstrate that a centralised approach to care planning has positive outcomes for community nurses, who are able to spend more time delivering direct patient care. However, there were challenges associated with the approach – particularly the capacity of an administrative process to intelligently allocate finite resources amongst patients with a range of care needs.

Conclusions The centralisation of care planning had implications for how community nurses conceptualised their role in the delivery and coordination of EOLC. Community nurses were positive regarding the alleviation of the administrative burden; however the approach challenged their professional

role as key worker – particularly in making judgments as to the nature and appropriateness of patient care packages.

Keywords: case studies, community health nursing, coordination, palliative care, professional role

Introduction

Recent policy developments in the UK health service, such as the *End of Life Care Strategy*¹ and the *Next Stage Review*², have radically raised the profile of palliative and end of life care (EOLC). The publication of these policy visions has prompted considerable deliberation of the need for service improvements in the organisation and delivery of palliative care, to ensure high quality and equitable services for patients who are nearing the end of life. This policy emphasis in EOLC has focused on redesign of existing services (rather than increasing staff numbers), to meet the variable needs of local populations.

The *End of Life Care Strategy*¹ emphasises the importance of meeting the individual care needs and preferences of patients who are nearing the end of life, including their place of care and death. Research suggests that many people would wish to be cared for and die at home, however in practice considerably fewer people achieve this preference.³ As such, many attempts at service redesign have concentrated on increasing the proportion of people who are cared for and able to die in their own home. This shift towards greater EOLC in the community has implications for community healthcare providers, who are increasingly called upon to support patients who are nearing the end of life and their families.

Initiatives have been designed to create a systematic, centralised approach for coordination across EOLC providers. Patients who are nearing the end of life interact with a range of community providers, including specialist nurses, community nurses and healthcare assistants, GPs, personal care providers and equipment stores. A centralised process means that community nurses could make one telephone call to an administrative centre, which then coordinated a care package from these providers on their behalf. This centralised process intends to allow district nurses greater time to deliver direct patient care, rather than administrative coordination.

This research aims to consider the impact that this shift to community care has had on community healthcare providers, specifically focusing on a regionally centralised approach to EOLC coordination.

Methods

This paper draws on findings from case studies of two large primary care trust (PCT) regions in England, which have made a focused attempt to shift EOLC to the community. Across the two case studies, 102 semi-structured interviews were conducted with a range of healthcare managers and professionals involved in the coordination and delivery of EOLC. These healthcare managers and professionals were based in a range of care settings, including acute, community and hospice environments (see Table 1). The interviews were supported by two focus groups involving ten participants (see Table 2), observation of key local palliative care planning meetings, and documentary analysis of strategic and operational papers.

This qualitative study relied largely on the analysis of the semi-structured interviews – particularly those interviews with community healthcare professionals.

Table 1 Interviewees by role

Role	Number of interviews
District nurse	8
Healthcare assistant (community)	2
Hospice nurse	3
Macmillan nurse	6
Medical professional (including GPs)	9
Community practice nurse	6
Senior service manager	11
Service manager	33
Social worker	3
Specialist nurse	10
Ward nurse	11
Total	102

Table 2 Focus group participants

Role	Number of participants
District nurse	4
Case manager	3
Social worker	1
Ward nurse	2
Total	10

This qualitative approach utilised more open research methods that allowed for the complexity of context and for the various perspectives of research participants – both shared and individual. The purpose of this analysis, therefore, was to understand the context from the perspectives of the participants involved and to look at what is meaningful to these individuals. This approach was considered well suited to the research question posed in this paper, which sought to understand the impact that shifting EOLC to the community (and centralising care coordination) had on community healthcare providers.

All of the data collected – interview transcripts, documents and field/meeting notes – were managed using the NVivo software package (QSR International) to organise the resulting data. A thematic coding framework was established prior to data analysis based on the research question and objectives, and data were deductively sorted on this basis. The analysis provided the basis for generating key findings and learning relating to the impact of a centralised approach to EOLC coordination on community healthcare providers. As the research sought to identify common responses to the shifts in care coordination, findings are presented across case studies, with specific vignettes or differences between the cases highlighted in the analytic discussion.

Results: centralised coordination of end of life care in the community

Within both case study sites, specific initiatives had been implemented that were designed to provide the infrastructure in the acute and community settings to support and maintain patients in the community who were nearing the end of life. The emphasis was on creating a systematic, centralised approach for coordination across EOLC providers. Community nurses

could make one telephone call to an administrative centre, which then coordinated care packages on their behalf, including telephoning the multiple care providers required, confirming availability, and then communicating the care package arrangements to the particular patient and/or carer. There were some community services that were not included in this centralised approach, such as GP visits and equipment services. This commentary will focus on how these shifts towards a more centralised model of care coordination were perceived by community nurses.

The primary intention of centralising administrative coordination of EOLC was to address concerns that the time spent by community nurses in arranging care packages constituted a significant barrier to providing responsive and holistic care. An objective of improving administrative processes was to streamline the processes for arranging care packages.

Predominantly, interviewees reported positively that centralised processes had freed up some of their time, by reducing the burden of less clinical parts of their workload. Community nurses described this as a time consuming process, involving many telephone calls, paperwork, and periods of time spent waiting for care providers to return calls. This lengthy process had previously restricted the amount of clinical time that community nurses could spend with all of their patients, including those approaching the end of life.

Those community nurses who reported that the new process had saved them time were asked how they had been able to utilise this saved time. The majority responded that they had been able to invest more time in delivering care for all patients (not solely patients nearing the end of life). As a consequence, many interviewees also commented that they had been able to deliver a better quality of care – their time could be spent undertaking comprehensive assessments and delivering holistic care, rather than coordinating care packages and undertaking the associated paperwork.

Several community nurses commented more specifically that they spend the saved time with more complex patients. As a result of a push to ensure that patients nearing the end of life are identified within the acute setting and discharged from hospital at an earlier date, patients are referred to community nurses at an earlier stage of their pathway. This indicates that they have responsibility for coordinating care over a longer time period and that their caseload is also likely to contain a range of patients with more complex needs, who may have greater levels of dependency. Some community nurses felt unable to quantify how they have used the time which has been saved, and responded that it had simply been ‘absorbed’ into their existing workload.

In addition, other benefits of the centralisation were also identified. One interviewee suggested that the shifts have enabled an improved degree of continuity,

particularly in the event that a community nurse is absent from work, through sickness for example. The centralised point of coordination meant that if a community nurse was absent from work, another health-care professional was able to access patient care information, ensuring continuity of provision. Some interviewees also suggested that the introduction of the centralised approach enabled care to be planned in a more organised fashion, and accorded them greater control over the care planning process. They could now plan care in a more proactive fashion, reducing the number of instances where they have had to put in place care packages quickly to respond to urgent need. This also had positive implications for patients and informal carers, for whom communication regarding the care they were to provide was considered by interviewees to be more systematic and reliable. Interviewees reported that informal carers often have difficulties accessing necessary information regarding schedules of visits and knowing the correct points of contact, and are often relied upon to be somewhat responsible for care coordination. This centralised process was seen to alleviate some of that burden.

The majority of interviewees described the centralised approach in very positive terms, particularly regarding the impact which the service had on the work of community nurses and communication across providers, and with patients and carers. However, some challenges were identified. Several interviewees felt that the central service had actually had a detrimental impact on the level of communication between existing community professionals. In particular, some interviewees expressed concern that, since the introduction of the approach, there had been less communication between community nurses and other care agencies, to which they previously referred patients directly. However, no interviewees reported that the changes in communication had impacted directly on quality of care, or on the patient/carer experience.

Another concern that interviewees raised was the ability of the administrators (i.e. non-clinicians) in a centralised coordination capacity to prioritise patients' needs across finite resource availability, and to allocate care packages accordingly. A benefit of the centralised approach was that the process could allow a satellite view of services and availability across the whole of a region – that the administrators were able to see where services were in place for one patient, and where there may be areas of unmet need in another area. However, since those working in the centralised process did not have a clinical background, they were unable to make clinical prioritisation decisions with these finite resources.

Several interviewees expressed concern that this may lead to an inequitable allocation of resources. Since the centralised processes were unable to prioritise need between different patients, a situation could

possibly arise where care is booked for one patient, which as a result limited the care that could be put in place for a patient subsequently referred, regardless of whether or not their need is greater. Although these concerns were expressed by the nurses interviewed, they were unable to highlight specific examples of such inequitable allocation occurring in practice.

Similarly, some interviewees commented that the administrators may lack capacity to challenge assessments and referrals which are made for patient care packages. Prior to the centralised process, community nurses were responsible for coordinating care packages. Consequently, there was an inbuilt self-checking mechanism as community nurses had to review care packages on an ongoing basis and had a role in ensuring that care could be delivered within available resources, and in accordance with patient need. Some interviewees expressed concern that, since the centralised coordination, some community nurses had tended to over-order care due to the lifted burden of actually arranging the care package themselves. One interviewee used the analogy of the centralised process as a 'sweetie shop'. Again, this has prompted some concern that such over ordering of care packages may result in an inequitable allocation of resources across palliative patients.

Seemingly, although the administrative coordination of care had been streamlined through the centralised approach, this appeared to have hindered the direct communication between the organisations delivering patient care.

Discussion

Recent government policy has raised the profile of care planning for patients who are nearing the end of life. Much of this care is provided in the community setting, and focuses on reducing admissions into acute hospitals and providing a comprehensive care package to support this. This paper has explored the impact of this policy on community healthcare providers, as they endeavour to meet this responsibility. There were many positive responses to the centralisation of care coordination, including that the approach:

- enabled community nurses to spend more time with patients, particularly those with complex needs;
- enabled community nurses to be more proactive in developing EOLC packages, thus reducing 'last-minute' responses, and;
- promoted continuity of care through coordinated back-up when key workers were absent.

However, interviewees also raised several challenges or concerns, such as:

- communication between professionals had been adversely effected due to centralisation of processes
- care coordination led by administrators did not have the necessary professional expertise to prioritise patient needs, allocate resources equitably or challenge assessment and referrals, and
- the process reduced resource-conscious decision-making amongst professionals and led to over-ordering of care provision.

These findings raise a number of implications for care provision. The findings suggest that a centralised care coordination process may benefit from greater clinical input, in order to ensure that care is allocated in a considered, systematic and equitable manner. A similar example would be referral management schemes in general practice, where concerns have been expressed regarding the capacity of a centralised administrative system to make quite complex decisions regarding patients' care needs⁴

As the administrative care coordination function had been removed from community nurses, there were reports that direct communication across professionals had declined. As such, it is suggested that there is a need to foster forums for professionals networking, learning and sharing to maintain communication across professional groups. The same care coordination centre could be used as a hub for inter-professional education and as a learning centre or forum.

The context presented here highlights the value of allowing community nurses to concentrate on delivering patient care, and removing administrative burdens that could be performed through a centralised, administrative process. Paradoxically, this example also highlights the challenges that such an innovation poses to how community nurses define their role as key worker and how they communicate with their provider colleagues. The above suggestions would potentially reduce the detrimental impact of centralised coordination, whilst retaining its positives and not undermining the professional role of community

healthcare providers. This more coordinated process will evidently become the focus of further scrutiny, as the health service copes with the need to improve productivity and find efficiencies.

ETHICAL APPROVAL

The research described in this paper was granted approval by Oxfordshire Research Ethics Committee B (ref 07/H0605/94).

CONFLICTS OF INTEREST

None.

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