

End of Life Papers

Primary and secondary care collaboration for end of life care

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Key messages

- End of life care does not deliver what people say they want and this is symptomatic of a system that admits and keeps too many people in hospital because of the lack of suitable alternatives
- End of life care needs to be built on more robust community services that integrate the skills of a broad range of professionals
- Much of this care can be based in homes but there is likely to be a need for some bed-based capacity as well
- This will be a challenge to the system because it will reduce the need for acute hospital beds, but will provide the care that people need

Why this matters to me

We are not providing the right service for many of our older people. Some will be admitted to hospital because there are not suitable alternatives and some will remain in hospital beyond the time when they have a need for acute care. During this period they are at considerable risk of coming to harm because the environment of an acute ward is not geared to their needs. In addition to being morally indefensible for patients, this is also hard for hospital staff to cope with and places the acute system under undue pressure. We need to provide the right service for patients and deal with the consequences for the health system in a rational, planned way. Having seen the adverse consequences of this system for both patients and staff it is clear that we need to have the courage to change this situation.

ABSTRACT

Background The NHS does not deliver the care that people want at the end of life and receives large numbers of complaints about care in hospitals. This is a symptom of a wider problem which leads to over-hospitalisation of elderly people. This was demonstrated clearly in a hospital utilisation study in a south London borough which showed that over 40% of patients needed to be cared for in settings other than the hospital. Community services were also providing care inappropriately.

Discussion Three issues need to be addressed:

1. An integrated community service, working with both general practice and consultants from the hospital to provide a flexible response to patients' needs over time. This would focus on maintaining

people in the community rather than admitting them to hospital. This would be true for people approaching the end of their lives.

2. Additional, flexible service capacity both in people's homes and in bed-based services including for those people awaiting a continuing care assessment.

3. A system of incentives for hospitals to shift their approach to managing such patients. With these things in place, the delivery of the end of life care service that people have expressly said they want will be feasible.

Keywords: community health services, palliative care

Introduction

End of life care is one of the areas highlighted for attention in Lord Darzi's Next Stage Review.¹ When

the basic facts about end of life care are viewed it is no surprise that this is now a priority area. The End of Life

Care Working Group in London found that 66% of people die in hospital, whilst, when asked about preferred place of death, 57% say they would prefer to die at home and 25% in specialist palliative care or a hospice.² The gap between the number of people dying at home and those who express a preference for doing so is 37%. Nationally, 54% of hospital complaints relate to people who have died in hospital.³ There are few services or industries that would tolerate such a high level of complaints relating to one area of its work without addressing it with a high degree of energy and commitment.

A great deal has been done to coordinate end of life care in the community. Macmillan nurses, district nurses and community matrons, GPs and many other practitioners use Liverpool Care Pathway, Gold Standard Framework, Local Enhanced Services, team meetings and locally-developed initiatives to coordinate end of life care. Out of hours 'special patient notes', rapid response teams and on-call palliative care consultants help out of hours practitioners to remain faithful to the personalised plans intended to help people die in their place of choice. In spite of this, the service as experienced by patients and carers remains poor.

In this paper I suggest how we can improve services for end of life care through joint working between primary and secondary care, flexible bed capacity in the community, and hospital incentives. I draw on my past experience as a hospital chief executive, my present work in an end of life care project (Healthcare for London), and a PCT study of appropriateness of hospital admission.

My own experience

Between 1998 and 2007 I worked in an acute trust that was a multi-site organisation just outside London. In the late 1990s, as part of local plans to move more service provision to community settings, we undertook a study of hospital bed utilisation. We found that around 40% of patients could have been more appropriately managed elsewhere. I believe that most hospitals in the UK would have found a similar thing. The PCT study referred to below shows that we have not significantly affected this position despite care closer to home being a policy requirement for those 10 years.

As Chief Executive between 2004 and 2007 I signed off complaints letters. I became very aware of the shortcomings of hospitals, as an environment for end of life care. The letters from relatives were often a litany of complaints about poor communication, lack of dignity and respect, and 'incidents' that caused them great distress. As a consequence we implemented the Liverpool Care Pathway and helped staff with the

difficult issue of identifying dying patients. We also worked more closely with a local hospice. In spite of this we made very limited impact. I came to realise that the structure and working of the NHS was itself an obstacle to quality care. Working on the NHS London end of life project has helped me to see that we need to address these structural problems across in the health system in a way that tackles some of the fundamental problems of capacity, co-ordination and approach to the question of dying itself. This approach offers, I believe, the prospect of providing a more bespoke service for patients, supporting them to have a real choice about their end of life care. Currently the health system does not have the capacity in the right services to offer this wider choice and nor does it use the skills of generalists and specialists in a way that provides a well co-ordinated response for individuals and their families.

The key lessons I have learned are that whilst co-ordination may occur to differing degrees in primary and community services and in the hospital, good communication between them remains a largely elusive goal. We are far too dependent on hospitals and put too many people in them that would be better cared for in community and primary care settings. But there is simply not the capacity in the community to manage the 40% of patients who could be there rather than in hospital. The 'system' does not function in a way that supports the development of out of hospital care – we do not commission in a way that will redress this situation; payment mechanisms do not encourage community-based provision.

PCT study of hospital bed utilisation

A PCT in south London, reaching from the suburbs to an inner London catchment population, commissioned a study in 2008 to test the appropriateness of hospital admission and stays. On one day the reviewers looked at the use of 353 acute hospital beds, all but 12 of which were on one site.

The study used the Appropriateness Evaluation Protocol that has been developed for assessing potentially unnecessary hospital days of care.⁴ Twenty-seven objective criteria related to medical services, nursing/life support services and patient condition factors are incorporated into the protocol. These include: pulse rate (<50 per minute, >140 per minute); blood pressure (systolic <90 or >200 mm Hg, diastolic <60 or >120 mm Hg); acute loss of sight or hearing; acute loss of ability to move body part; intravenous medications and/or fluid replacement; vital sign monitoring every two hours or more often). If any one of the criteria is

met, the day in hospital is deemed 'appropriate'. The tool demonstrates a high rate of consistency of view between different reviewers.

The headline findings

The study identified that 155/353 patients in hospital could have been managed in other places of care (described in Figure 1).

The study showed that nearly half of these 155 patients need not have been admitted and that for around half of the 155 admission could have been avoided altogether. 26/155 needed rapid access to diagnostics – this could be accessible to GPs without hospital admission. Another 19 could have been managed at home with different interventions from professionals in the community. The remainder needed some form of bed-based care. The average cost of an emergency hospital admission is £1500. If this proportion of patients in hospital who need not be is similar in all 31 London PCTs, London is spending about £7.2 million a week in hospitals that would be better targeted at the community. That equates to nearly £375 million a year.

The health characteristics of those in hospital

The majority of patients in hospital who could be managed elsewhere were elderly frail people with multiple co-morbidities. Figure 2 shows that 229/473 (48%) patients had two or more co-morbidities. Over 60% of patients aged 75–89 had two or more co-morbidities.

Elderly frail people with multiple morbidities require similar kinds of healthcare support as those who are at the end of their life. If we are to have robust end of life services outside hospital, they need to be integrated with core services for managing people with long term conditions in the community. This will require a considerable increase in the scale of provision in the community and far better coordination.

Discussion

The main lessons that I take away from my own experience and this PCT study are that we are using

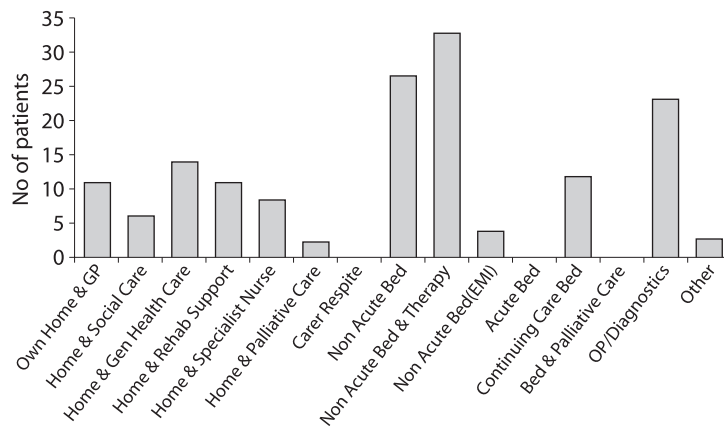


Figure 1 Alternative places of care other than hospital

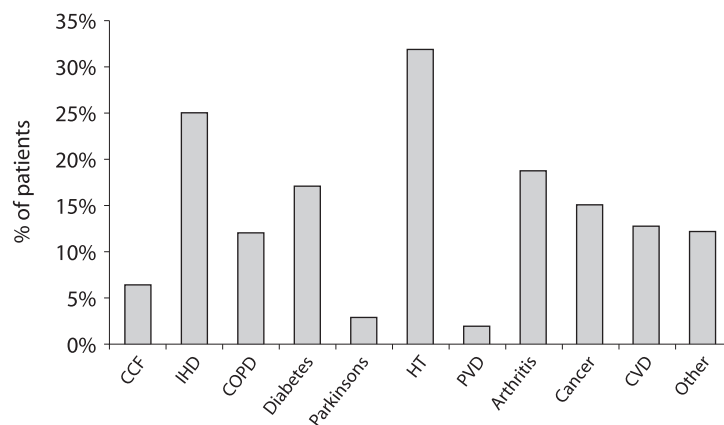


Figure 2 Occurrence of co-morbidities

our resources, particularly the workforce, inappropriately to meet patients' needs; hospitals are often not the best environment for end of life care and the lack of integrated planning between primary and secondary care gets in the way of good end of life care.

Currently our organisational constructs have pushed primary and secondary care clinicians further apart. This is exacerbated by managerial attitudes in both PCTs and hospitals, which often have undercurrents of an adversarial approach, with neither fully addressing the question of how to affect the transfer of care to primary and community care settings.

The way in which hospitals are incentivised is wrong. Presently hospitals are paid for the number of people they admit and see in outpatients. The incentive is to hospitalise. In spite of this, many doctors in hospital try not to admit patients where it is not appropriate. They are also, as we know, under pressure to discharge because of the demand on hospital beds. Much of this pressure comes from the high number of elderly frail patients who are no longer in need of acute medical care. If we want to shift the pattern of service provision we need incentives for maintaining people out of hospital rather than waiting until their exacerbation of their condition reaches a point where hospital is the only practical option.

The fundamental problem is that the infrastructure for community services and particularly for the management of chronic conditions is not adequate to cope with the demand. Spend remains in the acute sector, where many clinicians and managers are frustrated by the number of inappropriate admissions and stays for patients. All of London's health systems will, at times, find their community services are 'full' yet there are many people in hospital who need the service. Making this shift in our use of resources will pose a difficult financial challenge in the period of change, particularly as we are facing the most difficult financial position the NHS has known, and presents a longer-term issue for hospital funding. If, however, we are to deliver the best care for people we collectively have to face up to these difficult challenges. It will also be essential to address productivity issues in the community. Rachel Addicot's article indicates that a central point of co-ordination of care is one way of using resources more effectively, but there is more work to do to make this system more sensitive to clinical needs.

There is also an important moral dimension to this situation. As a system we are knowingly providing inappropriate care and, in doing so, we are putting many older, frail people at risk of harm. The level of falls and infections in hospitals is significant, with the consequence being extended stays in hospital and further disablement. As long as the wider problem of the appropriate management of people with chronic conditions and the frail elderly remains unaddressed it will be both logistically difficult and costly to deliver

an end of life service which meets the expectations of patients. In addition to the problem of the capacity of community services the other key issues we need to address are multi-disciplinary working and alignment of incentives, which are discussed further below.

To deliver a high quality service for both the chronically ill and frail elderly, we need primary and secondary care clinicians to work coherently together, in a highly co-ordinated fashion.

I will identify three things that could help to move towards this.

Primary/secondary care team-working and joint planning

Future policy must reduce the present polarisation of primary and secondary care. Both sectors must work together to design, deliver and evaluate integrated services focused on maintenance. We need to establish both the concept and the practice of broadly-based multi-disciplinary groupings of staff who deliver an integrated service in community settings. The driving principle for this service should be that the team can match its skills with the needs of the patient as those needs change over time. This would include managing dying patients at home or in care homes. To plan and test models able to do this, primary and secondary care practitioners and managers need to become skilled at systems modelling and evaluating whole systems of care. Everyone needs to be better skilled at appreciating what others can offer, and acknowledging the strengths and weaknesses of what we offer ourselves.

Designing and integrating such a service requires the ongoing involvement of general practitioners; care of the elderly physicians; other physicians who have patients with chronic conditions; the district nursing services; specialist nurses and community matrons for conditions such as heart failure and COPD; therapists; generic care workers and LAS staff. The community nursing service might provide the best focal point for both the service and the linkage with general practice. For example district nurses could follow the lead of community matrons and act as the case managers for patients, co-ordinating and flexing the care inputs according to changing needs. The extent of medical input in different settings is unlikely to be high, but when it is needed it is essential that it is provided swiftly and with good team spirit.

Hospital staff would continue to work in the hospital but also work more flexibly into the community. This would give them greater awareness of what community services can provide and would support co-ordination between the hospital and primary care.

The service should provide a rapid response, which could include referring patients to hospital for an assessment but, wherever possible, working to ensure

that those 40% of patients who do not need to be in hospital are placed in the right environment for their needs. Clearly, this would include people who are dying. Without this extended infrastructure we may continue to struggle to deliver the service that people want and should receive.

Developing this type of service would depend on building both competencies and trust amongst the professionals working in it. Consideration needs to be given to the organisational arrangements that would support such a service. Some form of structure to implement the change and to co-ordinate care is required and a clinical network with an integrated governance system may provide a suitable vehicle to deliver this change.

Additional, flexible capacity

The resources required to create additional capacity in the community, both money and staff, are mainly being used in the acute sector. The transition from hospital to community provision would need to be an incremental development with a number of stages to make it feasible in a constrained financial environment. The first stage could be to enhance productivity in community services, using a tool like the Productive Community Services to manage those patients in hospital who could be managed at home. In addition, staff from the acute sector could support early discharge schemes. This would release capacity in bed-based community services, which could be used to meet the needs of those patients who could not be managed at home but who do not need to be in hospital. Some of the community bed-based capacity would provide an appropriate alternative to hospital for those patients who are fit for discharge but who are going through the continuing care assessment process. This would better meet their needs as an environment more geared to nursing care and rehabilitation could be developed. Some of the workforce would need to move from the acute sector to support this shift. Further incremental changes in resource for community services could be built on the back of these developments. Without this staged process it will be very difficult to make the necessary investments in community provision.

Incentives for hospitals to avoid admission and discharge quickly

Payment by Results was, until the introduction of the Commissioning for Quality and Innovation (CQUIN) incentives, entirely an activity-based payment system. CQUIN is a small change in value terms. It will increase

in significance but does not appear to be the vehicle to achieve the shift in care envisaged here. Payments that encourage the maintenance of people in the community need to be developed to support joint working and planning between primary and secondary care. Currently the NHS has the inherent contradiction of a policy to move care out of hospitals and a payment system which encourages the opposite. The development of community provision to match the demand demonstrated in the review of beds would make substantial inroads into the bed base required in hospitals and the income of the acute sector. Such a significant challenge may be perceived as a threat in the acute sector unless they are also given some incentives to support a shift of care to the community. PCTs will need to plan rigorously with their provider services to affect this shift in where patients are managed.

Conclusion

The actions that need to be taken to address these issues are:

- PCTs need to develop a mechanism for primary and secondary care practitioners to plan and deliver services focused on maintaining people at home where this is clinically feasible and economic
- PCTs need to commission services that increase community capacity and to work with providers to address the workforce implications of moving services.
- The Department of Health needs to devise payments for hospitals, community services and primary care practitioners that reward the management of patients in community settings when appropriate to their needs.

These changes might reverse some of the systemic obstacles to robust community provision. I believe they will also help us to manage more patients in the community at the end of their lives and meet people's expectations for a dignified death.

ETHICAL APPROVAL

This is a personal reflection on the UK healthcare system based on evidence from a bed study in a London PCT and did not require ethical approval.

CONFLICTS OF INTEREST

None.

REFERENCES

- 1 Department of Health. *NHS Next Stage Review Leading Local Change*. London, DOH, 2008.
- 2 Dewar S, Chantler C, Dash P and George R on behalf of the End of Life Clinical Working Group. *End of Life Clinical Working Group, Final Report*. End of Life Clinical Working Group, 2007.
- 3 Department of Health. *End of Life Care Strategy: promoting high quality care for all adults at the end of life*. London: DOH, 2008.
- 4 Lang T, Liberati A, Tampieri A *et al*. A European version of the Appropriateness Evaluation Protocol. *International Journal of Technology Assessment in Healthcare* 1999;15:185–97.

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