

Editorials

End-of-life care:

identification, communication, training, and commissioning

More than 50% of those with terminal illness wish to die at home, but surveys confirm consistently that less than 20% of those with chronic illnesses do.¹ The cost of end-of-life care for patients in hospital compared to community is thought to be higher. With the proportion of deaths in hospital predicted to increase,² it is important to address what the obstacles are to allowing patients at the end of their life, to be cared for, and die at home?

MORTALITY STATISTICS

End-of-life care has been highlighted as a national priority in the government white paper *Our Health, Our Choice, Our Say*, National Institute of Clinical Excellence guidance, and the Department of Health End of life strategy. It is one of 12 national priorities for the Quality, Innovation, Productivity and Prevention (QIPP) programme. One indicator associated with a 'good death' is whether patients are cared for, and die, in their place of choice.

Approximately 500 000 people die in the UK each year; 58% die in hospitals, 18% die at home, 17% in care homes, and 4% in hospices.³ England has higher rates of deaths in hospital compared to neighbouring countries (Figure 1).⁴

A systematic review has shown the majority (49–78%) of patients with advanced cancer would prefer die at home⁵ but approximately 23% do. The figures for those dying of chronic organ diseases are worse. Homes deaths for those with pulmonary disease, heart failure, and renal failure are 19%, 10.8%, and 11.5% respectively.⁶

Palliative care team input has been shown to result in better satisfaction, symptom control, reduced emergency admissions, and shorter lengths of stay in hospital.⁷ It is worth highlighting that the involvement of palliative care specialists does not accelerate dying, which is often feared by patients and carers.⁸

CLINICAL CHALLENGES

Managing a patient at the end of their life has many clinical and practical challenges. These include the following.

Identification of patients

Tools such as the Gold Standards Framework Prognostic Indicators have been developed to aid identification of patients who may need end-of-life care. The tool requires asking the question 'Would you be surprised if the patient were to die in the next few months, weeks, days?'

This is followed by a look at disease specific indicators and indicators of general decline.

Approximately 1% of the population die each year so an average GP can expect to face 20 deaths per year of which only one to two are sudden or unexpected in retrospect.⁹ This indicates how many patients a practice can expect to have on their end-of-life register.

Improving communication

Once identified, the conversation with patients about preferred place of care/death and resuscitation status (a hurdle in itself) needs to be recorded and shared with all providers. Currently there is no national consensus on how this is done.

A total of 99% of practices have a palliative care register — a Quality Outcomes Framework target. Use of the Gold Standards Framework and of quarterly meetings to discuss these patients is more variable with evidence suggesting its use in more than 60% of practices.¹⁰

Coordinate My Care (CMC) is one recently developed clinical service underpinned by an electronic solution to share patient data. It is active in general practices, out-of-hours GPs, hospitals, hospices, district nursing clusters, the respiratory and cardiac specialist nursing teams, and the night nursing service. Of those on CMC, 70% achieve community place of death, and 80% achieve their preferred place of death.¹¹

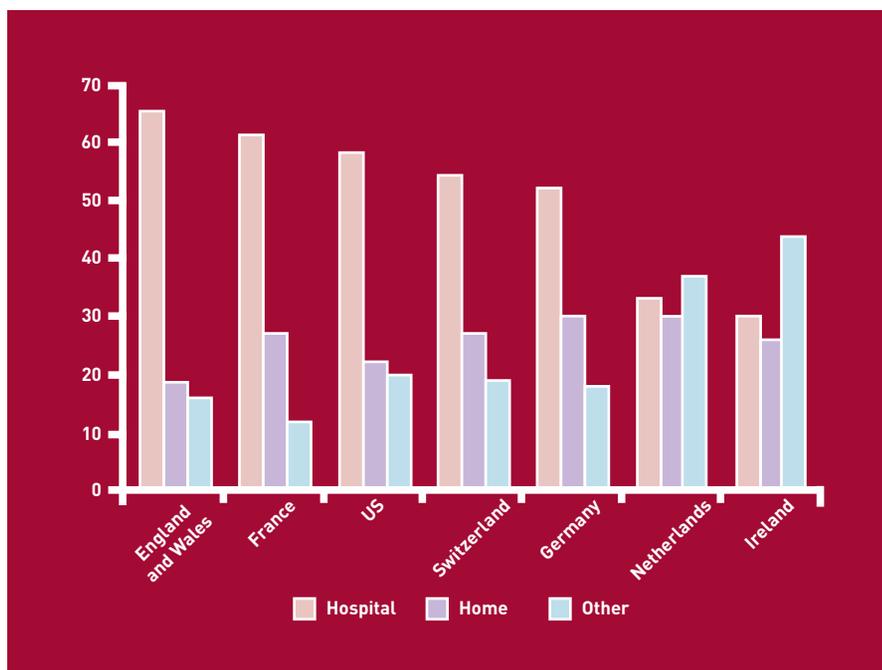
We anticipate that such solutions are not being used more readily due to, among other reasons, lack of time to enter/update data, resistance to learning another software, lack of interoperability, and insufficient training. This is currently being addressed at an individual practice and wider level.

Until GP electronic patient records align with that of hospitals and out-of-hours services, we need a tool to coordinate care between the acute and community settings, ideally one that is identical nationally to ease information sharing. This could set the trend for the convergence of all electronic patient records nationally.

Improving training

The End of Life Care Good Practice Guide states that nationally only 29% of doctors and 18% of nurses have pre-registration training in end-of-life care. Furthermore, only 5% of staff in care/nursing homes has

Figure 1. Comparison of place of death.⁴ Reproduced with permission from WHO Regional Office for Europe.



“... the majority (49–78%) of patients with advanced cancer would prefer die at home but approximately 23% do.”

staff qualified to NVQ Level 3 with some end-of-life care component. *Healthcare for London, A Framework for Action*, highlighted that less than one-quarter of GP practices across London were using best practice models for end-of-life care.⁸

Without an appropriately trained workforce in the community, good quality care and reductions in hospital admissions cannot be achieved.

COMMISSIONING CHALLENGES

The potential cost savings from greater use of home and hospice based end-of-life care in England have been predicted from statistical models.¹² They state that approximately £1.8 billion are spent on providing care for 127 000 patients who died from cancer (£14 236 per patient), and £553 million, (£18 771 per patient) for approximately 30 000 with organ failure.

Different scenario simulations that looked at decreases in unplanned admissions and in length of stay for cancer patients, showed reductions in expenditure; for example, a 10% reduction in unplanned admissions combined with a 3-day reduction in the length of stay could result in £104 million spend potentially avoided in per annum.¹²

What about the burden this puts on community resources? When the care of yet another patient in the community can no longer be absorbed within the limited hospice beds or nurse schedules, commissioners need to take into account the need to divert funding to accommodate this.

Spending by primary care trusts (PCTs) on palliative care varies from £154 to more than £1600 per patient.⁸ In 2006–2007, hospices provided inpatient services to over 38 000 people and supported over 112 000 people in the community. Independent hospices provide approximately 2150 inpatient beds, while NHS hospices provide 450. On average, in 2006–2007, independent hospices received funding of only 31% of their net expenditure from PCTs. In 2008, 70% of hospices had only 1-year contracts with PCTs, limiting their ability to plan and develop services.¹

CONCLUSION

A number of reasons lead to unnecessary

hospital admissions: patients not appropriately identified as needing end-of-life care, lack of expertise and resources in the community, and patient information not being recorded or shared effectively between the groups involved in delivering care.

The challenge for commissioning groups is to identify how and where cost-effective good quality end-of-life care can be provided. Statistical models provide convincing data that shifting care into the community is more economical, but there are no prospective data that actually compare the cost of a patient journey in hospital versus community, and look at the quality of the care delivered. While the evidence is being generated, the onus is on healthcare providers to identify patients likely to need end-of-life care with the aid of available tools, make it a priority to update their palliative care knowledge and promote appropriate information sharing between care providers.

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Competing interests

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