Dying for a change: junior doctors and care of the dying patient

It is inevitable that all junior doctors, probably early in their careers, will be called upon to provide medical care and support for patients who are dying. The needs of these patients may be complex, and they may not be able to communicate them effectively.

It is generally recognized that junior doctors feel under-prepared for the task of caring for dying patients, and are therefore probably providing sub-optimal care in this area.

This article looks at the care of dying patients in the acute hospital setting, and specifically at the role of junior doctors within the health-care team. Suggestions are made as to how junior doctors could feel more prepared for managing patients in the last hours of life.

Introduction: a 'good death'

The provision of excellent care for patients dying in the acute hospital setting is increasingly recognized as a priority within the NHS (Department of Health, 2011). Around 51% of deaths now occur in hospital, a number which has decreased slightly in the last 3 years, but which nevertheless represents the majority of deaths in the UK (Higginson and Gomes, 2008). The importance of providing a 'good death' for patients in hospital remains a huge priority.

The government's *End of Life Care Strategy* (Department of Health, 2008) acknowledged that what a good death entails will vary for each patient, but proposed that for most people dying well should involve:

1. Being treated as an individual, with dignity and respect
2. Being without pain and other symptoms
3. Being in familiar surroundings
4. Being in the company of close family and/or friends.

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Within this widely researched topic, others have found that factors considered important at the end of life by patients and family also include feeling prepared for death, achieving a sense of completion and being allowed to make decisions about treatment preferences (Steinhauser and Christakis, 2000).

None of these requirements for a good death seem unreasonable or unattainable; in fact one would hope that providing these aspects of care in the last stages of a patient's life would come naturally to all health-care professionals. The 2010 General Medical Council booklet *Treatment and Care Towards the End of Life* covers all these aspects. It also emphasizes that high quality care towards the end of life should focus not only on managing physical symptoms, but also on providing psychological, social and spiritual support to patients and their families (General Medical Council, 2010).

Despite the available guidance, excellence in end of life care in the acute setting continues to provide one of the greatest challenges in hospital medicine.

How are we doing?

A landmark study published in the *BMJ* in 1994 observed 50 hospital inpatients who were dying and found that they received unacceptably low levels of attention from nursing and senior medical staff in the last hours of life (Mills et al, 1994). Further studies from around the same time showed that people dying in hospital often suffered from poorly controlled symptoms, including severe pain, agitation and dyspnoea (Lynn et al, 1997).

Sadly, things do not seem to have progressed greatly since then. Over half of the complaints received by the Healthcare Commission between 2004 and 2006 related to care in the last stages of life (Healthcare Commission, 2007). The Department of Health published the results of the first National VOICES Survey of Bereaved People (Department of Health, 2012), commissioned in line with the *End of Life Care Strategy*. The findings were disappointing for hospital deaths. Of 22 000 families surveyed, 20% of those whose relatives had died in a hospice reported the care as outstanding, compared with only 7% whose relatives had died in hospital. Pain control in the last 3 months of life was found to be excellent in 36% of hospital deaths, compared with 62% of hospice deaths.

The Liverpool Care Pathway controversy

Before July 2013, the Liverpool Care Pathway for the Dying Patient was regarded as embodying best practice in the care of the dying, and was used widely in the community and in hospital. It was developed with the intention of providing hospice standards of practice in terminal care, regardless of the location of the dying patient. Many hospital doctors found the document a valuable resource in caring for the dying and managing their symptoms while awaiting specialist advice.

Nevertheless reports of poor end of life care in some hospitals led to widespread alarm and pervasive mistrust of the way in which the Liverpool Care Pathway was being used. Baroness Neuberger's independent review *More Care, Less Pathway* (Department of Health, 2013) recommended national withdrawal of the Liverpool Care Pathway. The Leadership Alliance for the Care of Dying People, an NHS England policy group with representation from the major stakeholders, was subsequently set up to ensure that dying patients 'receive high quality care, tailored to their needs and wishes and delivered with compassion and competence' (Leadership Alliance for the Care of Dying People, 2014a). Recommendations have been published, with the document highlighting that the way in which these goals are achieved will vary, depending on the setting and needs of the dying person. The five priorities are that, when it is thought that a person may be in the last few days or hours of life, it is essential to:

1. Recognize this possibility, communicate clearly and make decisions in accordance with the person's wishes
2. Communicate sensitively and compassionately with the patient and those important to him/her
3. Involve the patient and those important to him/her in decisions about treatment and care, to the extent that the patient wants
4. Support the needs of families and others identified as important to the dying person
5. Plan and do – develop, coordinate and deliver, with compassion, an individualized care plan that involves food and drink, symptom control, and psychological, social and spiritual support (Leadership Alliance for the Care of Dying People, 2014b).

Barriers to excellent care

A particular problem in hospital seems to be the timely recognition and documentation of approaching death. An audit of 435 hospital deaths in 2009 found that although it was possible to anticipate a large proportion of deaths in the acute hospital setting, 87% of patients were recognized as dying less than 72 hours before their death (Gibbins et al, 2009). The report highlighted that if clinicians were under-confident in making the diagnosis of dying, then patients were less likely to benefit from specialist end of life care.

The problem does not seem to be confined to the last hours and days of life. Medical staff also appear to have difficulty identifying the palliative care needs of patients who are still receiving active treatment. A survey conducted in the acute hospital setting found that while 36% of all inpatients had palliative care needs according to the Gold Standard Framework criteria, fewer than half of these had been identified as such by doctors (Gardiner et al, 2013).

It is accepted that making the diagnosis of dying can be a great challenge, especially for doctors with little experience of end of life care. Understandably, doctors are reluctant to label a person as 'dying' if there is a reasonable chance that he/she may recover with further active treatment. One study found that doctors' estimates of prognosis in terminally ill patients are usually over-optimistic (Christakis and Lamont, 2000), which may adversely affect the care given to patients at the end of their lives by the continuation of inappropriate therapies.

Baroness Neuberger's review (Department of Health, 2013) stated that although the Liverpool Care Pathway should be withdrawn from use, clinicians should not default to the practice of treating all patients as though they are curable. The review specifically mentions the importance of timely recognition of dying, stating that: 'the decision to withdraw or not to start a life-prolonging treatment should be taken in the cool light of day by the senior responsible clinician in consultation with the healthcare team' (Department of Health, 2013). It recommends that such decisions should not be made out of hours, or by staff without the requisite training and competence.

These recommendations come alongside a general consensus that an attitudinal shift is required for the medical profession when it comes to caring for dying patients in hospital. It is increasingly recognized that consideration of symptom control, planning for possible end-of-life care, and discussions about patient preferences should go alongside active management (where appropriate), rather than only after it has finished (Gibbins et al, 2009).

Diagnosing dying

Diagnosing dying is an important skill for hospital doctors as it enables the timely switching of therapeutic priorities from life prolongation to palliation, clear communication with relatives and unified multidisciplinary working. This can be very difficult in a setting where patients are often being aggressively managed because of potential reversibility. Timely identification of those patients whose deterioration is irreversible can be helped by appropriate involvement from senior clinicians, careful and frequent assessments, and regular communication with patients and their loved ones.

Once reversible causes have been excluded, these signs point towards a diagnosis of dying:

- Decreasing food and liquid intake
- Shortening attention span and disorientation
- Decreasing conscious level
- Increasing difficulty in swallowing, particularly tablets
- Bedbound with increasing fatigue and weakness.

In patients with advanced cancer the speed at which these changes develop may give an indication of the likely timing of death; deterioration over days suggests that death will occur over a matter of days. Similarly for deterioration over hours, and over weeks, death may occur in the course of hours or weeks respectively (Twycross et al, 2011).

Junior doctors' roles in palliative care

Ideally, reports on the importance of early recognition of dying patients will contribute to a change in culture and an improvement in the preparation and forward planning aspects of palliative care in hospitals. It is inevitable, however, that some patients will follow an unpredictable course, deteriorating outside of working hours or when senior reviews are difficult to obtain.

In these cases, it is imperative that the junior doctor called to review the patient is competent in basic aspects of symptom control and palliative care. The doctor should at least feel confident in initiating treatment for pain, nausea, agitation and dyspnoea – in the same way that he or she would feel confident initiating treatment for an exacerbation of asthma.

Concern is growing about how underprepared many junior doctors feel for the daunting task of caring for patients in the last hours of life. The *End of Life Care Strategy* reports that of all workforce groups, secondary care doctors have some of the greatest training needs when it comes to caring for dying patients (Department of Health, 2008). A study of health-care workers' perspectives on the use of the Liverpool Care Pathway found that dying patients were less likely to be placed on a care of the dying pathway if they did not have access to timely senior review (Freemantle and Seymour, 2012) – this presumably reflects not only junior doctors' unwillingness to make decisions about withdrawal of active treatment, but also their inexperience in recognizing when a patient is actively dying.

Undergraduate training

So why are newly qualified doctors lacking in confidence when it comes to diagnosing and caring for dying patients? The *End of Life Care Strategy* report suggests that the problem starts at medical school, with wide variations in palliative care training in and the tendency towards non-assessment of this key area of medical practice.

A qualitative study of newly qualified doctors agreed that undergraduate medical education is currently failing to prepare junior doctors for their role in caring for dying patients (Gibbins et al, 2011). The doctors participating in the study admitted that their skills and knowledge were limited, and revealed that much of their learning in this area came from 'trial and error'.

Lack of formal training in palliative care at university – and little in the way of assessments on the subject – certainly contribute to medical students' poor knowledge base in this particular area. Gibbins et al (2010) examined the structure and content of palliative care teaching in different UK medical schools. They found that while facts and knowledge were thought to be important, the emphasis was on helping medical students overcome the same fears held by the lay public about death, dying and hospices. Although de-mystifying death is an essential part of training, the lack of focus on practical aspects of symptom control must contribute to junior doctors' feelings of being under-prepared for caring for dying patients in the acute setting.

Another problem seems to be lack of exposure to dying patients in medical school. It is certainly anecdotally true that when approached by medical students looking for patients to examine on the ward, most doctors will skip over any patients nearing the end of their life – 'Don't go and see him, he's dying'. This may well be appropriate – there is usually a desire among staff to keep the patient as peaceful as possible, and relatives may object to medical students interrupting the last few hours with their loved one.

Appropriate as it may be, however, there is no doubt that this attitude can prevent medical students' exposure to dying patients. There develops a real possibility that the first dying patient they encounter may be during their first set of nights as an first year foundation doctor on call, when they are being expected to formulate a management plan – with or without senior support.

Postgraduate training

If medical school appears to be inadequately preparing junior doctors in the task of caring for dying patients, especially in terms of exposure, then it may be that more emphasis needs to be placed on the subject during foundation training. The foundation curriculum is relatively non-specific about outcomes and competencies in palliative care (Foundation Programme, 2012), stating that first year foundation doctors should: 'Understand the principles of providing high quality end of life care, including the use of DNAR [do not attempt resuscitation] orders as outlined in *Treatment and care towards the end of life: good practice in decision making* (GMC, 2010)'. It stresses the medicolegal aspects of the do not attempt resuscitation form, as well as the importance of following patients' wishes and good communication with relatives.

The curriculum does also state the importance of recognizing the value of 'diagnosing dying', but there is no mention of specific medical knowledge or of understanding the pharmacological treatment used for symptom control.

Many hospitals do not offer a dedicated session on palliative care as part of their foundation teaching programme. The majority of teaching in the foundation teaching programme seems to be on managing acutely unwell medical and surgical patients.

Solutions

Baroness Neuberger's document, while emphasizing the importance of senior involvement in the care of dying patients, also addresses the importance of good training in this area. Training needs are discussed throughout the document, with suggestions that proficiency in caring for dying patients should be regularly assessed as part of revalidation.

As is often the case with shifts in attitude, if this change is to have a lasting impact then it needs to be led by those in the early stages of training. With the majority of patients dying in hospital, and the inevitability of out of hours cover being predominantly provided by junior doctors, it is essential that trainees are well prepared for providing excellent care in the last days and hours of a patient's life. The government's ongoing interest in the topic should be reflected by greater emphasis on care of the dying in the undergraduate medical curriculum. There should be more dedicated training time, more teaching on practical approaches to symptom control, and more rigorous assessment methods.

Accepting that direct contact with dying patients may be difficult for undergraduates, improving skills might be achieved through high-fidelity mannequin simulation for challenging end-of-life care scenarios. Observed structured clinical examination stations in finals should include stations on prescribing for acute palliative care.

As suggested by the Association for Palliative Medicine (2006), core end-of-life competencies should be prioritized in the curriculum and possessed by all UK medical graduates.

Aligning medical students' attitudes to the importance of their postgraduate role in palliative care might be achieved through presentations given by family members of patients who died in hospital and received, in their view, suboptimal treatment. These could be contrasted with presentations by those who felt that their relative received excellent care. The lasting effect of a traumatic death on the family, and indeed of a death that was well handled, should bring the importance of the subject into sharp emotional focus. Furthermore, encouraging medical students to engage in contemplative practices to explore the inevitability of their own mortality and that of their loved ones may also help to prioritize excellence in care of the dying (Halifax, 2008).

Beyond medical school, rigorous training in the management of dying patients should continue into the foundation years and beyond. Dedicated sessions should be provided as part of the foundation teaching programme, and it should be mandatory for each foundation doctor to have a minimum number of workplace-based assessments on the topic of caring for the dying patient. It should be heavily emphasized that whichever specialty these junior doctors eventually choose, they will almost inevitably care for dying patients and should ensure that they are prepared for this challenge as and when it arises.

Conclusions

Unpreventable dying is sometimes seen as an embarrassing clinical failure, and dying patients are given less attention than those whose survival chances are greater. It is now widely accepted that dying should be seen as a medical emergency, requiring the same swift action, attention to detail and skill as all other emergencies. As patients only die once, there is only one chance to get it right. This sense of urgency, coupled with increased training and assessment, should leave doctors better equipped to competently manage dying patients in the acute hospital setting. **BJHM**

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TOP TIPS

- It is vitally important to recognize a patient who may be nearing the end of life, even if active life-prolonging treatment is also ongoing.
- This recognition and acknowledgement of approaching death should be shared with all relevant staff, relatives, and the patient if appropriate.
- Decisions about withdrawing life-prolonging treatments need to come from senior physicians, but all doctors should be competent in assessing the needs of dying patients and prescribing for symptom control as necessary.
- A patient dying with unrelieved symptoms should be seen as a medical emergency, and all junior doctors should be equipped with the skills and knowledge to manage it as such.

KEY POINTS

- A large proportion of the population die in hospital, but often their care is found to be sub-optimal.
- Palliative care is seen as a specialty for seniors, but many patients die out of hours with little senior support available for juniors.
- Junior doctors often feel under-prepared for caring for dying patients in hospital.
- This is an area of great concern, and should be addressed both in undergraduate and postgraduate training.
- Timely involvement of palliative care teams may help, both in maintaining the patient's comfort and in supporting the junior doctors looking after patients.