

'If only someone had told me . . .'

A review of the care of patients dying in hospital

Polly Edmonds and Angie Rogers

ABSTRACT – Approximately half of all patients who die do so in hospital. Despite the advent of palliative care in the UK, there is evidence that the care that many patients receive in the final phase of their illness in hospital is poor. Building on a study of bereaved relatives' views of the information provided by an inner city hospital trust during an admission in which a patient died, this article explores the factors that may contribute to sub-optimal care for patients dying in hospital. In particular, a lack of open communication, difficulties in accurate prognostication and a lack of planning of end-of-life care can all result in poor care. Strategies to improve care, such as the use of integrated care pathways, advance directives and education initiatives, are discussed.

KEY WORDS: advance directives, communication, death, dying, end-of-life care, palliative care

Introduction

Approximately half of all patients who die in the UK do so in hospital. There is evidence to suggest that these patients have multiple symptoms,¹ and that the care many of these patients receive in the dying phase can be poor. Observational studies have shown that many dying patients do not receive basic comfort care (such as mouth care), are not given assistance eating and drinking, and that contact between healthcare professionals and patients is minimal.^{2,3} Costello's recent observational study of patients dying on care of the elderly wards showed that nurses tended to focus on meeting patients' physical needs, while avoiding open communication about prognosis. In consequence, they rarely addressed important aspects of psychological and spiritual care.³

Despite numerous studies that have highlighted the benefits of open communication at the end of life among cancer patients,⁴ these needs are often unmet.⁵⁻⁷ Recent studies using the views of bereaved carers (informants) to evaluate the care given to cancer patients in the last year of life confirm that poor communication at the end of life remains commonplace.^{8,9}

Experience of dying in an inner London teaching hospital

In 1998, a post-bereavement survey was conducted as part of a programme to identify and address the needs of patients dying in an inner London teaching hospital trust. This had arisen out of concerns regarding the care of this patient group. The methodology for this survey has previously been reported.¹⁰ Of the 182 informants invited to participate in the study, 78 (43%) returned completed questionnaires. Thirty-six (20%) of those invited expressed a wish not to participate and 68 (37%) did not respond. There were no differences between the responders and non-responders. The majority (95%) of informants classified themselves as white; 54% were a spouse and 27% a son or daughter of the deceased. The most common cause of death was cardiovascular diseases (36%, including cerebrovascular disease); a further 20% had died from infective causes, predominantly bronchopneumonia; and in 13% the cause of death was cancer. There are several potential limitations to this study, including the low response rate and the lack of representation in informants from ethnic minority groups. In an area of high socio-economic deprivation, the views of informants who were unable to read or write in English may have been under-represented. Some doubts have been expressed about the reliability of such proxy reporting.¹¹⁻¹³ However, the research evidence suggests reasonable validity for this approach for service evaluations.⁹

Despite the study limitations, common themes arose from qualitative analysis of the data. For

Polly Edmonds
MB FRCP, Consultant
and Honorary
Senior Lecturer
Angie Rogers BA
MSc, Research
Fellow
Department of
Palliative Care and
Policy, King's
College, London

Clin Med
2003;3:149-52

Key Points

.....
Approximately half of all patients die in hospital
.....

Current evidence suggests that the care of patients dying in hospital is poor
.....

Factors in hospital contributing to poor care include a lack of open communication, difficulties in prognostication (so that patients are not diagnosed as dying) and a lack of advance planning
.....

Education, advance directives and care pathways may all have a role in improving care but are yet to be evaluated in this context
.....

example, although healthcare professionals appeared to have spent adequate time with the deceased and their carers, informants would have liked more information about the deceased's condition. Several respondents gave examples where a lack of open communication between the deceased and healthcare professionals led to great distress, specifically relating to information regarding prognosis. Informants appeared to value both effective communication and the potential of open communication about prognosis. However, when patients' relatives did talk to healthcare professionals about the deceased's condition and/or treatment, 'hospital speak' and/or the use of euphemisms could create barriers.

Examples were also cited where a lack of planning with regard to physical symptoms, particularly outside normal working hours, led to inadequate symptom control. This inadequate advance planning of care was also evident with regard to end-of-life decisions, such as issues regarding withholding and withdrawing treatment, continuing active treatments, and place of care/death. Informants expressed regret that they were not involved in end-of-life decision-making, that they were not present at the time of death, or that the deceased did not die at home. In addition, a number of instances were detailed in which care provided for dying patients was hindered by a lack of coordination and/or communication between healthcare professionals and/or services.

These findings identify a number of issues that could arise as a result of poor information and communication. Difficulties in talking about a patient's condition to the patient, their carers and other healthcare teams or services have a direct effect on the quality of the patient's death. The low response rate to our survey limits its generalisability for the rest of the UK. However, evidence in the literature from both the UK and abroad supports our findings.

A good death

Several authors have discussed the concept of a 'good death'. Analysis of qualitative data obtained by focus groups with US patients, families and healthcare providers identified six major components of a good death: pain and symptom management, clear decision-making, preparation for death, completion, contributing to others and affirmation of the whole person.¹⁴ These findings reflect the 12 principles of a good death highlighted by a report from Age Concern in the UK (see Box 1).¹⁵

Literature review

Open communication

In both the UK and the USA, the advantages of open discussion about death and dying have gained almost universal acceptance. In recent years, there has been a shift to open communication not only about diagnosis but also about prognosis, especially among cancer patients.¹⁶ Open communication has become almost a prerequisite for a good death as it facilitates effective symptom control and allows all those involved in a patient's care

to plan their end-of-life care effectively, including treatment decisions and place of care or death. However, there is evidence to suggest that despite their apparent commitment to open discussion, doctors and nurses may remain reluctant to talk about death and dying with the patients they care for.^{3,17,18}

Prognostication

Prognostication is crucial for successful planning of end-of-life care. It is increasingly acknowledged that patients and those close to them have very individual and changing needs with regard to knowing and accepting a prognosis.¹⁹ It may be difficult to make accurate prognostic judgements for patients suffering from non-malignant conditions,²⁰ where the pattern of deterioration is less predictable than for cancer patients. This may be especially true for older patients and those with multiple diagnoses. However, up to one-fifth of patients with non-cancer diagnosis in the last year of their life are reported to suspect that they are dying.¹¹ In order for patients and their relatives to be well informed about a patient's prognosis, those caring for them first have to acknowledge that the patient is dying or that death is the most likely outcome in given circumstances.

Doctors tend to be systematically over-optimistic when estimating prognosis in seriously ill patients.²¹ This appears to be true for all groups of doctors, and to be more pronounced the longer the duration of the doctor-patient relationship. Many patients with advanced, chronic illness will have developed a long relationship with clinicians involved in their care, but the lack of objective prognostication may impact adversely on the patient's end-of-life care. One study in the USA undertook focus groups with patients with advanced chronic illness, their families and healthcare professionals involved in end-of-life care.²² These examined preferences regarding preparation for the end of life, and informed a national survey of end-of-life

Box 1. Principles of a good death.¹⁵

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptoms
- To have choice and control over where death occurs (ie at home or elsewhere)
- To have access to information and expertise of whatever kind is necessary
- To have access to any spiritual and emotional support required
- To have access to hospice care in any location, not only in hospital
- To have control over who is present and who shares the end
- To be able to issue advance directives which ensure that wishes are respected
- To have time to say goodbye, and control over other aspects of timing
- To be able to leave when it is time to go, and not to have life prolonged pointlessly

preferences. All the groups agreed that preparation for death was important. However, patients were more likely than physicians to want to plan funerals and know the timing of death but less likely to want to discuss personal fears.

Planning of end-of-life care

Difficulties in accurate prognostication have an impact on the planning of effective end-of-life care. Current evidence suggests that many of the patients who die in hospital have poorly controlled symptoms,¹ inadequate psychosocial support and basic nursing care.^{2,3} Mills *et al*'s observation study of the care of patients dying in hospital, conducted in 1983, identified the practice of distancing and isolation of patients by both medical and nursing staff, which increased as death approached, hindering effective communication. Although these observations were made almost 20 years ago, more recent studies suggest that, despite the advent of palliative care services, the care of hospitalised dying patients remains poor.

The SUPPORT study in the USA confirmed shortcomings in the care of seriously ill hospital patients.²² The investigators also identified that aggressive life-sustaining treatments (including care in an intensive care unit and mechanical ventilation) were continued up until the time of many patients' deaths, even though family members reported that patients would have preferred comfort care, even if this shortened life.²³ Active treatment up until and including the day of death for patients with advanced cancer in the hospital setting has also been reported in Australia.²⁴

There is conflicting evidence regarding patients' treatment preferences at the end of life. Fried *et al* reported that the burden of treatment, its outcomes and the likelihood of its outcomes all influenced the treatment preferences of older patients who were seriously ill.²⁵ Unrealistically optimistic expectations of the outcomes of treatment can also lead patients to request interventions, such as cardiopulmonary resuscitation (CPR), that doctors believe are inappropriate. Patients' choices are influenced by the provision of accurate information regarding the outcomes of treatment; one study demonstrated that patients were far less likely to request CPR when they were made aware of the low probability of a successful outcome.²⁶ Without effective communication between patients, families and healthcare providers, these issues may not be addressed and inappropriate or futile treatment may be continued by default.

Strategies to improve care of the dying

Role of advance directives – The use of advance directives is becoming more commonplace, particularly in the USA. These have been widely advocated as a means of extending patient autonomy to situations when they become incompetent. In the UK, advance directives are now legally binding if they are specific for the given clinical situation. Data from the SUPPORT study indicate that advance directives were seldom used, as they were not considered applicable in the majority of cases.²⁷ This study also found that advance directives did not substantially

enhance communication or decision-making about resuscitation.²⁸ Despite their legal status in the UK, a recent questionnaire survey of UK NHS trusts found that only around one-quarter of trusts, mainly those providing acute services, have developed or intended to develop policies on advance directives.²⁹

Integrated care pathways – In the UK, one strategy to enhance the care of dying patients has been the use of an integrated care pathway for dying patients.³⁰ The pathway is designed for patients estimated to be in the last days of life using specified criteria (Box 2).³¹ It encourages regular monitoring and anticipatory prescribing for physical symptoms such as pain, agitation and breathlessness,³² and nursing interventions focused on patient comfort. The pathway also sets out goals for adequate communication regarding patient and carer insight, awareness of the current situation, preparedness for death and religious and spiritual support, both before and after the patient's death.

There is no evidence at present that the use of an integrated care pathway in the hospital setting improves the exchange of information and communication between patients, carers and healthcare professionals at the end of life. Despite this, the care pathway allows regular audit and monitoring of the process, quality and delivery of care and could be a powerful tool to improve education and quality of care of the dying in the general setting.

Education – An underlying principle of the palliative care movement has been that of education for all healthcare professionals to enhance holistic patient care. However, there is no evidence that this has enhanced care of the dying in the general rather than specialist (hospice) setting. An educational initiative in the USA aimed at promoting physicians' confidence in addressing end-of-life issues with their patients was ineffectual.³³ Specifically, following the education programme, physicians were no more able to promote either discussion of end-of-life issues or 'do not attempt resuscitation' orders. In the UK, a communication skills training programme for cancer and palliative care nurses was shown to be effective up to 2.5 years after completion of the course.³⁴ Importantly, nurses' skills at psychological assessment improved in the time following

Box 2. Criteria for starting an integrated care pathway for dying patients (adapted from Ref 32).

Patients should have a known diagnosis and have deteriorated despite appropriate medical intervention. The multiprofessional team have agreed the patient is dying and at least two of the following apply.

The patient:

- is bedbound
- is only able to take sips of fluids
- has impaired concentration
- is semi-comatose
- is no longer able to take tablets.

completion of the course, suggesting that they became more confident in managing patients' and families' psychological care. Whether such communication skills training has a direct effect on the care of dying patients has not been established. In the UK, palliative care teaching is relatively new in the undergraduate medical curriculum. The extent to which this teaching will impact on the care of dying patients is as yet unknown.

Conclusion

This review has highlighted the issues of effective communication, prognostication and planning to enhance end-of-life care. Despite the development of hospital-based palliative care services in the UK, patients dying in hospital and their families may still not experience effective and timely end-of-life care from healthcare professionals. There is a need for further research to improve both identification of the dying phase and patients' and families' experiences. Improvements in the care of dying patients are likely to require systematic changes in addition to educational initiatives.

Acknowledgements

The authors would like to thank Saffron Karlsen who undertook data entry and the quantitative analysis, and Julia Addington-Hall for her help in the development of a hospital-specific VOICES.

References

- Costello J. Nursing older dying patients; findings from an ethnographic study of death and dying in elderly care wards. *J Adv Nursing* 2001; **35**:59–68.
- Meridith C, Symmonds P, Webster L, Lamont D *et al*. Information needs of cancer patients in West Scotland: cross sectional survey of patients' views. *BMJ* 1996; **313**:724–6.
- Rogers AE, Addington-Hall JM, Aberly AJ, McCoy ASM *et al*. Knowledge and communication difficulties for patients with chronic heart failure: qualitative study. *BMJ* 2000; **321**:605–7.
- McCarthy M, Addington-Hall JM, Lay M. Communication and choice in dying from heart disease. *J R Soc Med* 1997; **90**:128–31.
- Addington-Hall JM, Lay M, Altmann D, McCarthy M. Symptom control and communication with health professionals, and hospital care of stroke patients in their last year of life as reported by surviving family, friends and officials. *Stroke* 1995; **26** (12):2242–8.
- Rogers A, Karlsen S, Addington-Hall J. 'All the services were excellent. It is when the human element comes in that things go wrong': dissatisfaction with hospital care in the last year of life. *J Adv Nursing* 2000; **31**(4):768–74.
- Rogers A, Karlsen S, Addington-Hall JM. Dying for care: the experiences of terminally ill cancer patients in hospital in inner city health district. *Palliat Med* 2000; **14**:53–4.
- Addington-Hall JM, Walker L, Jones C, Karlsen S, McCarthy M. A randomised controlled trial of postal versus interviewer administration of a questionnaire measuring satisfaction with and use of services received in the year before death. *J Epidemiol Comm Health* 1998; **52**: 802–7.
- Fakhoury WKH. Satisfaction with palliative care: what should we be aware of? *Int J Nursing Studies* 1998; **35**:171–6.
- Higginson I, Priest P, McCarthy M. Are bereaved family members a valid proxy for a patient's assessment of dying? *Soc Sci Med* 1994; **38**:553–7.
- Hinton J. How reliable are relatives' reports of terminal illness? Patients and relatives accounts compared. *Soc Sci Med* 1996; **43**:1229–36.
- Steinhaus K, Clipp EC, McNeilly M, Christakis N *et al*. In search of a good death: observations of patients, relatives and providers. *Ann Int Med* 2000; **132**(10):825–32.
- Debate of the Age, Health and Care Study Group. *The future of health and care of older people: the best is yet to come*. London: Age Concern, 1999.
- Seale CF, Addington-Hall JM, McCarthy M. Awareness of dying: prevalence, cause and consequences. *Soc Sci Med* 1997; **45**:477–84.
- Pincombe J, Brown M, Thorne D, Ballantyne A, McCutcheon. Care of dying patients in the acute hospital. *Prog Palliat Care* 2000; **8**:71–7.
- Field D, Copp G. Communication and awareness about dying in the 1990s. *Palliat Med* 1999; **13**:459–68.
- Timmermanns S. Dying of awareness: the theory of awareness contexts revisited. *Sociol Health Illness* 1994; **16**:322–39.
- Lynn J, Harrell F, Cohn F, Wagner D, Connors AF. Prognosis of seriously ill hospitalised patients on the days before death: implications for patient care and public policy. *New Horizon* 1997; **5**(1):56–61.
- Christakis N, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ* 2000; **320**:469–72.
- Steinhaus KE, Christakis NA, Clipp EC, McNeilly M *et al*. Preparing for the end of life: preferences of patients, families, physicians and other care providers. *J Pain Symptom Manage* 2001; **22**:727–37.
- SUPPORT Principle Investigators. A controlled trial to improve care for seriously ill hospitalized patients. *JAMA* 1995; **274**:1591–8.
- Lynn J, Teno JM, Phillips RS, Wu AW, *et al*. Perceptions by family members of the dying experience of older and seriously ill patients. *Ann Int Med* 1997; **126**:97–106.
- Middlewood S, Gardner G, Gardner A. Dying in hospital: medical failure or natural outcome? *J Pain Symptom Manage* 2001; **22**:1035–41.
- Fried TR, Bradley EH, Towle ER, Allore H. Understanding the treatment preferences of seriously ill patients. *NEJM* 2002; **14**:1061–6.
- Murphy DJ, Burrows D, Santilli S, Kemp AW *et al*. The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation. *NEJM* 1994; **330**:545–9.
- Teno JM, Stevens M, Spornak S, Lynn J. Role of written advance directives in decision making. *J Gen Intern Med* 1998; **3**:439–46.
- Teno JM, Lynn J, Wenger N, Phillips RS *et al*. Advance directives in end of life decision making: lessons from the Patient Self-Determination Act and the SUPPORT Project. *J Am Geriatr Soc* 1997; **45**:500–7.
- Diggory P, Judd M. Advance directives: questionnaire survey of NHS Trusts. *BMJ* 2000; **320**:24–5.
- Overill S. A practical guide to care pathways. *J Integrated Care* 1998; **2**:93–8.
- Ellershaw J, Foster A, Murphy D, Sjea T, Overill S. Developing an integrated care pathway for the dying patient. *Eur J Pall Care* 1997; **4**(6): 203–7.
- Ellershaw J, Smith C, Overill S, Walker S, Aldridge J. Care of the dying: Setting standards for symptom control in the last 48 hours of life. *J Pain Symptom Manage* 2001; **21**:12–17.
- Shorr AF, Niven AS, Katz DE, Parker JM, Eliasson AH. Regulatory and education initiatives fail to promote discussions regarding end of life care. *J Pain Symptom Manage* 2000; **19**:168–73.
- Wilkinson S, Bailey K, Aldridge J, Roberts A. A longitudinal evaluation of a communication skills programme. *Palliat Med* 1999; **13**(4):341–8.