Recognizing dying in terminal illness

Recognizing dying in terminally ill patients is a complex clinical skill. This article outlines the approach to the decision, common difficulties encountered in patients with both malignant and non-malignant disease, and a simple approach to considering the question 'Is this patient dying?'

Recognizing dying, the last few hours or days of life, can be complex and difficult, and has been the subject of controversy, both within and outside medicine. A key article by Ellershaw and Ward (2003) describes a number of barriers, consequences and learning objectives regarding this area of clinical diagnosis. Despite further research exploring the diagnosis of dying, a simple approach using objective decision aids and rules remains elusive. However, failure to recognize dying has serious consequences for patients, their families, clinicians and use of health resources. Dame Cicely Saunders (1984), the founder of the modern hospice movement, commented that: 'How people die remains in the memory of those who live on'.

This article outlines issues pertinent to diagnosing dying in terminal illness, i.e. where death is an inevitable outcome. Current practice is summarized, acknowledging that the foundations of the decision process are thorough assessment, avoidance of 'blanket' rules, awareness of the complexities involved, regular review of decisions, and an ability to convey uncertainty while maintaining trust.

'Recognizing dying' as a concept

The nature of 'recognizing dying' may be viewed in two similar but distinct ways, although in practice, the application of these views may overlap. Dying can be understood as a physiological process – a sequence of events occurring in a patient who is deteriorating irreversibly, and which signifies a 'point of no return', beyond which no interventions can affect the outcome. This approach is reflected in much of the language of end of life care, with references to 'the dying phase' and 'recognition of dying' (Coackley and Ellershaw, 2007).

In contrast, dying may be viewed as an accumulation of negative physiological events, each of which remains potentially treatable; death is therefore a 'final straw' in an increasingly sick patient. This view is borne out by advice to treat or exclude reversible causes before diagnosing dying, and the recognition that this diagnosis may be reversed (Marie Curie Palliative Care Institute Liverpool, 2009). In this situation, dying is more difficult to define and identify in advance, seen only as those who are critically ill but whose condition continues to deteriorate.

While the question may appear academic, it was highlighted and debated some time ago in the wider scientific literature (Kass, 1971; Morison, 1971), and it influences approaches to research and practice. In some clinical contexts, the distinction is clearer; an otherwise healthy person dying as a result of an acute illness such as pneumonia may represent a failure to compensate for repeated insults. A patient with advanced progressive malignant disease, with multiple organ failure, who is failing to respond to attempts to reverse his/her condition, may be more clearly defined as dying. While it is difficult to attempt to tease these perspectives apart, there are consequences associated with the erroneous application of either approach (*Table 1*). Assuming the first perspective risks failing to consider cases where the diagnosis may need to be undone (Morita et al, 2003). Assuming the second risks inappropriately attempting to treat patients whose condition is irreversibly deteriorating (Middlewood et al, 2001).

High stakes nature of decisions

High stakes outcomes surround a diagnosis of dying. Failing to treat reversible conditions may result in preventable deaths; concern about such errors prompted a newspaper article (Devlin, 2009) and subsequent national debate. Conversely, failing to recognize dying also has serious results (*Table 1*) (Ellershaw and Ward, 2003).

Some of the negative outcomes in *Table 1* can be attenuated by clear and honest communication of uncertainty, good multidisciplinary communication, regular review and a focus on symptom control irrespective of the management aims. These outcomes are given in italics. Thus, accuracy in recognizing dying is not the only factor in the optimal management of these patients.

Table 1 shows that the outcome of an error, whichever way that error occurs, is significant. There is no decision that can be deemed to be consistently correct; there is no 'safety net'. This may be contrasted with some other clinical contexts. In some cases, where the risk–benefit ratio of a treatment strongly supports one course of action, sensibly applied 'blanket' decisions may be appropriate; an example is the use of thromboprophylaxis in high-risk surgical patients (Wille-Jørgensen et al, 2004).

Dr Paul M Taylor *is Clinical Research Fellow, Hull York Medical School, University of York, York YO10 5DD and* **Dr Miriam Johnson** *is Reader in Palliative Medicine, Hull York Medical School, and Honorary Consultant, St Catherine's Hospice, Scarborough*

Correspondence to: Dr PM Taylor

In addition to the high stakes involved in the decision, the ultimate outcome when attempting to diagnose dying is binary. In clinical contexts where the outcomes are relative, incorrect decisions may result in relative differences, such as delayed discharge, poorer pain control and need for further courses of medication. Errors, while not ideal, can be ameliorated with time and regular review, and so this relative impact can be factored into decision-making guidance. An example would be analgesic titration guidelines, which generally advise starting with low doses and titrating to effect; the clinician errs on the side of a safer decision at the expense of delayed achievement of pain control (Twycross and Wilcock, 2007).

The high stakes nature of the decision, and the binary nature of the outcome, mean that diagnosing dying will always require careful and critical thought. There is no 'hard and fast' set of rules that may be applied in a uniform manner. In the face of this difficulty, there is a risk that clinicians will take refuge in failing to review a decision that the patient is dying, or failing to recognize dying.

Prognostication

Prognostication is closely related to diagnosing dying and, while the terms have distinct meanings, they are often used interchangeably. Clearly defined methods exist to identify prognostic factors in specific illnesses (Royston et al, 2009), and support the identification of groups of patients with a median prognosis as short as several weeks. The Palliative Prognostic Score is one such example (Glare, 2004). Individual factors that have been shown to be associated with approaching death vary according to underlying diagnosis but, in terminal cancer patients, include poor performance status, anorexia, dyspnoea, clinical prediction of survival, leukocytosis and reduced lymphocyte count.

Clearly, poor prognostic factors and their associated models have a role in helping clinicians to identify which patients are at a higher risk of death in a given period of time. Nevertheless, it should not be assumed that factors which have prognostic significance at one time scale have a similar significance in another – in heart failure, for example, long-term poor prognostic markers such as obesity, hypercholesterolaemia and hypertension appear to have a paradoxical 'protective' effect in the short term (Kalantar-Zadeh et al, 2004). This 'reverse epidemiology' may be a statistical phenomenon or may highlight subtle changes in physiology in patients approaching the end of their life.

In addition, caution must be taken when applying prognostic models outside of the study population in whom they were validated (Moons et al, 2009). Prognostic models are often generated in specific research contexts, and any difference between the study population and the population to whom the model is applied may affect the reliability of such results.

Table 1. Consequences of treating a patient as 'dying' or 'reversibly sick'

Decision	Diagnosed as dying	Diagnosed as reversibly sick
Dying patient	Focus on symptom control, dignity and privacy	Inappropriate cardiopulmonary resuscitation attempts
	Accurate communication and involvement of patient in decisions	Inappropriate interventions of no or limited benefit
	Appropriate use of Liverpool Care Pathway	Limitation of privacy or time with family in final days
	Scope for implementation of preferred place of care and advanced decisions	*Patient and/or family unaware of approaching death*
	Scope for family and patient to be aware and prepared for death	*Patient and/or family lose trust as a result of unacknowledged deterioration*
	Discontinuation of inappropriate interventions or needlessly prolonging dying	*Conflicting messages for patient and/or family from multiprofessional team*
		Patient dies with uncontrolled symptoms, resulting in a distressing and undignified death
		Complaints relating to care
		Cultural and spiritual needs not met
Reversibly sick patient	Failure to treat reversible condition	Appropriate acute interventions
	Subsequent increased risk of mortality and/or morbidity	Clear goal for interventions
	Loss of trust in event of later reversal of decisions	Focus on reversing acute deterioration
	Conflicting messages from within the multiprofessional team	Accurate communication with scope to involve patient wishes for management priorities
	Complaints relating to care	

Outcomes in italics can be attenuated, as described in the text. Adapted from Ellershaw and Ward (2003)

More recently, prognostic research has proposed clinical markers that may be associated with a prognosis in the order of 1–2 weeks (Chiang et al, 2010; Ohde et al, 2011). In addition to the cautions outlined in the application of prognostic models above, such studies risk sacrificing sensitivity for predictive power – correctly predicting that high score patients have a high risk of death, but potentially assigning a lower risk score to a significant number of patients who do go on to die.

A further key point in any application of statistics is the difference between individuals and populations. Applying a model derived from a population to an individual may not be appropriate, especially when one of the outcomes is death. For example, a specific patient population may have a median prognosis of 3 months, with an interquartile range of 1–8 months. Nevertheless, when dealing with an individual, it is that person's specific prognosis which is of interest. An individual patient will survive for a specific period of time; he or she will not be '50% alive' in 3 months and then '25% alive' in 8 months.

So, while these methods are an important part of our repertoire for understanding dying in providing a context for clinical decisions, they must be interpreted in keeping with their limitations. Specifically, it is not necessarily appropriate, nor recommended by the inventors of such models, to extrapolate uncritically from one timeframe or clinical question to another, nor to rely solely on existing techniques in recognizing the dying patient. In addition, even the most well-performing models available include an inherent element of uncertainty.

Trajectories

Disease trajectory is a related concept to prognostication (Murray et al, 2005). Knowledge of the disease trajectory is obviously important for recognizing the dying patient. According to traditional models of disease trajectory, a person with terminal cancer presenting with clear symptomatic evidence of rapid disease progression is likely to continue to deteriorate. A person presenting with an acute deterioration on a background of chronic organ failure may well improve in the short term, survive to discharge and live for months. Such considerations clearly have an impact on clinicians' ability to recognize someone who is dying. It is important to assess a patient's current deterioration, and thus the likelihood of possible reversibility, in the light of known poor prognostic markers and where the patient appears to be in his/her disease trajectory, rather than managing each clinical issue in isolation.

Reversibility

When assessing a sick terminally ill patient, in whom the 'diagnosis of dying' is possible, the extent to which an acute deterioration may be reversible can be difficult to assess and must be carefully considered. The burden of the treatment and the likelihood of response to the treatment in the context of disease trajectory, severity and stage, together with information on prognostic markers, should be taken into account. In addition, the degree of reversibility possible is important. For example, it may be deemed that there is a chance that cardiopulmonary resuscitation may restore a cardiac output, but that further post-arrest recovery in intensive care is highly unlikely or impossible. This conclusion will affect the clinical decision to attempt to reverse cardiorespiratory arrest should it occur. Thus the impact of management of acute reversible causes, and its role in benefit/burden decisions, is an additional complicating factor.

Another important feature in assessment of reversibility and appropriateness of possible treatment options is the speed of deterioration – whether there is time for the treatment to take effect before death occurs. In cancer, disease-modifying treatments, such as chemotherapy and radiotherapy, rarely have an immediate (i.e. within hours) positive impact on symptom control or quality of life. Exceptions may be made for procedures such as inserting stents into occluded vessels or draining ascites or effusions, but interventions aimed at targeting the malignant lesion itself often have their own side effects, or require a degree of fitness to be appropriate. It would be unusual, for instance, to consider, or indeed offer, the use of chemotherapy or radical radiotherapy in a cancer patient who was thought to be dying.

However, in patients with organ failure, some interventions aimed at improving symptoms are also interventions that may reverse the underlying deterioration. Intravenous diuretics and nitrates in heart failure (Adler et al, 2009), or inhaled bronchodilators, steroids and ventilatory support in chronic obstructive pulmonary disease (Leach, 2005), are examples of interventions that may improve a patient's symptoms and also help the patient recover from an acute deterioration, if recovery is possible. This blurred distinction in the aim of treatment, coupled with the organ-failure disease trajectory of episodic, acute deteriorations, may hinder the clinician in accurately assessing the potential reversibility of the clinical situation.

Taking the current situation in the light of the events of the preceding few months is crucial, as is regular reassessment, maintaining watch for an improvement within an expected timeframe. In addition, where the benefits and burdens of interventions are finely balanced and unpredictable, the patient's wishes are highly significant. The impact of interventions is framed, at least in part, in terms of the patient's symptom control. Given that symptoms are subjective, as is the impact of any medical intervention, then such decisions cannot be separated from patient wish.

Current practice

Evidence for diagnosing dying is drawn from a combination of observational data and expert opinion. Traditional signs associated with approaching death

include deteriorating performance status, decreasing or fluctuating conscious level, withdrawal, weakness, reduced oral intake and difficulty with oral medications (Twycross and Wilcock, 2001; Fürst and Doyle, 2005). The significance of these signs, however, may vary according to underlying diagnosis. In addition, each of them may vary during the course of an acute or chronic illness, and so must be interpreted in light of the overall clinical picture of the patient.

The Liverpool Care of the Dying Pathway version 11 (Marie Curie Palliative Care Institute Liverpool, 2005) originally drew on these factors to highlight an appropriate time to commence the pathway, using the presence of a number of clinical signs. While these were not characterized as 'signs of approaching death' (the documentation suggested they be considered only when 'the multiprofessional team has agreed that the patient is dying' and all potentially reversible factors had been considered), they might be inappropriately interpreted as such; this led to criticism in the press (Devlin, 2009).

The most recent version (version 12) of the Liverpool Care Pathway has a different supported decision process, placing greater emphasis on team decision making and regular review, and removing any specified signs that may be misapplied (Marie Curie Palliative Care Institute Liverpool, 2009). Instead, the decision-making process begins with the statement 'The team believe the patient is dying', and prompts a reassessment at least every 3 days. While this does not include specific guidance on how dying is recognized, it clearly addresses the criticisms of 'tick-box medicine' and allows scope for careful, clinical assessment and review.

An observational study, reported as a conference presentation, highlighted several clinical signs that may be observed in imminently dying patients (Menten and Hufkens, 2004). These included somnolence, anuria, livid spots, 'death rattle' and apnoea. An earlier Japanese study (Morita et al, 1998) recorded the mean time before death that a number of clinical signs could be observed; specifically death rattle, cyanosed extremities, pulseless radial artery, 'respiration with mandibular movements', increased opioid requirements and decreased conscious level. Both of these studies were designed to be observational – they do not give (nor did they set out to give) a relative measure of the strength of association of these signs.

Such signs may also occur in critically sick patients but, if seen in patients for whom no other interventions are appropriate, usually signify that the patient is 'imminently dying'. However, these signs may occur too late in the disease process for certain decisions to be implemented; it may not be possible for a patient, thought to have a prognosis of hours, to be transferred to a preferred place of care.

It is interesting, therefore, that current practice rests to a large extent on clinical acumen and experience. Taking the Liverpool Care Pathway criteria as an example of guidelines in this field, the need to assess a patient as a whole, to seek the opinions of colleagues, to exclude reversible problems and to be prepared to review decisions are key points.

Attempting to identify a clear set of guidelines or signs by which the diagnosis of dying may be made is likely to remain a difficult challenge. Further research is ongoing in this area to explore the feasibility of using objective signs in recognizing dying, the strength of associations of such signs with risk of death, as well as considering which signs, if any, are appropriate. In addition, an ongoing pilot, the AMBER care bundle (Carey et al, 2010), incorporates some of the complexities discussed above into a decision framework. This framework accounts for uncertainty in the transition from reversibly sick to dying, and promotes clear communication, advance planning and regular review as a key component of the care of such patients.

Conclusions

Whichever approach is used to understand dying, there is scope to recognize such patients and manage them appropriately providing a risk/burden assessment of each potential intervention is made in the context of trajectory and presence of poor prognostic features. However, there are no simple rules or clear guidelines by which such patients may be identified; there is inherent uncertainty involved in the decision-making process. Existing prognostic techniques are limited at short and focussed time scales. Furthermore, margins of error that may be acceptable for certain decisions are less so when combining an uncertain decision with a high stakes binary outcome. For these reasons, recognizing dying will, at least for the immediate future, continue to be a difficult but important clinical skill. **BJHM**

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KEY POINTS

- Communicate clearly and honestly.
- Ensure good symptom control, irrespective of aim of treatment.
- Focus, wherever possible, on patient preferences.
- Accept uncertainty, and communicate this appropriately.
- Allow discretion in the interpretation and application of objective signs.
- Recognize the limits inherent to applying formal prognostic methods to diagnosing dying.
- Assess the risk/benefit balance of any treatment.
- Consider the likely degree of reversibility possible.
- Ensure regular multidisciplinary team review.

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