DIAGNOSING DYING: SYMPTOMS AND SIGNS OF END-STAGE DISEASE

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After being given a terminal diagnosis, patients and their families/carers often enquire about the prognosis. However, determining individual patients' prognoses is challenging for healthcare professionals. This article reviews the complexities of predicting prognosis and diagnosing the process of dying. It aims to improve nurses' understanding of the dying process and to inform clinical practice across all care settings. It is essential that nurses and other members of the healthcare team recognise when the dying process is beginning, so that the patient, family members and carers can be informed. The key issues in relation to determining prognosis are diagnosis, the individual's performance status and the increase of symptom burden and disease progression. The article discusses disease trajectories associated with specific conditions, the common signs and symptoms of the dying phase and common clinical indicators that are found at the very end of life and which suggest that a patient is beginning to die. *Conflicts of interest: none*

KEY WORDS

Dying
Last 48 hours
Palliative and end-of-life care
Prognosis
Symptom burden

When a terminal diagnosis is given, patients, families and carers often ask 'how long?' Prognosis is important to all concerned. It is fundamental to enabling informed decisions to be made about end-of-life care and to facilitate open communication between the healthcare professional, patient and carer. However, healthcare professionals face many challenges when determining prognosis. The predictive aspect of prognosis is widely variable. For example, patients who have extensive malignant disease may outlive their prognosis, whilst others may die very rapidly, despite being given a 'good prognosis'. This makes the process of prognostication a complex one.

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The initiation of the Liverpool Care Pathway for the Dying Patient (LCP) (Ellershaw and Wilkinson, 2003) requires the healthcare professional to predict that the patient is likely to die in the next few days. The general criteria for commencing a patient on the LCP are that the patient is bed-bound, semi-comatose, unable to take tablets and only able to have sips of fluid. These signs tend to be found in patients with cancer. The dying phase is not always as clear in other chronic, incurable diseases such as heart failure (Ellershaw and Ward, 2003). Obviously, the factors cited in the LCP could identify any number of patients, e.g. someone who has had a severe cerebrovascular accident and who may recover. Therefore, other factors need to be taken into account, e.g. a diagnosis of a life-limiting illness and the failure of active and curative treatment (Higgs, 1999). In addition, an examination of symptoms should take place before concluding that death is imminent and reversible causes for the decline considered and addressed. Symptom burden (Reuben et al, 1988) and serum albumin levels (Phillips et al, 1989) have been found to have an impact on mortality. When diagnosing that a patient is dying it is important that all members of the healthcare team agree that the patient is in the end stages of life, otherwise the patient may be subject to variable management. In addition, communication between the professionals, patient and family/carers can be contradictory (Ellershaw and Ward, 2003).

The advantage of identifying dying is that it makes it possible for all involved to acknowledge that death is imminent. This may facilitate further conversations between the patient and the family/carers about preferred place of care and the patient's final wishes. This fosters what Glaser and Strauss (1965) describe as 'open awareness', where everyone is aware of the terminal diagnosis. This is the ultimate goal (refer to *Table 1* for Glaser and Strauss's four types of awareness of dying). As Praill (2000) stated: 'The challenge...is to meet the needs of all who are dying and those who care for them, in the place of their choice and in a way that is most appropriate to them.'

It has been found that psychological as well as physical states can influence

how the patient and their carers cope with the terminal illness and the dying process. Sheldon (1997) identified the complex issues relating to the psychosocial aspects of palliative and end-of-life care. She included a discussion about the various models of grief before and after death, citing Kübler-Ross's (1969) five-stage model (denial, anger, bargaining, depression, acceptance) and Buckman's (1992) three-stage model (initial stage, when a threat is faced, chronic stage, including depression and possible resolution, and final stage, in which the ability to manage the inevitable death occurs). However, Sheldon (1997) supports Corr (1991–1992) as a pioneer of a different perspective which moves away from these models and appears to embody the ethos of palliative care and its more holistic approach. Corr's focus shifts towards the dying person achieving a task-related perspective, where the person focuses on physical, social, spiritual and psychological needs and addresses these needs before death (Corr, 1991–1992).

Methodology

A literature review was performed to investigate evidence of which clinical indicators, signs and symptoms might be indicative of dying. The aim of the review was to improve the understanding of the dying process and inform clinical practice across all settings. The literature examined focused predominately on people with cancer, but with acknowledgement of other long-term illnesses. A range of health-oriented databases were searched, including CINAHL (Cumulative Index to Nursing and Allied Health Literature) and PubMed. The internet search engine Google was also utilised to gather a broader spectrum of information available to the general public. Key words and terms were: 'death', 'diagnosis', 'dying', 'last 48 hours', 'palliative care', 'prognosis', 'serum albumin' and 'hypoalbuminaemia'. The search was initially confined to the years 1985–2008. Seminal works identified by the search, published prior to 1985, were included. The inclusion criteria were: adults, English journals, the focus being on cancer and other life-limiting diseases, dying, palliative care and low serum albumin levels. The exclusion criteria were: not before 1985, paediatrics, non-English journals and the focus being on curable diseases. Further articles, letters and reference books were gathered via cross-referencing in identified papers. Performance measures and physical and psychological state were identified as key factors, as these are used to assess the potential for treatment or the progression of the disease, as are increased symptom burden and a low serum albumin level.

This article will examine the complexities associated with predicting prognosis and diagnosing dying. It will first discuss probable disease trajectories dependent on diagnosis, before examining in more detail the clinical signs and symptoms that indicate a person has a limited prognosis and that the last few days of life are approaching. It is not the intention of this article to discuss symptom management at the end of life, nor has it been possible to incorporate all the signs and symptoms associated with all life-limiting diseases. This article will only concentrate on the more usual indicators that death is approaching. The intention is to improve nurses' understanding of clinical signs and symptoms associated with the terminal stage of disease so that they can better prepare patients and their families/friends/carers.

Disease trajectories

Glaser and Strauss (1968) first described disease trajectories and typical patterns of deterioration. This seminal work remains central to the literature related to dying trajectories. Trajectory is defined in two steps: the course of the illness over a period of time; and the shape or rate in functional ability, i.e. a gradual decline over a period of time or a sudden death (Glaser and Strauss, 1968). People who die suddenly and unexpectedly will have high function and rapid decline. However, the literature generally describes three main illness trajectories for people with progressive chronic illnesses.

Steady progression with a clear terminal phase

This trajectory usually applies to people with cancer. People who have a potentially curable cancer may, at diagnosis, have a high function but as the disease progresses their function declines. There is generally a decline in physical health over a period of weeks, months or, in some cases, years, punctuated by the positive or negative effects of treatment. The process may end in a rapid decline in the 3 months leading up to death. Weight loss, reduction in performance status and impaired ability for self-care tend to occur in the last few months (Glaser and Strauss, 1968; Lunney et al, 2003; Murray et al, 2005).

Gradual decline, punctuated by episodes of acute deterioration and some recovery

This trajectory tends to be seen in people with organ failure, e.g. heart or lung. Patients are usually ill for many months or years with occasional, acute, often severe, exacerbations. Deteriorations

Table 1

The four types of awareness of dying

Closed awareness: the patient is not aware they are dying but clinicians are aware that this is the case
Suspected awareness: patient tries to find out if they are dying because they suspect that this is the case
Mutual pretence: the patient and staff do not acknowledge openly with each other that the patient is dying although both parties believe this to be the case
Open awareness: this is when the patient, staff and family/friends can acknowledge, in their interactions with each other, that the patient is dying

Source: Glaser and Strauss (1965)

Table 2

Factors that may indicate a poor prognosis in patients with heart failure

Previous admissions with worsening heart failure
No identifiable reversible cause
Receiving the optimum amount of conventional drugs that are tolerated
Deteriorating renal function
Failure to respond within 2 or 3 days to necessary changes in diuretic or vasodilator drugs

Source: Ellershaw and Ward (2003)

are generally associated with admission to hospital and intensive treatment. Each exacerbation may result in death. However, when the patient survives such episodes, there is usually deterioration in health and functional status. The timing of death remains uncertain. There may be a sudden, seemingly unexpected death or a gradual decline punctuated by peaks and troughs that continue throughout the disease process (Glaser and Strauss, 1968; Lunney et al, 2003; Murray et al, 2005). Consequently, it can be more difficult to predict prognosis in patients with, for example, heart failure than it is in patients with cancer. Worsening symptoms are not necessarily the result of progression of the heart disease but reversible (albeit only temporary) causes such as chest infection or anaemia (Ellershaw and Ward, 2003). Factors that may indicate that a person with heart failure has a poor prognosis are listed in *Table 2*.

Prolonged, progressive, gradual decline

This is typical of frail, elderly people or people with dementia. Patients may have low functional capacity at the start, which continues to decline throughout the last years of life. The decline can be lengthy or the trajectory may be cut short by death after an acute event, such as a fractured neck of femur following a fall, or pneumonia. There tends to be reduced functional capacity in the final year of life (Glaser and Strauss, 1968; Lunney et al, 2003; Murray et al, 2005). The dwindling trajectory in old and frail people can make the task of diagnosing when a person is beginning to die challenging (Lynn and Adamson, 2003).

Murray et al (2005) acknowledged that the problem with using 'trajectories' in terms of predicting prognosis is that people are living longer, may have co-morbidities and have varying social circumstances that affect prognosis. People may also have two trajectories running in parallel, i.e. cancer and heart failure. Therefore, patients should not be 'categorised' into a particular trajectory depending on their diagnosis. Their condition must be subject to regular reviews. Rates of progression along the trajectory vary and patients can die at any stage (Ellershaw and Ward, 2003; Lunney et al, 2003; Murray et al, 2005). Therefore, in order to predict when a person is coming to the end of life the healthcare team should take into account reduction in performance status, reduced independence with activities of living, as well as clinical signs and symptoms.

Tools such as the Eastern Cooperative Oncology Group (ECOG) Performance Status (Oken et al, 1982), the Karnofsky Performance Scale (KPS) (Karnofsky and Burchenal, 1949), and the Palliative Prognostic Score (Maltoni et al, 1994) aim to examine the functional status of the patient in order to demonstrate the trend of deterioration. For example, the ECOG Performance Status tool is used to assess how a patient's disease is progressing and how it affects activities of living and to determine appropriate treatment and prognosis (*Figure 1*).

This article will now discuss the clinical signs and symptoms indicating that a person has a reduced life expectancy.

Clinical signs and symptoms of reduced life expectancy

Clinical signs and symptoms are linked to reduced life expectancy (Reuben et al, 1988). Some of the main signs and symptoms of advanced disease are listed in *Table 3*. Their presence is an important consideration when diagnosing reduced life expectancy. They highlight the severity of the patient's condition (Toscani et al, 2005). All have an impact on quality of life. Diagnosis and performance status are indicative of likely prognosis and those with a poor performance status and functional ability are likely to die more rapidly. Symptom burden tends to increase as both malignant and non-malignant diseases progress. Therefore, symptom burden is an important factor in predicting the likely time of death (Addington-Hall et al, 1998; Twycross and Lichter, 2004).

Anorexia (loss of appetite) and cachexia (wasting of physical appearance) are common in cases of advanced malignancy. They are directly linked to morbidity (O'Neill, 2004). The precise

Grade	ECOG Performance Status
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light housework, office work
2	Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited self-care, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair
5	Dead

Source: Oken et al (1982); Eastern Cooperative Oncology Group, Robert Comis MD, Group Chair

Figure 1. Eastern Cooperative Oncology Group (ECOG) Performance Status.

Table 3

Common signs and symptoms of advanced disease

Anorexia and cancer cachexia
Dysphagia
Dry mouth
Nausea and vomiting
Dyspnoea
Drowsiness and fatigue

cause is not clear. The main signs and symptoms of cancer cachexia are: profound weight loss, muscle wasting, increased resting metabolic rate and metabolic abnormalities, chronic nausea, reduced appetite and food intake, decreased motor and mental skills and weakness and fatigue. Food supplementation and artificial feeding do not reverse the weight loss. Contributory factors to anorexia include taste changes, reduction in energy levels and a low mood (O'Neill, 2004).

There are a number of causes of dysphagia (difficulty swallowing) in advanced disease. They include: oral problems such as dry mouth, mucosal infection and poor dentition, pharyngeal and oesophageal pathology leading to obstruction, neurological problems such as in the case of motor neurone disease and multiple sclerosis, nerve damage following, for example, tumour infiltration, increased drowsiness and reflux oesophagitis (Swan and Edmonds, 2004). A dry mouth (xerostomia) can result from reduced saliva production, as a side-effect of drugs such as morphine and anticholinergics, poor oral intake and anxiety (Swan and Edmonds, 2004).

Nausea and vomiting are a common symptom and sign in advanced disease. Nausea is found in about 6–44% of patients with cancer and vomiting in 4–25% (Pace, 2004). People with non-malignant diseases can also suffer from these distressing conditions. The causes of nausea and vomiting in advanced disease vary which makes treatment challenging. It is important to gain a detailed history to ascertain likely causes (Pace, 2004). Primary and secondary lung cancer, chronic obstructive pulmonary disease and heart disease are all risk factors for dyspnoea (breathlessness) (Edmonds, 2004). Dyspnoea is another sign that is frequently seen in advanced disease (both malignant and non-malignant) and can increase in the final stages.

Fatigue is a common experience for patients at the end of life (Walsh et al, 2000) and is present in both malignant and non-malignant disease (O'Regan, 2008). The intensity and pattern of the fatigue vary between patients (Curt, 2001). Fatigue may be exacerbated by disease progression, sleep disturbances, breathlessness, pain, poor nutrition and depression. It may be a side-effect of medications, e.g. opioids and antiemetics. All reversible causes must be identified and treated as patients at the end of life report fatigue to be one of the most distressing symptoms (O'Regan, 2008).

Other clinical indicators that suggest limited prognosis include the blood picture and metabolic factors. Discussion of these is outside the remit of this article. However, for the patient who was undergoing active treatment in an acute hospital setting regular blood tests will have been taken, including serum albumin levels. These, in addition to other signs and symptoms, can provide the healthcare professionals with a picture that may indicate the patient is dying. A consistently low or dropping serum albumin level, in conjunction with other prognostic indicators, can indicate a poor prognosis (Phillips et al, 1989; Herrmann et al, 1992; Epinosa et al, 1995; Goldwasser and Feldman, 1997). Serum albumin is a major protein in blood plasma that is important in maintaining the osmotic pressure of the blood (Anderson et al, 1994). The normal serum albumin blood concentration is 35–55g/l. Hypoalbuminaemia refers to low serum albumin, i.e. less than 34g/l in the blood (Anderson et al, 1994). During the end stages of life, blood tests are less common as the burden of treatment is reduced. Therefore, nurses should observe for the signs of low serum albumin levels. The most common and obvious sign is peripheral oedema resulting from excessive accumulation of interstitial fluid (Works and Maxwell, 2000). The causes of peripheral oedema include reduced muscle activity (which facilitates fluid return from the peripheries to the central circulatory system), hypoalbuminaemia, venous or lymphatic obstruction and malnutrition (Maxwell, 1993). These occur in patients with advanced disease, especially cancer, and have a significant impact on the quality of life of the individual (Works and Maxwell, 2000). A low serum albumin level is a variable that could be reversible (Herrmann et al, 1992) with either human albumin solution or parenteral nutrition. However, for treatment to be appropriate, the situation has to be reversible. For the patient with terminal cancer, this may not be the case. Nevertheless, in conjunction with other clinical signs and symptoms, the level of serum albumin is worthy of consideration when predicting prognosis.

Clinical indicators, signs and symptoms that a person is in the last few weeks/days of life

There appears to be a clear 'terminal phase' for most patients with chronic, progressive diseases, particularly cancer (Murray et al, 2005). Lichter and Hunt's (1990) longitudinal study of 200 consecutive hospice patients focused on the symptoms experienced in the last 48 hours of life. The results demonstrated that 36% of patients had increasing symptoms in the time leading up to their death, i.e. it is the symptom burden that indicated that death was approaching. This, when examined alongside disease trajectories, can help inform the health professional with regard to prognosis.

In 1991, Lindley-Davis undertook a retrospective audit of 11 patients' case notes with the aim of identifying the 'defining characteristics' relating to the dying process. Although it was a small study, it preceded the work of Ellershaw and Ward (2003), The National Council for Palliative Care (2006) and the Marie Curie Palliative Care Institute (2007). It defined the dying process in a measurable fashion, suggesting that there are four types of indicators for approaching death in the terminal phase (Lindley-Davis, 1991) (*Table 4*). All aspects are key to understanding the dying process.

Table 4

Four types of indicators for approaching death as perceived by Lindley-Davis (1991)

- **Sociological:** when the patient withdraws from social interactions and distances him/herself
- **Psychic:** when the individual accepts that death is imminent and retreats into him/herself
- **Biologic:** resulting in a reduced level of consciousness
- **Physiologic:** when vital organs, e.g. lungs, brain and heart, no longer operate effectively

Certain key changes that occur when a person enters the final dying phase are highlighted in *Table 5*. The dying person is usually profoundly weak and bed-bound, requiring assistance with all activities of living. They may also appear to have withdrawn from the world, i.e. spending more and more time sleeping and being very drowsy when awake (Marie Curie Palliative Care Institute, 2007).

The person may be disorientated in time and place, have difficulty concentrating and a reduced ability to cooperate with simple instructions (The National Council for Palliative Care, 2006). Consciousness levels will reduce and consequently the person will be unable to take diet and fluids and will find swallowing medications difficult (The National Council for Palliative Care, 2006). These signs are the indicators that are identified on the LCP (Ellershaw and Wilkinson, 2003).

Pain is a symptom that does not necessarily become more severe at the end of life if it has been controlled previously. However, as the person who is in the last days of life tends to lose consciousness, it is essential to observe for non-verbal expressions of pain such as grimacing and restlessness (Sykes, 2004; Morris, 2009). Retained, noisy, respiratory secretions (often referred to as the 'death rattle') are common at the end of life, during the last 48 hours. This condition is caused by salivary or bronchial secretions collecting in the oropharynx. Although most patients are unaware of the condition because of reduced levels of consciousness, it can be very distressing to witness for family/friends as well as the healthcare practitioners caring for the dying person (Sykes, 2004; Clark and Butler, 2009).

It is estimated that between 25% and 85% of patients who are dying may experience symptoms associated with restlessness before death (Fainsinger et al, 2000; Sykes and Thorns, 2003). The dying person may also become increasingly disorientated (Brajtman, 2003). Possible causes of restlessness include uncontrolled pain, a full bladder and bowel, breathlessness, nausea, fear of dying, withdrawal of certain medications and electrolyte imbalance (Kyle, 2009). All reversible causes must be treated if that is what the patient wishes after discussion with their medical team.

When a person is very close to death breathing can become shallow and sometimes there are long pauses between breaths (apnoea) (also known as Cheyne-Stokes respiration) (Anderson et al, 1994). Peripheral vascular shutdown can cause the skin to become pale and cool, particularly the hands and legs. The pulse can become weak and thready. These signs indicate that death may occur within a few hours or sometimes sooner (Hockley, 2007). Despite common characteristics the process of dying is unique to each person (Marie Curie Palliative Care Institute, 2007). It is also important to note that symptoms do not necessarily become more acute at the end of life (Sykes, 2004). People often feel tranquil (Marie Curie Palliative Care Institute, 2007). It must never be forgotten when caring for a dying person that the hearing of that person is the last 'sense' to fail (Worcester, 1945).

Conclusions

Predicting prognosis and diagnosing dying is complex. However, performance status, disease trajectories and symptom burden can assist healthcare professionals when communicating with patients and families/carers that death is imminent. Serum albumin levels should possibly be examined routinely and compared with other indicators such as performance status and symptom burden to help identify dying, especially if the patient is in the acute setting. It is vital that disease trajectory processes are understood (Lunney et al, 2003; Murray et al, 2005). All healthcare professionals should continue to use their individual knowledge, skills and intuition to identify dying. In summary, diagnosing dying remains a complex and challenging process that is reliant on numerous physical, biological and psychosocial factors. EOLC

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Table 5

Key changes that can occur when a person enters the dying phase

Profound weakness
Withdrawal from the world
Reduced cognition
Reduced levels of consciousness
Reduced intake of diet and fluids
Difficulty with swallowing medications
Retained bronchial secretions
Increased nausea and vomiting
Terminal agitation
Reduction in urine output
Cessation of bowel movement
Uraemia (in renal failure): build up of toxins usually excreted by the kidneys (but it needs to be decided if this is going to be treated as treatment would include blood tests and active intervention)

Source: Sykes (2004); The National Council for Palliative Care (2006); Marie Curie Palliative Care Institute (2007); Clark and Butler (2009); Morris (2009)

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Key Points

- Disease trajectories play a useful part in diagnosing dying by outlining a likely progression of the illness.
- Diagnosis and performance status affect, and are indicative of, the person's physical state and may be helpful in monitoring the likely outcome following treatment.
- Physical and psychological states can influence how the patient copes with terminal illness and the dying process.