

# Patterns of dying: palliative care for non-malignant disease

FEM Murtagh, M Preston and I Higginson

**ABSTRACT** – As awareness grows of the palliative care needs of those diagnosed with advanced life-threatening illness other than cancer, consideration needs to be given to how to address these needs. This paper focuses on palliative care for those with such diagnoses by describing variations in illness trajectory according to diagnosis, and exploring how this may affect provision of palliative care.

**KEY WORDS:** dying, illness trajectory, non-malignant disease, palliative care, person-focus, prognosis

There are similarities and differences between those dying from chronic non-malignant diseases and those dying from cancer. Understanding these similarities and differences throws light on what palliative care can offer, identifies the range of needs of cancer and non-cancer patients, and those who might benefit from palliative care.

## Palliative care: the new World Health Organization definition

Palliative care emerged from recognition of the suffering experienced by dying people, the negative effect that care sometimes had, and the constraints imposed by prevailing attitudes to death and dying.<sup>1</sup> Innovative pioneers launched the hospice and palliative care movement and sustained them during their early years. Subsequently, palliative care spread more widely, gained increasing acceptance and support both professionally and from the public, and developed an academic base of research and education. It became a recognised medical specialty in the UK in 1987, and in 2003 there were 100 countries with some form of hospice or palliative care services.<sup>2</sup>

The emphasis palliative care places on quality of life, and the consideration it has for psychosocial and spiritual, as well as physical, care is reflected in the recently updated WHO 2002 definition of palliative care (Box 1).<sup>3</sup> This definition includes all advanced life-threatening illnesses, of whatever diagnosis, rather than making sole reference to cancer, as in the earlier 1990 definition.<sup>4</sup>

## Who needs palliative care?

Traditionally, palliative care programmes and facilities have concentrated on the needs of cancer patients. The annual report of specialist palliative care services in the UK for 1999–2000 indicated that 94% of all patients seen within these services have a cancer diagnosis,<sup>5</sup> but as far back as 1998, specialists in palliative care became increasingly aware that those dying with chronic non-malignant diseases also had extensive palliative care needs.<sup>6</sup>

Specialist palliative care touches most other specialities and debate continues about the degree to which palliative care is specialist or generalist.<sup>7–9</sup> Definitions of the general palliative care approach, palliative interventions, and specialist palliative care have been compiled.<sup>10,11</sup> Fordham has argued that most medical specialties have implicit or explicit criteria for including certain patients and excluding others, whether this is based on an organ system or particular disease category, and that palliative care is unusual in deriving from a philosophy that has the potential for excluding nobody.<sup>9</sup> Whatever perspective is adopted in this debate, application of palliative

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### Box 1. World Health Organization 2002 definition of palliative care.<sup>3</sup>

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor to postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

care across the wider range of non-malignant diagnoses entails collaborative working between palliative care and other specialties, and detailed combined reflection on what is and is not appropriate to improve care and quality of life for patients.

This requires a gradual change in perspective, with advancing disease, from the disease-centred to the person-centred, from an 'all out' concentration on treatment towards a concerted focus on quality of life. In achieving this change, it is helpful to:

- understand the functional trajectories of different illnesses
- undertake a combined exploration of the overlap of active and palliative treatments
- recognise dying (which may be an increasingly slow process in the context of the advanced technology and treatment available)
- adopt an honest approach to uncertainty
- develop a sound appreciation of the complexity and difficulty of end-of-life issues.

### Trajectories in cancer and non-cancer illnesses

As far back as 1968, different patterns of dying have been described.<sup>12</sup> Glaser and Strauss described three patterns of dying:

- abrupt and sudden death
- expected death of varying duration (both short-term and lingering)
- 'entry-reentry' deaths involving frequent acute deteriorations, often with hospital admission, with an underlying steady decline.

Others have focused on identifying the 'period of active treatment', and the 'period of terminal care', in relation to cancer patients.<sup>13–15</sup> Saunders especially stresses the extent of the overlap of these two periods, as the focus shifts gradually, rather than suddenly, from control of tumour to control of symptoms.<sup>14</sup> Attempts were made to define and describe the epidemiology of the terminal period by McCusker.<sup>15</sup> She found a mean duration of the terminal phase of 94 days, but with a small proportion of patients contributing to a wide range from 1 to 1,340 days.

As palliative care broadens to include those with non-malignant diagnoses, so attempts have been made to determine how functional decline differs among different types of illness and to devise trajectories of function against time to portray this.<sup>16</sup> The original work in devising these trajectories arose from Medicare claims data in the USA, but it has subsequently been replicated with a large prospective longitudinal study of activities of daily living data and the change in these over time.<sup>17</sup> These trajectories refer to the last year of life.

In cancer, people do not usually suffer severe restriction in activity until the final stages of the illness, when the disease stops responding to anti-cancer treatments. The illness trajectory therefore is of a slow overall decline until anti-cancer treatments are stopped, followed by a relatively rapid decline in function towards the end of life (Fig 1a). These expected deaths are likely to have a fairly predictable terminal phase, which corresponds to

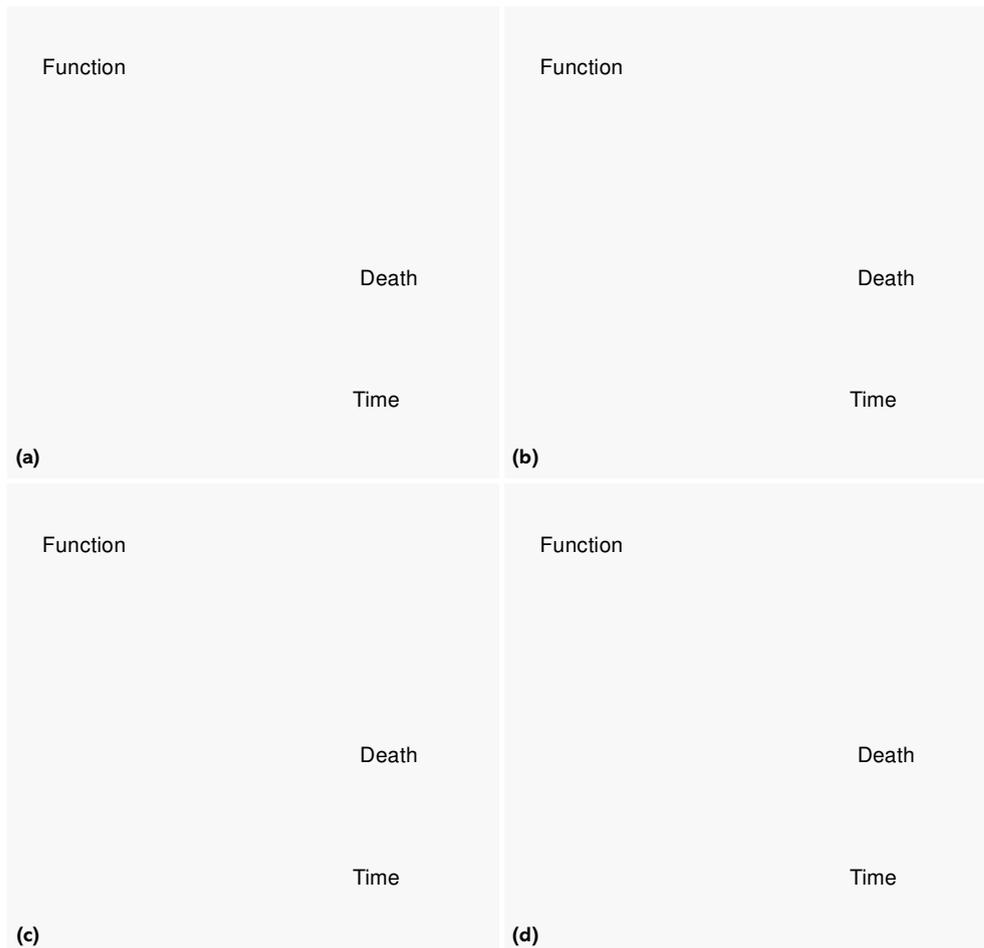
the terminal period described by McCusker,<sup>15</sup> where there is time to anticipate palliative needs and plan for end-of-life care. It may also largely match the public expectation of dying from cancer. As treatment options for some cancers increase, the functional trajectory associated with them may change. An example of this might be the increased survival but sometimes rising morbidity and lower functional level now seen in those diagnosed with breast or prostate cancer and bone metastases. This transforms the trajectory of the final year of life to follow a slower decline, and the illness course may be more similar to that of a chronic non-malignant disease.

The trajectory of those dying from heart failure follows a very different course, with sudden acute deteriorations followed by substantial improvements, but with an underlying downward trend in function (Fig 1b). Deteriorations may be associated with hospitalisations and intensive active treatment. This pattern is also followed by those dying from chronic lung disease, with a similar pattern of acute relapse, active treatment and improvement, but underlying steady decline. This may not be true for all organ failure. The trajectory of patients dying from end-stage renal failure was not described separately by Lunney *et al*, but categorised together with all other causes of death. Clinical experience suggests that the trajectory in end-stage renal failure may be that of a steady decline, with the rate of this decline varying according to the underlying renal pathology and other patient factors (Fig 1c). The high levels of co-morbidity with renal disease (especially cardiovascular and cerebrovascular disease) make this trajectory particularly difficult to predict. Those with dementia or general frailty have a much lower baseline level of functioning, with a declining but variable downward course towards death (Fig 1d).

People dying of heart disease,<sup>18–22</sup> stroke,<sup>18,23</sup> dementia,<sup>18,24</sup> and many other conditions have many burdensome symptoms, communication issues and other unresolved palliative needs in the last year of life. Patients dying from motor neurone disease or from other progressive neurological conditions have as many symptoms as those dying from cancer.<sup>25</sup> Population-based studies using random samples of deaths, and relying on reports of bereaved carers, indicate many more symptom problems in the last year of life among those suffering from progressive non-malignant disease than among those suffering from cancer,<sup>26</sup> not only because of the greater prevalence of symptoms but also because of the more protracted trajectory of decline in non-malignant conditions.

### How much palliative care is needed?

About 2,800 people per 1,000,000 population die from cancer each year in the UK; 25–65% of these will need help from a palliative care support team, and 15–25% will need inpatient hospice care.<sup>26</sup> About 6,900 people per 1,000,000 population die from causes other than cancer each year, and although some of these people will die suddenly or with no identifiable terminal period, many will have circulatory, respiratory or neurological diseases with prevalence of symptoms comparable to that suffered by cancer patients.<sup>26</sup> The considerable variations in the



**Fig 1.** (a) Model of a common trajectory in cancer (adapted from Lunney *et al*<sup>16,17</sup>). (b) Model of a common trajectory in organ failure, for example heart failure (adapted from Lunney *et al*<sup>16,17</sup>). (c) Model of a common illness trajectories in endstage renal failure (developed from clinical collaboration). (d) Model of a common trajectory in dementia or frailty (adapted from Lunney *et al*<sup>16,17</sup>).

disease trajectories of these non-cancer diseases will influence what palliative care might be appropriate, and how it is best delivered (Box 2).

In those diseases with an ‘entry–reentry’ pattern, such as heart failure and chronic lung disease, decisions about *when* palliative care is appropriate are particularly difficult. Professionals, patient and family can all become accustomed to periods of severe illness, with subsequent dramatic improvement, which may bring a false perspective and detract from awareness of the overall decline. Prognosis is difficult to estimate with such a course. Recognition of dying is especially difficult. Which deterioration will be the one from which there is no recovery? Patients may be well known to their general practitioner or specialist, a factor known to contribute to a more optimistic prognostic assessment by the professional.<sup>27</sup> Active treatment and palliative treatment may well need to run concurrently throughout the illness, and the correct emphasis to be given to each will be difficult to determine. Equally, illnesses that display a low level of function over a long time, such as dementia or general frailty, will cause equal or greater difficulty in identifying when a switch from active to palliative care is appropriate. Neither is mutually exclusive, but the particular balance of decision-making may be very hard to judge.

*How* palliative care is delivered will also be affected by these disease trajectories. A patient with poor overall function may be in a nursing home for months or years before dying. Care delivery may need to continue in that setting, with usual carers (general practice team, nursing home staff) appropriately skilled and resourced to deliver palliative care until the end of life. Flexibility of approach is essential. The model of care may emphasise the role of specialists in palliative care as providing education and support, rather than actual care delivery, as, for example, within a hospice.

*What* palliative care is needed will also vary. Different diseases, with their variable disease trajectories, will present considerable variation in palliative care requirements. These need to be discussed openly between the specialists of the appropriate discipline, primary care teams and palliative specialists. There is an urgent need, too, for good quality research into the needs of different populations. Epidemiological data on prevalence and severity of symptoms, evidence on quality of life, and qualitative research to explore patient perspectives on dying from a particular illness are urgently needed. Often there has been a history of focus on the disease, with fruitful advances in treatments, but less emphasis on quality of life when the disease becomes untreatable.

**Box 2. Trajectory-related factors influencing palliative care delivery.***When palliative care is delivered:*

- timing in relation to death
- uncertainty about prognosis
- uncertainty about active versus palliative treatment balance
- lack of evidence on timing of palliative care delivery.

*How palliative care is delivered:*

- setting (home, nursing home, hospital, hospice)
- model of palliative care delivery
- lack of evidence as to appropriate models of care.

*What palliative care is needed:*

- prevalence of disease
- prevalence and severity of symptoms
- available resources.

*Who delivers palliative care*

- current specialist team
- general practice team
- other community team
- specialist palliative care team.

*Who delivers palliative care is also important. Clearly, the relatively small specialty of palliative care cannot hope to deliver care across the spectrum of all cancer and non-malignant disease, nor would it wish to. All professional carers should have basic skills and knowledge in palliative care, defined as 'general palliative care'.<sup>10,11</sup> What is needed is open debate, increased awareness, and collaborative working towards creative options to improve care. Excellent palliative care operates through skilled multiprofessional teams, and all professional groups need to participate in this debate. Following Department of Health recommendations,<sup>28,29</sup> there are growing numbers of nurse specialists and nurse consultants within the different specialties who have increasing clinical responsibility, and who need to be included in this dialogue.*

*Quality of care must be improved, by whichever route. Care of the dying has improved dramatically since the first steps towards the modern palliative care movement, but it has been biased towards cancer patients. This raises issues of inequity for those with non-malignant incurable diseases, which are only now*

**Key Points**

**Palliative care in the UK is provided mostly for people with cancer**

**Evidence increasingly shows that those with non-cancer diagnoses have comparable palliative care needs**

**Variations in disease trajectory with different diagnoses affect ways of matching palliative care to patient need**

**Imaginative collaboration between the different specialties, including primary care and palliative care, is required to address the present inequity**

beginning to be recognised. Moves to meet this challenge will be true to the founding philosophy of palliative care, and continue to reflect the vision of the innovative pioneers of the early years.

**The difficulties of recognising dying**

The ability of professionals to recognise dying and predict survival is known to be poor. There is good evidence that both doctors and nurses are inaccurate in their prognoses for terminally ill patients, and that the error is systematically optimistic. There have been two systematic reviews of survival prediction in cancer patients,<sup>30,31</sup> but less is known about survival prediction in non-malignant disease. In cancer patients, doctors' estimations are known to be inaccurate and over-optimistic, but they do appear to become more accurate closer to death. A study including both cancer and non-cancer terminally ill patients indicates that doctors' prognostic accuracy, or lack of it, is independent of diagnosis,<sup>27</sup> suggesting that prognosis prediction may be no better in non-malignant disease. Undue optimism about survival prospects will contribute to late consideration of palliative care, whether this be provided within the original specialty, by specialist palliative care services or collaboratively. Professionals who do not realise how little time is left may miss the chance to devote time to improving the quality of the patient's remaining life, and deny patients the opportunity to prepare for death.

**Person focus not disease focus**

Improving prognostic accuracy alone is not enough. Ability to recognise dying requires a difference of approach, a change of focus from disease-centred to person-centred. In the last days of life, the recognition of dying is often complex and difficult. There is sometimes reluctance to diagnose dying if *any* hope of improvement exists, and of course it is always possible to hope for improvement, especially if much investment has been made in providing complex or innovative interventions or treatments in previous months. What matters is how realistic or unrealistic that hope may be. Professionals with a high level of expertise may find it particularly hard to step back and make a realistic assessment of the chances of survival. As discussed by Higgs, they may instead use avoidance behaviour, either fighting death until the bitter end or allowing its reality to remain unconsidered.<sup>32</sup> Making an assessment of the chances of survival in a disease-orientated context is inextricably linked with the perceptions of 'success' and 'failure', whereas a focus on the individual patient necessitates a switch away from 'failed' treatment towards improving quality of life.

Palliative care comes from a different perspective, seeing success or failure not in terms of successful treatment of disease, but in terms of the ability to enable a 'good' death (a death free from distressing symptoms, with psychosocial and spiritual needs addressed, and the chance for patients and family to face the inevitable without additional fear or misinformation). This is closely matched to patients' own wishes,<sup>33,34</sup> giving them more autonomy and reducing powerlessness in the face of death.

**Box 3. Active management of uncertainty.***The professional*

- Recognise uncertainty, both one's own and that of other professionals.
- Be honest with patients about it.
- Encourage open discussion of it among the multidisciplinary team.

*The patient*

- Discover how much the patient wants to know.
- Discover how the patient feels about uncertainty.
- Allow the patient to dictate amount and pace of information.
- Avoid collusion with patient or family.

**Dealing with uncertainty**

Uncertainty, especially about prognosis, can be a difficult area to deal with when working with dying patients. Specialists in all disciplines develop expertise in their field in order to reduce uncertainty. Recognising the limitations of that expertise and experience is an important skill, but it can be elusive. The key skill is that of bringing uncertainty into the open, for oneself, within the professional team, and with the patient and family. Unacknowledged uncertainty causes problems; acknowledged uncertainty, although not easy, can clarify and build trust between patient and professional.

Uncertainty is inherent in the practice of medicine, but particularly in prognosis prediction. The functional trajectories associated with different illnesses demonstrate that this may be particularly problematic for some non-malignant diagnoses. Attempts have been made to draw up guidelines for determining prognosis in some non-cancer diseases.<sup>35</sup> These do not overcome the difficulties of addressing uncertainty, both for the professional and with the patient, but Box 3 highlights some practical strategies to help deal with uncertainty.

**End-of-life care**

End-of-life care is complex and wide ranging, and many areas within it might be discussed. Edmonds and Rogers highlight some of the factors which may contribute to suboptimal care of patients dying in hospital, and suggest strategies to improve this care.<sup>36</sup> One of these strategies is the use of the integrated care pathway for the dying. This is a good example of increasing patient, rather than disease focus, in the last few days of life. Developed in the USA in the 1980s, integrated care pathways (ICPs) are an example of a method of implementing best practice and incorporating guidelines into the care of patients with a specific clinical problem.<sup>37</sup> They also provide an excellent tool for quality assurance. Deviation from the pathway is recorded as a 'variance', analysis of which enables estimation of quality of care and can promote changes to practice.

An ICP for dying patients<sup>38</sup> has been developed in the UK, which many palliative care teams have adopted and implemented locally. Its use is increasing throughout different set-

**CASE STUDY**

A 85-year-old woman was admitted with worsening breathlessness and oedema. She was known to have a history of ischaemic heart disease, diabetes mellitus, and end-stage renal failure secondary to diabetic nephropathy. Together with the patient and her family, the decision had been taken four months earlier to manage her renal failure conservatively, without renal replacement therapy.

Her creatinine clearance was estimated to be 4 ml/minute (using the Cockcroft Gault formula). She was commenced on the ICP for the dying patient when it was clear she had only a few days to live. At this stage, she was semi-conscious and unable to swallow safely. Her regular tramadol analgesia was converted to diamorphine 5 mg over 24 hours (delivered subcutaneously using a Graseby infusion pump). This dose was significantly less than the usual conversion because of her renal impairment. On day 1 of commencing the pathway, assessment of family communication needs was required, among other goals. The ward staff quickly identified poor communication between two key family members, and worked to both clarify and overcome this.

On day 2, incident pain was identified, documented as a care goal not achieved, and thus noted as a variance from the pathway. Following clinical guidelines, appropriate breakthrough subcutaneous medication was administered on two occasions and her infusion increased to diamorphine 10 mg per 24 hours, with good effect.

On day 3 she experienced noisy respiratory tract secretions, again a variance from the pathway, and these were successfully treated with a single dose of subcutaneous glycopyrronium 200 µg. She died peacefully later that day with her immediate family members present.

tings, crossing the boundaries of hospital, hospice and community, although it still needs formal evaluation as to which are the best ways to implement it. At King's College Hospital, London, the ICP for dying patients has been in use over the past three years. During 2002, 64% of those patients commenced on the ICP had non-malignant diagnoses,<sup>39</sup> and the ICP enabled a focus on appropriate care goals for the last few days of life. The pathway has core goals and protocols:

- physical care and comfort measures
- psychological and insight measures
- religious and spiritual support
- communication with family and others
- communication with primary healthcare team
- bereavement planning.

The pathway is patient- and family-focused, and the criteria relate to the patient's clinical condition rather than any specific disease. In practice, this ICP for dying patients can be used for those with any terminal condition. The case study shown here demonstrates use of the ICP for the dying patient.

**Conclusions**

Increasingly, the palliative care needs of those with non-cancer diagnoses are being recognised. Key to anticipating these

palliative care needs is an understanding of the functional trajectories which different diseases follow during the last year of life. These trajectories need to be better defined and better understood, and there is a need for continuing research both into the epidemiology of this phase and into the symptoms, communication issues and other palliative care needs occurring for patients with different diseases. It is essential that the different specialties and professionals involved in care delivery collaborate across boundaries both in undertaking this research and in providing seamless and effective care for patients. Specialist palliative care itself needs to develop increasing flexibility and adaptability to respond to the changing requirements that emerge from creative dialogue and collaborative research. The goal is that of reducing inequity and providing care for patients on the basis of need rather than diagnosis.

The individual teams and professionals involved in day-to-day patient care need to improve their ability to recognise when a patient is dying. This requires an open approach to uncertainty, and a willingness to shift focus away from the disease, about which we may know a great deal, towards a focus on the person before us, about whom we may know much less. Listening to their preferences and enabling their end-of-life choices will lead to greater patient empowerment, which should be available for cancer and non-cancer patients alike.

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