

Scott A Murray on
spiritual needs at the
end of life

Spiritual support in palliative care

key points

The author leads an innovative research group developing palliative care which is accessible for people with all life-threatening illnesses, is delivered in the community, and explores spiritual distress at the end of life.

There are three characteristic trajectories of physical decline at the end of life: a cancer trajectory with steady progression and usually a clear terminal phase; an organ failure trajectory with gradual decline punctuated by episodes of acute deterioration and eventually a seemingly unexpected death; and a frailty trajectory of prolonged gradual decline, typical of physical frailty and dementia.

These trajectories also have a spiritual dimension, and this understanding allows spiritual support to be planned and delivered to patients and their carers to relieve distress and help in the search for meaning and purpose.

Scott Murray graduated in Aberdeen, and served as a medical missionary at Chogoria Hospital, Kenya for seven years. Returning to general practice in Edinburgh, he used a community participatory approach learnt in Africa to help develop medical and social care in an economically poor area in central Edinburgh. More recently he has started to research the experiences and needs of people at the end of life, suspecting that the spiritual dimension may be relatively neglected in current palliative care practice.

He currently leads an innovative group at Edinburgh University that seeks to carry out research to develop palliative care which is accessible for people with all life-threatening illnesses, is delivered in the community where more people may wish to die, and which explores spiritual distress at the end of life. In 2008 he won a competition in the *BMJ* by highlighting end of life care beyond cancer as a neglected area in medicine. 'Palliative care for all' is now prioritised by the *BMJ* and its sister journals for publishing research and for developing learning resources.

Dying is a multidimensional experience. It is not just a physical demise, and as doctors we must strive to identify and meet the multidimensional needs of people with progressive disease. Centuries ago, spiritual care dominated end of life

care. Although palliative care set out 40 years ago to address the suffering of 'total pain', including lack of personal integrity and inner peace, spiritual distress at the end of life has been relatively unexplored.¹ But it is accepted that quality of life is modified by all dimensions of personhood.²

Three characteristic trajectories

Recent studies in the USA³ and by our Primary Palliative Care Research team in Edinburgh University⁴ have identified that most people with progressive chronic illness follow one of three characteristic trajectories of physical decline at the end of life.

These include a **cancer** trajectory with steady progression and usually a clear terminal phase; an **organ failure** trajectory with gradual decline punctuated by episodes of acute deterioration and eventually a seemingly unexpected death; and a **frailty** trajectory of prolonged gradual decline, typical of physical frailty and dementia. Figure 1 illustrates this, and estimates the number of patients each year who die on each trajectory per general practitioner with a list of 2,000 patients. These trajectories have recently informed End of Life Strategies in England and in Scotland and are now in the mainstream of palliative care education. Consideration of these patterns may help clinicians anticipate likely physical needs in the last year of life and plan care that integrates disease modifying and palliative care.

Other dimensions of need

But what is going on with the other dimensions of need? Spiritual issues are frequently very significant for people living and dying with lung cancer and heart failure.⁵ Might there be typical patterns of social, psychological and spiritual needs towards the end of life? We conducted a secondary analysis of in-depth serial interviews which we had carried out in recent studies to answer this question.^{6,7}

Defining and assessing spiritual needs is problematic. We used a definition relevant in the secular UK NHS context: *spiritual needs are the needs and expectations that human beings have to find meaning and purpose in life; such needs may be specifically religious but even people who have no religious faith or who are not members of an organised religion have belief systems relating to meaning and purpose.*⁸

We did indeed find characteristic social, psychological and spiritual end of life patterns as we read and re-read the in-depth serial interviews which were conducted every three months in the last year of life, with participants talking about their main worries and concerns.⁹ In lung cancer, the social trajectory mirrored physical decline while the psychological and spiritual wellbeing decreased together at four key transitions: at diagnosis, after getting home after initial treatment, during disease progression, and in the terminal stage. In advanced heart failure, social and psychological decline both tended to track the physical decline while spiritual distress exhibited background fluctuations (see Figures 2 and 3).

We have published our detailed findings⁹ but an outline of the spiritual 'trajectories' follows:

Lung cancer

For patients with lung cancer we learned that most people at diagnosis considered the prospect of suffering and dying – and many considered it even earlier, during the period leading to a formal diagnosis. Returning home at the end of inpatient treatment, many patients expressed issues about emptiness and searching, struggled to return to their own life, and questioned their self worth and their value to others.

At disease progression or recurrence, some people wondered what they had achieved in their lives and what needed to be done before death. Some patients, perceiving they had no future, felt that their life in the present was pointless.

In the terminal phase an acceptance of death was sometimes apparent. Some worried if they had been good enough during their life and feared to die, and others felt confident in their death knowing that death was a transition rather than the end: 'It oscillates terribly between a total and absolute panic and an excitement to see what it's going to be like'.

Figure 1. Number of deaths in each trajectory, out of the average 20 deaths each year per UK general practice list of 2000 patients.

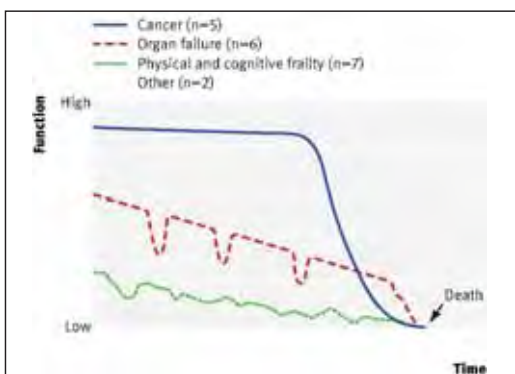


Figure 2. Physical, social, psychological and spiritual wellbeing in the last year of life.

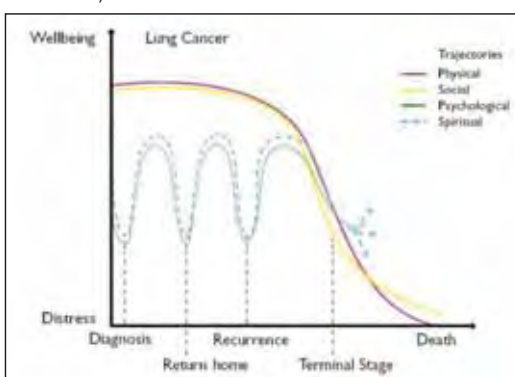
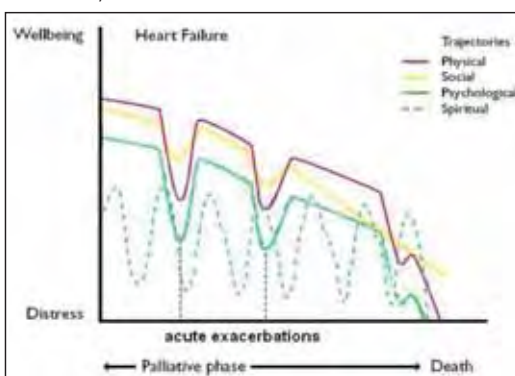


Figure 3. Physical, social, psychological and spiritual wellbeing in the last year of life.



Dying is a multidimensional experience. It is not just a physical demise, and as doctors we must strive to identify and meet the multidimensional needs of people with progressive disease

Graphics: BMJ

Heart failure

Spiritual needs in people with heart failure reflected a progressive loss of identity and growing dependence. As their illness incapacitated them, patients who felt valued and affirmed described being more able to come to terms with their life and retain a sense of worth and meaning. Suffering was sometimes moderated by positive aspects such as love, hope, trust, and forgiveness. While some were supported and comforted by their religious belief, others wondered about judgment or divine indifference. 'Where is God in all this? Has God forsaken me?'

'4D' care planning

The extent to which these findings from Scotland are generalisable to different national, social,



references

1. Saunders C. Into the valley of the shadow of death: a personal therapeutic journey. *BMJ* 1996; 313:1599-1601
2. Cassell E. *The nature of suffering*. New York: Oxford University Press, 1991
3. Lunney J *et al*. Patterns of functional decline at the end of life. *JAMA* 2003; 289:2387-2392
4. Murray S *et al*. Illness trajectories and palliative care. *Clinical Review. BMJ* 2005; 330:1007-11
5. Murray S *et al*. Exploring the spiritual needs of people dying of lung cancer or heart failure: prospective qualitative interview study. *Pall Med* 2004; 18:39-45
6. Grant E *et al*. Spiritual issues and needs: perspectives from patients with advanced cancer and non-malignant disease. A qualitative study. *Pall Supp Care* 2004; 2:371-78
7. Murray S *et al*. Dying of lung cancer or heart failure: prospective qualitative interview study of patients and their carers in the community. *BMJ* 2002; 325:929-32
8. Institute of Medicine. *Approaching death, improving care at the end of life*. Washington DC: National Academy Press, 1997
9. Murray S *et al*. Patterns of social, psychological and spiritual decline towards the end of life in lung cancer and heart failure. *Journal of Pain & Symptom Management* 2007; 34:393-402
10. Murray S *et al*. Palliative care in chronic illness. *BMJ* 2005; 330:611-612
11. Murray S, Sheikh A. Care for all at the end of life. *BMJ* 2008; 336:958-959

ethnic and religious groups is unknown. Individual patients will die, some unexpectedly, at different stages in these trajectories and rates of progression vary. However, I have found that mapping out these patterns to medical students and doctors has allowed them to understand that care planning must be four dimensional, or '4D'.

We can anticipate and share with patients when they are likely to be distressed. Explanation to patients and their carers about when practical, emotional and existential issues might be expected to occur, and the services available, can empower them and their carers, and this can be very reassuring for all. In Hippocrates' day, the physician who could foretell the course of the illness was the most highly esteemed, even if he could not alter it.²

This mapping thus helps build a big picture, a wide perspective to help us understand and anticipate the likely needs of individuals. This holistic approach, considering each dimension of need, may moderate the current 'technological imperative' when care is focused on interventions to prolong life, with sometimes overzealous and futile treatment. Considering these different trajectories brings spiritual assessment and care into focus, and highlights that many patients have spiritual issues from *diagnosis* of cancer or chronic life threatening illness, not just at the very end of life.

What is 'spiritual support'?

The implication of this is that spiritual support should be available for patients from diagnosis, sooner rather than later. But what is spiritual support? We asked a number of patients with advanced illness in the community how they got 'spiritual support', and they tended to reflect and respond as follows: 'It was the nurse who sat down and listened and...' A patient-centred approach that supports people in their own worldview while allowing for expression of fear, doubt and anxiety may help patients in their search for meaning and purpose, and prevent spiritual concerns amounting to disabling spiritual distress. As Dr Derek Doyle used to teach, we need both the courage and to take the time to 'sit down and shut up'.

Adopting patient-centred supportive care: possible questions¹⁰

- What's the most important issue in your life right now?
- What helps you keep going?
- How do you see the future?
- What is your greatest worry or concern?
- Are there ever times when you feel down?
- If things got worse, where would you like to be cared for?

spiritual support should be available for patients from diagnosis, sooner rather than later

Allowing patients to raise spiritual and religious issues may be therapeutic, as may the use of a gentle prompt, such as: 'You seem fine today, but do you ever feel down or a bit low?' This may allow them to reveal their personally-felt narrative, rather than the public account they may tend to offer, as patients often have competing narratives in their minds. Patients may sometimes ask us about our own beliefs. When asked about my own faith I've often found it useful to acknowledge the question and say that I will explain, but first I tend to reflect the question back to the patient to ask them about their beliefs. This is because they may just be looking for an opportunity to express where they are on this issue.

A welcome innovation

The concept of illness trajectories, not only physical, but also those of social, psychological and spiritual wellbeing or distress, is a welcome innovation to help understand the lived experience of dying. Carers may also have social, psychological and spiritual issues simultaneously with their loved one. We must now use this understanding to plan services which respond to patients' needs, which will include holistic care from the diagnosis of a life-threatening illness. Lessons learnt in caring for patients who die of cancer must also be extended to embrace patients in general – the majority of whom die from other conditions.¹¹

Scott A Murray is St Columba's Professor of Primary Palliative Care in the University of Edinburgh.
Scott.Murray@ed.ac.uk

For further information about the Primary Palliative Care Research Team at Edinburgh University see www.homepages.ed.ac.uk/smurray1

Acknowledgements

I am very grateful to Dr Ian MacCormick and other Edinburgh CMF members for commenting on a draft of this article.