

## EDITORIAL

# Palliative care for non-malignant disease?

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The Minister for Health and Ageing recently announced \$4.5 million of Commonwealth funding for palliative care programs in Australia. Importantly, these funds and the programs they support are not constrained within the traditional boundaries of palliation for patients with terminal malignant disease. Indeed, the new language for palliative care in Australia describes 'quality care' for **all** people who are dying.

Palliation beyond malignant disease has many far-reaching implications. In the future clinicians will no doubt have to apply these programs in an environment of limited resources and funding. The effectiveness and impact of these new programs will need to be evaluated as they are presently unknown. For the moment, however, it is important to understand why certain patients with non-malignant disease would benefit from palliation at the end of life and how they can be readily identified.

We are currently experiencing an epidemic of old and fragile patients with chronic cardiorespiratory disease. Congestive heart failure is the commonest cause of emergency hospitalisation in those aged over 65 years<sup>1</sup>, while chronic

obstructive pulmonary disease (COPD) accounts for around one in 20 deaths.<sup>2</sup> Importantly, at this stage, neither disease is curable.

Patients with end-stage heart failure typically have an extremely poor quality of life, punctuated by frequent hospitalisations and a prognosis that is comparable to that of common malignancies.<sup>1</sup> Dyspnoea, confusion, pain, anxiety and depression are very common during the last few days of life. Once cognisant of the terminal nature of their illness, many patients would prefer 'comfort care' and do not wish active resuscitation. Despite this there is a relative lack of patient (and carer) preparation for death.

One study specifically compared the illness trajectories, needs and pattern of health care utilisation of patients 'dying' from heart failure or lung cancer.<sup>3</sup> The illness trajectory of lung cancer was much more predictable, while the management of heart failure was characterised by poor co-ordination and a lack of continuity of care.<sup>3</sup> Another study found that although COPD has a similar prognosis to lung cancer, it is often associated with a poorer quality of life and more emergency hospitalisations.<sup>2</sup> Moreover, 40% of patients suggested they wanted more information about their illness, but very few requested detailed information, implying that a more accurate description of their prognosis would be distressing.<sup>2</sup>

It is clear, therefore, that many patients with end-stage cardiorespiratory disease deserve greater attention to palliation. However, given the inherent need to ration finite healthcare resources, a pragmatic approach to implementation is required.

There is strong argument for offering palliation to anyone who, in all probability, is **likely** to die within the next 12 months.<sup>1</sup> It is particularly important, therefore, for the clinician to remember to apply the principles of palliative care on the basis of 'need' rather than 'diagnosis'.

Clearly, extending palliation beyond malignancy raises a number of complex issues. Clinicians will be forced to overcome a natural desire to be optimistic and to avoid alarming patients unnecessarily with thoughts of impending death. It is in the best interests of the patient if the clinician comes to the conclusion that all therapeutic options are exhausted – even if the patient has not reached the same conclusion. Despite the problem of 'denial' at the end of life, it is the frequent wish of patients that the doctor begins discussions about death.<sup>2</sup> However, there is an inherent problem in predicting the illness trajectory of COPD and heart failure.

### In this issue ...

Although the new drugs for lung cancer discussed by Michael Boyer may help some people, patients will still need palliative care. However, according to Simon Stewart we should not be restricting palliative care to patients with cancer. Many patients with medical illnesses also have avoidable suffering before death.

Many deaths in the Aboriginal community occur prematurely. Richard Murray relates some of the important prescribing issues for indigenous Australians. Improvements in Aboriginal health will require legislative changes as well as good prescribing.

While Spiros Fourlanos and Peter Greenberg educate us about the causes of a low sodium concentration, John Attia reminds us that diagnostic tests are not infallible.

For example, in the SUPPORT Study some patients with heart failure had been predicted to have a greater than 50% chance of surviving six months, but died just three days later.<sup>4</sup>

Not knowing how long the patient will live creates a situation of uncertainty that can, in theory, 'paralyse' doctors, potentially preventing them from implementing palliative care.<sup>1</sup> In all probability there is no solution to such 'treatment paralysis' without specific, professional guidelines and an increase in consumer expectations to prompt appropriate end-of-life care.

Palliative care represents holistic management that has moved beyond medical cure. It focuses on the physical, psychological, social and spiritual problems of the patient at the end of their life.<sup>2</sup> In simple terms, it equates to providing a good quality end to life by whatever means possible.<sup>1</sup> This includes enabling people to put their affairs in order and to prepare for the future.

Although palliation has historically focused on terminal malignancy, most people who are physically deteriorating and approaching the end of life experience similar problems. Four main issues are common to all patients who are expected to live less than 12 months:

- deficits in basic self-care
- emotional distress
- pain and chronic symptoms
- malnutrition.<sup>5</sup>

In COPD and heart failure, persistent dyspnoea, with associated limitations on all activities of daily living, is particularly distressing. Dealing with such problems requires a multidisciplinary approach combined with the core palliative care values of open and sensitive communication, a whole patient and carer approach, attention to symptom control and therapeutic dialogue.

Although it is clear we are responding inadequately to an increasingly important issue seen in clinics and wards all over the developed world, we are currently witnessing a shift in our thinking about extending palliative care to non-malignant,

terminal disease. Applying palliation on the basis of 'need' rather than 'diagnosis' raises a number of difficult issues for clinicians and their patients alike. However, the potential benefits of palliative care can ensure a quality end of life for more individuals, and should not be denied on the basis of being too hard.

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### Self-test questions

*The following statements are either true or false (answers on page 119)*

1. Patients with chronic obstructive pulmonary disease may have a poorer quality of life than patients with lung cancer.
2. Predicting the duration of survival is harder to do for patients with congestive heart failure than for patients with lung cancer.

## Letters

Letters, which may not necessarily be published in full, should be restricted to not more than 250 words. When relevant, comment on the letter is sought from the author. Due to production schedules, it is normally not possible to publish letters received in response to material appearing in a particular issue earlier than the second or third subsequent issue.

### Hypertension: how low to go?

Editor, – Articles which challenge accepted orthodoxy are usually good reading, and Suzanne Hill's article on hypertension (*Aust Prescr* 2003;26:53-5) is no exception. A number of interesting points emerge from her critique of the HOT study.

I take it that Table 1 deals with the whole population studied, including the 20% who were no longer using felodipine by the end of the study. The reason for cessation was not given in the study, but if it was due to adverse effects (few people enjoy having swollen legs) the results do not flatter felodipine as a first-choice drug.

Although the risk reductions shown in Table 1 all fail to reach statistical significance, seven out of nine favour the target groups with higher diastolic blood pressure. It is very hard indeed to see how they can be interpreted as showing 'the benefits of lowering the diastolic blood pressure down to 82.6 mmHg'. Dr Hill rightly rejects that conclusion.

Perhaps the study can be classified with the many which assess the effect of a single treatment regimen on a single selection of end-points (or surrogate end-points). The authors of such studies seem to forget that it is possible to die of something other than the disorder they are investigating. Indeed, the more proficient we become at preventing death