

### **Geoffrey K Mitchell**

# Primary palliative care

## Facing twin challenges

As Australia's population ages, three things are inevitable: more people will develop chronic illnesses; more will grow very ill and more will die. Blueprints for the future suggest an increasingly important role for general practitioners and primary healthcare in palliative care.1

Palliative care is the care of people with life limiting illnesses, with a focus on the care of the patient and close family members.2 Once, it referred almost exclusively to cancer patients - invoked when the last attempt to rein in the spread of the cancer failed. It is now seen as the skill of symptom minimisation, regardless of the type of disease,<sup>3</sup> focusing on the physical, psychological, spiritual and practical. Specialist cancer services are starting to consider these issues earlier in the disease course, as patients can benefit from a focus on broader palliative issues in addition to reining in errant cells.4 Recent research has shown an increase in survival in patients with metastatic nonsmall cell cancer from early referral to palliative care.5

Cancer deaths account for only 30% of people who die. 6 Deterioration from cancer follows a reasonably predictable trajectory, and it is relatively easy to devise specialist care for these patients (around 80% of the patient load of specialist palliative care services comprises cancer patients<sup>7</sup>). What about the other 70%? People dying from nonmalignant diseases have different disease trajectories.8 Those with advanced organ failure frequently follow a path of relapses and remissions, with the final relapse leading to death. People who are very frail or suffer from dementia demonstrate a long, slow decline, with very high care needs. The indeterminate time periods until death make it challenging to provide 'classic' palliative care. And yet these patients die, and have a predictable, manageable symptom burden - as

do their close family carers. How can this be managed?

There will never be enough palliative care specialists to manage this growing tide general practice must play a role. To do this, we require two things: an understanding of what the problems are that nonmalignant palliative care patients and their carers have (GPs largely understand these problems9); and a means of making sure that appropriate care is available when needed. But when is that, when the end of life comes unpredictably? The answer to this second question lies in fostering a deliberate shift in our thinking, which is very similar to the shift promoted by the Enhanced Primary Care program. 10 Here, people with chronic disease are routinely assessed, problems that are causing reductions in good control of symptoms are identified (hopefully early), and plans put in place to bring these problems back into control. The objective is prolongation of a disease-free

Likewise, can we identify people who may die in the foreseeable future? Is it possible to put in place plans to deal with the spectrum

of problems that may arise, to either minimise their impact or deal with them promptly? In the United Kingdom, a comprehensive system of such care has been devised and successfully rolled out in both primary care and aged care facilities.<sup>11</sup> The first great challenge of primary palliative care in Australia is to develop and roll out a system that ensures that this case finding and care planning becomes a routine part of general practice care, and that the care is delivered in a timely way.3

Australian general practice research has found that case

conferencing between GPs and palliative care services can improve quality of life for patients. 12 There are many systemic barriers to the routine provision of this type of care in Australia. These need to be identified and solutions to account for them devised. There is currently a randomised controlled trial underway looking at whether a toolkit to help assess caregiver needs (supported by specific information for GPs) is effective in helping carers of patients with advanced cancer, and is practical within the Australian system. 13 We need to know that whatever systems are implemented work and are feasible in general practice, not foisted upon us. This type of research will help address part of this first research challenge of primary palliative care for

The challenge is magnified by the fact that 25% of the Australian general practice workforce chooses not to administer palliative care. 9,14 A picture of such a group in urban Sydney (New South Wales) is shown in *Table 1*.16 The features that distinguish these practitioners are the very features of Australia's future general practice workforce.15

#### Table 1. GPs in urban Sydney who do not deliver palliative care

Demographic characteristics (p<0.05)	
Younger	
Work part time	
Overseas trained	
Employees rather than practice owners	
Female (p<0.052)	
Stated reasons for not providing palliative care (all p<0.05)	
Do not do home visits	(75%)
Feel like there is inadequate support	(70%)
Family or personal commitments	(70%)
Lack of knowledge	(48%)
Lack of interest	(30%)
Emotional burden of care	(16%)

So, while the need for palliative care grows there is a risk that the proportion of GPs prepared to provide adequate care for palliative patients may fall. Innovative ways of enticing GPs to provide adequate palliative care is the second of the twin challenges of primary palliative care in Australia. These twin challenges will define the research agenda in this area over the next decade. These challenges must be addressed if Australian general practice is to provide as good as care at the end of life as it does in the rest of life's journey.

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