Palliative care beyond that for cancer in Australia

Geoffrey K Mitchell, Claire E Johnson, Keri Thomas and Scott A Murray

Internationally, the discipline of palliative care has five major challenges: (i) to reach beyond cancer; (ii) to start much earlier in the illness than terminal stages; (iii) to reach beyond the physical to other dimensions of care (social, psychological, existential); (iv) to extend from hospices and specialist services to generalists in hospitals and the community; and (v) to reach out more to support family carers.[1] In this article, we explore current inequalities in the provision of palliative care by both specialists and generalists (such as primary care and hospital clinicians), which favours people with cancer, and how it might be addressed in Australia.

ABSTRACT

- Only a quarter of patients' deaths are due to cancer, but the vast majority of the patients of specialist palliative care services have cancer as a primary diagnosis.
- Almost two-thirds of patients dying of an expected illness do not receive specialist palliative care at all, and this proportion is likely to increase as the population ages.
- Australian health system care for dying people needs systematic change so that people who may require palliative care in the foreseeable future are systematically identified, and have proactive care plans developed to meet their complex needs.
- This can be done in general practice and aged care, as shown by a model for such care in the United Kingdom.
- We explain the need for system change, and propose steps by which this might be achieved.

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The rationale to extend services beyond cancer

Australia's population is ageing, more people are dying expected deaths, and most of this burden is from non-malignant disease. In the United Kingdom, a typical general practitioner with 2000 patients will expect about 20 deaths annually, 18–19 of which are likely to be predictable.[1] The conditions leading to death in a United States cohort of previously well people aged 70 years or older were frailty (28%), any organ failure (21%), cancer (19%), advanced dementia (14%), sudden death (3%) and other conditions (15%).[2] Almost two-thirds of people who die an expected death will not be seen by a palliative care service.[3]

Three trajectories of physical decline in advanced illness have been described,[4] and the service delivery required for each differs. The acute trajectory (which occurs typically with cancer) is relatively predictable. It is the model on which palliative care services have been based, and the proportion of patients with cancer who receive specialist palliative care is relatively high.[3] By contrast, the trajectory to death with non-malignant progressive illness[4] is not as predictable. People with advanced organ failure like heart failure or chronic obstructive pulmonary disease are more likely to have relapses and remissions, with the prospect of recovery from most relapses. Frequently, people with such conditions are in the hands of hospital specialists, who are generally focused, rightly, on what it takes to prevent remissions, maximise function, and overcome relapses.[4]

However, with our ageing population, most patient deaths now follow the third trajectory of decline — those dying more gradually from frailty, multiorgan failure or comorbidity, including dementia.[4] The decline to death can take years.[5] The indicators that frail people face impending death are a mixture of physical, social and functional characteristics. Frail patients are largely cared for by generalist health care providers as they near the end of life, with little specialist palliative care input.[6] Frail ill people rely on care at home from spouses, near relatives and friends, or are in aged care facilities.[4] The proportion of very old people entering aged care facilities is rising, adding to the strain on an already under-resourced sector.[7]

Limited capacity of specialist palliative care services means that they are unlikely to become universally available in the foreseeable future for people such as these. Moreover, most people with organ failure or frailty do not need specialist input, and their palliative care needs can be well managed by generalists.[8]

In addition to physical distress, people with life-limiting diseases may experience psychosocial isolation, spiritual distress, the extra financial burden of treatments that may not be covered by any third party, costs of transport to and parking at tertiary hospitals, out-of-pocket medical expenses, and, for carers and patients alike, income foregone.[9] The discrepancy between the support offered to people with cancer compared with those with non-malignant conditions is significant. There are substantial gaps in quality of life as a result.[10]

Caregivers have needs that are under-recognised and undervalued, with both specialist and non-specialist services concentrating on the needs of the ill person. Caregivers' needs are not the official responsibility of any one health care provider. Twenty per cent of caregivers provide full-time or constant care.[11] They are burdened with care for which they have had little preparation and, in the process, may neglect their own health and social needs.[12,13]

Systematic management of non-malignant palliative care

There are two key tasks that will ensure that patients receive the care they require. The first is ensuring that the people who may require palliative care in the foreseeable future are identified in time to put relevant plans in place. The second is assessing patient needs regularly to ensure the correct level of specialist palliative care is being accessed. Such assessment has been the subject of a national research program, which has developed a needs-based assessment instrument. The Needs Assessment Tool: Progressive Disease — Cancer has been developed,[8] and is currently being adapted for non-malignant disease. For the remainder of this article, we concentrate on the first of the key tasks — identifying those who may soon require palliative care.

Dying patients are encountered at all levels of health care. Caring for patients at the end of their lives is everyone's business. Systematic awareness of the identity and needs of these people should be a core task, which will rapidly become more urgent with the ageing of the population. This does not mean that all of these needs have to be met by all services. However, recognising that these needs have to be met by someone, and shaping the health

1 The seven Cs of primary palliative care

- Communication
- Coordination
- Control of symptoms
- Continuity of care
- Continued learning
- Carer support
- Care of the dying pathway

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system to ensure that this occurs, is an urgent and strategic task that needs to be faced at all levels.

Systematic identification of patients who may die: a way forward in Australia

General practice is the only common medical setting where virtually all people whose deaths can be predicted are likely to be found. Virtually every patient has a GP, and virtually every GP deals with chronically ill patients with differing levels of severity of illness. Aged care facilities are another obvious place where people who may die might be found. A mechanism is required by which patients nearing the end of their lives are identified, and by which the needs of these patients and their carers are assessed and addressed in a systematic way.

The Gold Standards Framework (GSF), developed in the UK, is a model that has been developed to deal with this situation.[14,15] Its fundamental premise is that it should be possible to identify all patients who are likely to die a predictable death in general practice. A simple means of doing this is for GPs to ask, for each of their patients: “Would I be surprised if this patient died in the next 6 to 12 months?”[16] Patients identified by these means should then be assessed, and a comprehensive, multidisciplinary individual treatment plan should be developed that recognises the holistic needs of patients and their caregivers and families. This treatment plan will use allied health and specialist services as needed. The key to this process is that the general practice (or acute care facility) systematically seeks out these patients and systematically plans for anticipated medical, psychosocial and spiritual needs, and practical problems. Planning can be assisted by a systematic evaluation of palliative care needs, termed the seven Cs by the GSF program,[15] and shown in Box 1.

A recent systematic review has evaluated published evidence on the GSF in the UK.[17] After development over 10 years, and a planned rollout, basic GSF processes have been taken up by 98% of GPs after the GSF was introduced as an element of the National Health Service contract. The extent to which it has been adopted varies, and the review identified four areas that require improvement: (i) consistency of use; (ii) effectiveness for all relevant patients; (iii) improved equity by increasing the numbers of non-cancer patients registered; and (iv) the need for integrated quality improvement. The review also highlighted that effective implementation of this program requires considerable strategic planning, commitment and resources at both national and practice level.

Uptake of an adapted program by care homes in Britain has been enthusiastic and sustained, and measurable outcomes have included reductions in visits to emergency departments, avoidable hospital admissions and deaths in hospitals, and improved collaboration with GPs.[18] Some primary care trusts have paid for GSF training for individual nursing homes.

A number of demonstration projects in Australia have used individual elements of the GSF, notably in the rural palliative care program, although none has strategically introduced comprehensive GSF into routine practice.[19] These demonstration projects have emphasised the potential benefits, but also the unique difficulties inherent in this (or a similar) initiative being taken up systematically in Australia. Box 2 shows a comparison of factors in UK and Australian general practice that highlight impediments to the uptake of systematic case finding and case planning in Australia. A coordinated national approach, supported by initiatives that support practices to implement the GSF or a similar framework, and, importantly, to sustain the practices when that initial support is withdrawn, are essential to ensure that this practice becomes embedded as a core task of general practice.

2 Systematic issues that will impede the uptake of systematic case finding and case planning in Australian general practice for people who may require palliative care in the foreseeable future

Level at which issues apply	United Kingdom	Australia
Health system level	Policy of end-of-life care includes Gold Standards Framework	National Health and Hospitals Reform Commission recognises the importance of systematic palliative care provision, and the need to improve primary capacity to deliver palliative care
	National Health Service-funded central implementation body	No mechanism of central coordination
	Each person is registered with a single general practice	Patient registration does not exist
Practice level	Incentive payments for basic and advanced functions of Gold Standards Framework paid in the GP contract	No incentive payments for systematic case finding and planning
	Capitation payments and the Quality and Outcomes Framework* promote multidisciplinary care	Multidisciplinary care paid on a fee-for-service basis; increasing but not universal uptake of these funding opportunities
	General practice multidisciplinary care routine; management in place to ensure its delivery	Complex and requires management skill. Practice management required to implement it is not even and dependent on commitment of practice owners
Individual level	Acknowledged and paid for as core business of GPs	75% of GPs undertake palliative care; the 25% who don’t include those who are part-time, employees, younger, overseas-trained, concerned that they have inadequate skills, and who don’t do home visits[20]

* A set of outcomes against which a general practice’s performance is measured, and within which extra payments are linked to meeting targets for each outcome.

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A systematic program such as the GSF raises broader issues within general practice. For example, as with many other chronic disease management initiatives, successful implementation relies on management skills at the general practice level to take full advantage of the funding programs on offer. Attention is now being paid to what is required to develop and maintain these management and change-management skills.[21] Provision of after-hours service and the willingness to undertake house calls are critical elements of primary palliative care, but are not part of the professsional role of many GPs,[8,20] and this causes considerable concern for patients and specialist palliative care providers.[22] A wider, systematic examination of relevant issues and how to address them is warranted.

We need a coordinated national approach to primary care-based delivery of palliative care to patients to break down the systematic barriers that exist in Australia, especially for people with non-malignant conditions. Such an approach would bring together arms of health policy (primary care, palliative care, rural care, and aged care) that are administered separately in the Australian Government Department of Health and Ageing, and would require input from relevant professional bodies, relevant professionals on the ground and consumers. Such an approach is needed to identify and implement the best model of community-based palliative care to serve dying patients who do not have cancer.

Competing interests

Geoffrey Mitchell has received royalties from Radcliffe Publishing on sales of his book on primary palliative care, and has had travel expenses paid by the European Association for Palliative Care, the Goodfellow Foundation of New Zealand, and the the Antea Associazione, Italy, to present papers at conferences.

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