

Internationally, it is Time to Bridge the Gap between Primary and Secondary Healthcare Services for the Dying

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Abstract

Around two-thirds of people with incurable diseases in economically developed countries wish to die at home, but less than one-third succeed in doing so. Developing primary care-based services for the dying in the community is essential to reach and serve the whole population. Three typical “trajectories” or patterns of decline in the last year(s) of life have recently been described, and each of these may require different models of care to best meet the needs of patients. The palliative care approach must be urgently extended to patients with non-malignant conditions who have comparable concerns to and in some cases even greater and more prolonged unmet needs than cancer patients. Primary care professionals have the potential and ability to provide end-of-life care for most patients, given adequate training, resources and access to care facilities and specialist advice when needed. They are ideally placed to identify patients at diagnosis, hospital discharge or disease progression who might benefit from an early palliative care approach. In the UK, Australia and US, some important initiatives are gaining momentum to facilitate the delivery of primary palliative services. In Singapore, the involvement of family physicians in end-of-life care is very low. A local survey is currently being conducted to identify the challenges in getting more family physicians involved. Given adequate time and resources, community professionals throughout the world can provide effective, equitable, and accessible primary palliative care, and form a solid bridge of communication and support between primary and secondary care.

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Introduction

Around two-thirds of people with incurable diseases in economically developed countries wish to die at home, but less than one third succeed in doing so.^{1,2} Developing primary care-based services for the dying in the community is essential to reach and serve the whole population, and to provide care where many people wish. Such services could also provide supportive care from earlier in the course of the illness, and to people not only with cancer but also to those with organ failure, such as chronic obstructive pulmonary disease and cardiac failure, as well as to frail older people, who also could benefit from this approach. Current specialist palliative care services may have an important role in educating and supporting generalists both in the community and in hospitals.

Typical courses or “trajectories” of physical decline in

the last year(s) of life have recently been described, and each of these may require different models of care to best meet the needs of patients.³⁻⁵ In the UK, each family physician (general practitioner) has around 2000 patients to care for and around 20 of these patients die each year. Figure 1 shows that of these 20 patients, around 5 die from cancer, 6 from organ failure illnesses and 7 after prolonged cognitive or physical frailty. The remaining 2 patients die from accidents or sudden death (Gold Standards Framework, UK – http://www.goldstandardsframework.nhs.uk/non_cancer.php). These are exemplified by the cancer patient’s long high-function plateau followed by decline; with the decline punctuated by acute exacerbations seen commonly among patients with heart failure and obstructive lung disease; and the slow, progressive demise that comes typically from degenerative neurological diseases

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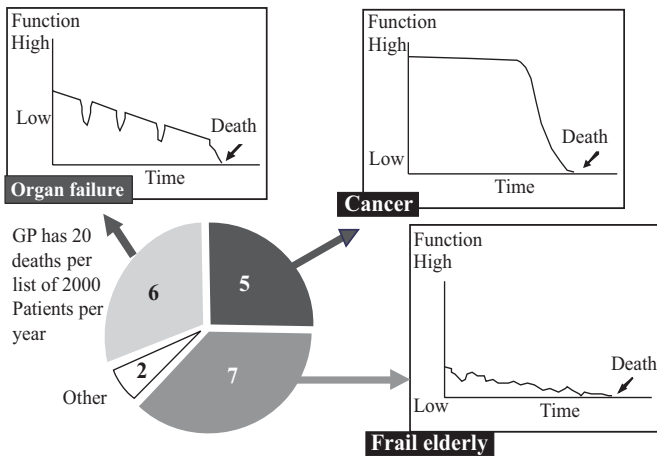


Fig. 1. Typical illness trajectories at the end of life.

and physical frailty with a prolonged period, typically years of slow dwindling.

Thus for the majority of our patients to benefit, the palliative care approach (which means anticipatory care that addresses all dimensions of needs), must be urgently extended to patients with non-malignant conditions who have comparable concerns to and in some cases even greater and more prolonged unmet needs than cancer patients.⁶ Progress to care for patients with non-malignant illness by palliative medicine specialists may be hampered by funding issues, lack of experience with non-malignant diseases and concerns about pressure on specialist services. Family physicians and nurses in the community should lead the way in instigating a palliative care approach for patients with life-limiting illness such as organ failure illness as well as the frail elderly. Internationally, such patients could be identified by family physicians or community nurses asking themselves a simple question: “Would I be surprised if my patient were to die in the next 12 months?”⁷ If the answer is “no”, then a palliative approach may be indicated. We should hope for the best, but plan for the inevitable. “Be prepared” makes sense. Failing to plan is planning to fail. Alternatively, anyone hospitalised due to cardiac failure or COPD (chronic obstructive pulmonary disorder) could be identified at discharge, holistically assessed and pro-actively managed in primary care, aided by a computerised recall system.

Primary care professionals have the potential and ability to provide end-of-life care for most patients, given adequate training, resources, access to day care and respite care and specialist advice when needed.⁸ They share common values with palliative care specialists – holistic, patient-centred

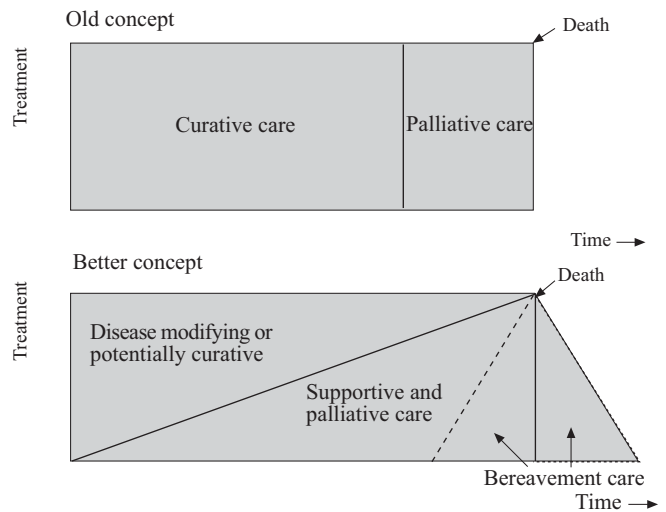


Fig. 2. Appropriate care near the end of life: from curative to active palliation.

care, delivered in the context of families and friends. These clinicians are also in a position to address the concerns of the patient’s family members – including care-giving and grief issues – as they are likely to also be the doctor or nurse for several family members. Palliative specialists recognise and support the essential role of primary care clinicians as providers of primary palliative care.⁹

Thus, family physicians are ideally placed to identify patients at diagnosis, hospital discharge or disease progression who might benefit from an early palliative care approach. Identifying such patients proactively could allow family physicians to deliver, simultaneously, active treatment and patient-centred supportive care, often in the context of a valued long-term relationship. In addition, there is a natural opportunity to consider the needs of the family after the patient’s death and so provide bereavement care, which is integral to palliative care (Fig. 2).

In the UK, some important initiatives are gaining momentum within primary care, such as the Gold Standards Framework, which encourages holistic, patient-centred care and thereby facilitates effective care in the community.¹⁰ In Australia, attention is being paid to involving GPs in multi-disciplinary team care and increasing their knowledge and skills in palliative care.^{11,12} In the US, evolving models of chronic care delivery¹³ and reimbursement could facilitate the delivery of primary palliative services.

In Singapore, palliative care services are seeing more patients with non-malignant illnesses. The proportion of patients admitted to a local inpatient palliative care unit with non-malignant life-threatening conditions has risen from 4.6% in 2003 to 7.3% in 2006.¹⁴ The proportion of home deaths among patients under the largest hospice

home care services was 54%, higher than the national average of 27%.^{15,16} Family physicians, who manage chronic medical conditions in the community, are in an ideal position to deliver primary palliative care to their patients who are dying at home. However, the involvement of family physicians in end-of-life care in Singapore is very low. There is no local study done to determine the reasons for this, but a local survey is currently being conducted on a group of family physicians. The findings of this survey will help to identify the challenges in getting more family physicians involved in providing primary palliative care. It is important to note that most of the hospice home care services in Singapore employ their own full-time doctors, rather than working with family physicians. The support given to family physicians by palliative medicine specialists is also limited due to the small pool of specialists available. Palliative medicine has only recently been granted “subspecialty” status in Singapore, and subspecialty training in palliative medicine has only officially commenced in May 2007. With more palliative medicine subspecialists in the future, the local authority can work with the hospice home care services and the family physicians in Singapore to narrow the gap between primary and secondary health care services for the dying.

Every person with a progressive illness has a right to good end-of-life care including good care in the community.¹⁷ Patients desire a reassuring professional presence in the face of death. Community professionals throughout the world are trusted by patients and are in a position to provide effective, equitable and accessible primary palliative care. This will happen only if they have adequate time and resources and work in a system where there is a solid bridge of communication and support between primary and secondary care.

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