



The potential for a structured approach to palliative and end of life care in the community in Australia

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REVIEW

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Abstract

The demand for palliative care (PC) in Australia is expected to increase as the population ages and the number of people with chronic and life-limiting conditions rises. With limited specialist PC resources available in the community, general practitioners (GPs) will increasingly provide and co-ordinate palliative and end-of-life (EOL) care. The majority of the last year of life of people with a life-limiting illness is spent in the community, hence, GPs are well placed to identify and care for people who may benefit from a palliative approach to care.

Currently, many people at EOL access PC care in a reactive, ad-hoc, fashion that is dependent on the knowledge, skills and interest of relevant health professionals. National standards and policy documents provide guidance for quality care at the EOL for all Australians. However, no mechanism has been proposed to ensure that such standards are routinely operationalised within the community.

The Gold Standards Framework (GSF) is a potential base on which an EOL framework for community care in Australia may be built. The GSF is an evidenced-based organisational system for providing best practice EOL care in general practice and residential aged care. It facilitates the identification of people for whom a palliative approach may be appropriate and provides a structure for the identification of needs, pro-active

care planning and ongoing monitoring of progress. Where the GSF has been implemented in the United Kingdom, significantly improved care processes have been reported.

While there are numerous barriers to the uptake of an unmodified GSF in Australia, it may provide the framework on which a structured model of PC in general practice is developed. We will examine the potential for such a structured approach to EOL care in the community and general practice in Australia.

Key Words

Palliative Care, End-of-life, primary care, general practice

Due to an ageing population and an associated increase in the number of people with chronic and life-limiting conditions, the demand for palliative care (PC) in Australia will increase in the future.¹ In 2008, there were 144,000 deaths in Australia, with the majority being from causes where death might be expected (major causes being cancer, heart disease, stroke, chronic lower respiratory disease, Dementia and diabetes).² With limited specialist PC resources available in the community,³ GPs will be increasingly expected to provide and co-ordinate palliative and end-of-life care (EOL).⁴

The majority of the last year of life of people with a life-limiting illness is spent being cared for in the community by primary health care providers,^{5, 6} hence, GPs are well placed to identify people who are approaching the EOL and may benefit from a palliative approach to care, as well as the needs of such patients and their caregivers in their life context. GPs are an important part of the network of care for people with advanced disease (especially non-malignant diseases) and, with support and training, are able to provide appropriate care for the majority of people at the EOL whose problems are not complex.⁷

Palliative care is defined as an approach to care that improves the quality of life of patients and families facing the problems associated with life-limiting illness. In addition, through early identification of needs, impeccable assessment and treatment, PC aims to address physical, psychosocial and spiritual concerns.⁸ PC may be delivered at different levels within the health system- patients being routinely cared for by GPs and



other primary care services at the community level. Where more complex problems are evident, patients may require varying levels of input from specialist PC services, with only a minority being cared for exclusively by them.⁹

However, there is some debate about the degree to which GPs' desire to be involved in providing PC,¹⁰ and their ability to provide it.⁷ Recent, unpublished research by the author (CJ) found that more than 30% of GPs from a national study of 640 did not wish to be involved in providing PC and research by Rhee, et al found that 25% of GPs in urban New South Wales were not involved in providing PC.¹⁰ This research identified a number of important systemic barriers contributing to the lack of involvement in PC such as lack of interest and knowledge, the need to conduct home visits, problems with after hours care due to personal commitments,¹⁰ problems related to the time involved in providing and coordinating PC and complexities involved in administering treatment.¹¹ GPs who are younger, a practice employee rather than practice owner, overseas trained or working part-time are less likely to provide PC.¹⁰ To ensure seamless access to community based PC for all people with life-limiting illnesses, it is imperative that such barriers are addressed in a way that utilises the strengths of general practice and may be successfully integrated into current practice.

Research suggests that GPs do not always identify patient and caregiver needs or when a palliative approach may be appropriate.¹² Ongoing education, a coordinated and multidisciplinary approach to care,^{13, 14} careful planning, and good communication by health professionals are central to best practice in the management of chronic diseases and EOL care.¹⁵ These characteristics are important to patients and caregivers at the EOL,^{8, 16-20} but do not always occur.²¹ Services are frequently fragmented with patients suffering with unmet needs and confusion about where to go to access help. Patients and caregivers report a need for better symptom management, coordination of care, planning of community support and access to specialist PC services- especially for people with non-cancer diagnoses.²²⁻²⁴

Furthermore, most PC is provided to people with cancer. Australian research shows that approximately two-thirds of people with a cancer diagnosis access specialist PC services compared to less than 10% of people with non-cancer diagnoses.^{25, 26} This may be because the disease trajectory for cancer is well defined with a relatively short period of decline prior to death that is well recognised. Comparatively, the long term, slow and uneven decline for non-malignant diseases such as end-stage organ failure (eg heart failure, renal failure), stroke, dementia, neurodegenerative disorders and frailty are less well provided for. Intermittent serious episodes in conditions such as heart and other organ failures and the prolonged functional decline seen in people with frailty and dementia are frequently overlooked as potential triggers to providing PC.²⁷ The challenge then is to identify a mechanism by which all people who have a life-limiting illness (both cancer and non-cancer) may be identified in general practice and offered appropriate palliative and EOL care.

Given the need for GPs to engage more proactively in the provision of PC, the necessity for a well organised, systematic and coordinated approach to PC in primary care is crucial to its success in Australia. While there are numerous differences between primary healthcare in Australia and the United Kingdom, the Gold Standards Framework (GSF) has been identified as the most practical model of care currently available that could potentially provide the basis for a structured framework for EOL care in primary care in Australian. The GSF developed and rolled-out throughout the UK in the last 10 years, is a systematic approach to optimising the organisation and quality of care delivered by generalist healthcare professionals. It is a flexible, evidence-based model of care that facilitates the identification of people within a general practice or community care setting who are likely to die within 12 months and supports comprehensive, proactive care planning to facilitate their EOL care.²⁸

The primary goals of the GSF are to provide patients with a terminal illness with: 1) consistent high quality care; 2) care alignment with patients' preferences; 3) pre-planning and anticipation of needs; 4) improved staff confidence and teamwork; and, 5) less hospital based care^{28, 29}-aims that are consistent with objectives of the Australian Government National Palliative Care Strategy³⁰ and the standards recommended by Palliative Care Australia.³¹ It is a program that aims for organisational change (ie changes the way care is provided at team/organisational level) and provides a structure through which important aspects of PC such as advance care planning and needs assessment may be integrated into routine care. At its simplest, implementation of the GSF involves a practice coordinator and lead GP. At a "foundation" level practices will have a palliative care register, implement regular team planning meetings and institute care plans for patients who may be in the last year of life. At a higher level of involvement, practices adopt a holistic, interdisciplinary approach, ensuring comprehensive coordinated EOL care.³²

A recent systematic review of the literature reporting the impact of the GSF in the last 10 years found that it has a high level of uptake in general practices at the Foundation Level (98%)-the level supported in National Health Service contracts³² and up to 60% being involved at higher level.²⁹ When adopted, the GSF has been shown to improve communication, co-ordination and continuity of care, symptom management, continuing EOL care education, carer support, access to community and specialist PC services and identification of people for whom a palliative approach may be beneficial.³³⁻³⁷ Improvements in quality and coordination of care enable more people to die where they choose and may reduce hospitalisations.³² Little direct evidence of the impact of the GSF on patients and caregivers is available. One small qualitative study (7 patients and 3 caregivers) found that most perceived that they had received good care but still identified problems in accessing care (particularly out of hours) and poor coordination of care.³⁸ While the GSF was generally



acceptable to health professionals and viewed as a useful framework for enhancing EOL, some perceived that it involved more paperwork and administrative tasks- especially for the person undertaking the coordination role..³⁴

Adoption of the GSF by care homes has resulted in decreases in hospital deaths and crisis admissions to hospital and an increase in advance care planning and use of EOL care pathways.³⁹

In practise, the GSF is simple, feasible, and logical and has clear steps for implementation already developed. Its flexibility allows for adaptation to individual practices and increases local ownership.³² Given the success of the GSF in the UK, developing a well defined and coordinated approach to providing the optimal standard of community PC such as the GSF is likely to contribute to equitable, high quality end-of-life care for all Australians.

As the concerns and difficulties encountered by Australian GPs in providing care at the EOL are similar to those identified in the UK, interest has been shown in adopting a similar approach to care in Australia.⁴⁰ However, as there are a number of significant differences between Australia and the UK in the way primary care is structured, delivered and funded,⁴¹ the GSF cannot feasibly be translated directly to primary practice in Australia without appropriate modification to accommodate these health system differences. Differences such as payment of GPs on a fee for service basis, the proportion of general practices that are privately operated, the limited availability of home and out-of-hours access and the opportunity for individual patients to access different GPs on each occasion of service necessitate an extensive and in-depth investigation of how these and other health services differences may feasibly be overcome. Furthermore mechanisms to address identified systemic barriers to engaging GPs in PC need to be developed. At a government level, there needs to be a national focus on EOL care with appropriate policy and regulation and local planning and service development.⁴² However, rather than developing an entirely new program it seems reasonable to utilise the evidence-base of the GSF and adapt it to the Australian health environment-a program that is supported by the developers of the GSF. An adapted framework will need to be extensively evaluated and a comprehensive roll-out strategy developed to support its integration into current general practice models.

The National Health and Hospitals Reform Commission⁴ has identified the need to strengthen EOL care in the community, including the use of multidisciplinary care teams and to improve the skills and support for primary care practitioners who care for people at the EOL. Currently, there is broad interest in developing comprehensive models of coordinated care for people at the EOL in Australia, however, interest is dispersed and currently lacks strategic direction. Numerous projects have sought to address the need to improve the quality of PC in the community in Australia. These projects are often developed at a grass roots level, adapted to meet specific needs within the individual community or care setting or have attempted to address specific elements of EOL care.⁴⁰

Development of an Australian primary care EOL Framework under one national program could bring these fragmented elements of EOL care together under one Framework. Such a program needs to be multifaceted and build upon all current projects and initiatives and must be able to be adapted to meet specific needs within individual community or care settings. Any new primary care framework must also aim for inbuilt sustainability (eg funding to ensure changed practice is maintained). Hence, part of any development program needs to include establishing and evaluating mechanisms to promote uptake and continuity. This includes adequate payment for general practice activities (eg by ensuring that Medicare Item numbers cover all activities associated with the Framework and that current Medicare item numbers are fully utilised) and may include developing the role of practice nurses to support the program. Of paramount importance in the development and rollout of such a Framework is the engagement of GPs- both at a planning and national implementation level as well as in individual practices.

Currently, and in the future, there will be increasing demands on all health resources in Australia, especially for people with life-limiting illnesses. Hence, the development of a systematic approach to optimising the organisation and quality of EOL and palliative care delivered by GPs and other primary care health professionals is increasingly important as the number of people with life-limiting illnesses and the elderly increases. However, to do this, the primary care sector will need to be adequately resourced, trained and organised. At present there are guidelines and policy documents that provide guidance for the delivery of optimal EOL^{30, 31, 43} and PC but no programs that provide structure for the systematic implementation or operationalisation of such guidance. Development of an Australian primary care EOL Framework, similar to the GSF, may address this gap in the provision of comprehensive EOL care.

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