

RURAL PALLIATIVE CARE: EXPLORATION OF THE PIVOTAL ROLE OF PRIMARY HEALTHCARE PROVIDERS

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Abstract

Primary healthcare providers are critical to the delivery of healthcare in Australia. For rural Australians these health professionals play a pivotal role in all aspects of health, from prevention, early diagnosis and treatment through to care at the end of life. The delivery of optimal palliative care for rural Australians is dependant upon a viable, well educated primary healthcare workforce. Recent initiatives by the Commonwealth Department of Health and Ageing, Royal College of General Practitioners and state health departments have made significant inroads into supporting rural palliative care delivery. There is a need for these programs to be extended to other rural healthcare providers.

The Commonwealth Department of Health and Ageing National Palliative Care Strategy identifies three core goals: increase awareness and understanding of palliative care; improve the quality and effectiveness of palliative care delivery; and support and promote partnerships to support delivery of palliative care.¹ To achieve these goals for all Australians requires a knowledge and recognition of the needs of the diversity of the Australian population. This paper focuses on the palliative care needs of rural Australians and recent initiatives undertaken to implement sustainable quality access to palliative care. Not included in this paper are the specific needs and issues associated with provision of palliative care to Indigenous Australians.

Background

In Australia, approximately one third of Australians live in rural areas² and another half a million reside in remote regions of the country. The overall incidence of cancer is similar in metropolitan and rural populations, however, mortality is higher for those individuals who live in rural regions, particularly so for men with prostate cancer and women with cervical or lung cancer. There is recognition that access to healthcare for individuals living in rural and remote areas of Australia has been problematic.^{3,5} Increased costs associated with healthcare delivery, decreasing numbers of rural healthcare providers and a growing trend toward centralisation of services impacted negatively on access to healthcare services for Australians living in rural and remote areas. Yet, with this decrease of healthcare services the needs for healthcare in rural and remote communities remain high, particularly in the area of palliative care. The need to develop alternative models for providing effective delivery of an appropriate mix and level of health services to rural communities, which differ in size and types, has been acknowledged by government and health authorities.⁶ This article will outline the steps being taken to address these gaps and support the ongoing delivery of palliative care by primary healthcare providers in rural, regional and remote Australia.

Previous work carried out by the author identified a range of unmet needs for palliative care patients and their families in rural and remote areas, including access to palliative care services, information about illness, practical care and support.^{4,7} Rural families have identified problems in accessing practical care, in particular, after hours care, where families reported difficulties associated with the provision of care to an ill family member, especially at night.^{4,7} Difficulties included symptom management, assessment of the patient's condition and uncertainties about how to comfort and solve practical care giving problems. Reduced healthcare provider input and limited choices for home care were identified and families also had limited knowledge of the existing local services. Economic and physical barriers such as distance, lack of transport and the need to travel, as well as reduced services from which to choose from, further impacted on the choices and availability of care for these rural families.⁷ Access to specialist counselling services and psychosocial services, such as bereavement counselling, are also known to be challenging areas in rural and remote communities.⁵

There is consistent evidence to indicate that many people with advanced cancer prefer to be cared for at home, especially in the last stages of life.^{8,9} This need to have care at home may be particularly important to those individuals living in rural or remote areas, who would otherwise experience isolation and distress if they were moved to regional or metropolitan centres for their end stage care. A number of studies have illustrated that specialist palliative care services in regional Australia are of high standard, however those individuals living in rural and remote areas do not always have access to these services.^{3,4} Therefore, there is a need to explore alternative models for providing palliative care for Australians living in rural and remote areas. These alternative models must be sustainable from both a resource and funding perspective.

In a systematic review of palliative care for rural populations undertaken in 2003, Evans and colleagues⁵

identified that the limited published work in this area identified problems in the delivery of palliative care in rural areas, focusing on the needs and barriers to providing palliative care. The author and colleagues¹⁰ argue that this reaction has diverted attention away from attempting to develop a complementary body of knowledge on approaches to rural and remote area palliative care. Palliative care services in rural and remote areas need to be 'responsive' and a set of broad principles to assist in developing such a service are proposed. Establishing alternative models of palliative care delivery in local health services has provided unique opportunities for planning more integrated care. A number of new programs have been developed and are currently being evaluated, in recognition of the need to work with rural communities to develop the new approaches to palliative care delivery (see table 1).

Rural palliative care provision

While specialist palliative care services, as seen in metropolitan settings, can be found in larger regional centres, for most rural and all remote centres, primary healthcare providers are responsible for the delivery of palliative care. This can lead to the view that the lack of specialist palliative care services of itself is a limitation

or reduction in the quality of palliative care for rural Australians. However, this view lacks supporting evidence and fails to acknowledge the benefits for maintaining primary carer led palliative care. These benefits include increased continuity of care, being cared for by health professionals who have a long standing professional relationship and knowledge of the individual and their family, and access to continuing care and bereavement support for family members. Equally important, rural health professionals have an increased knowledge and understanding of the broad issues within rural communities, the unique rural culture and the consequences of these factors on how the individual experiences their illness.

Rural palliative care healthcare team

A multidisciplinary team is seen as a major component in ensuring optimal palliative care. Achieving the breadth of professional palliative care expertise in rural Australia can be challenging. As with palliative care in metropolitan settings, medical and nursing care remain the major elements of care provision, after family care. On average, the Australian general practitioner (GP) will care for between five and 12 palliative care patients per year.¹¹⁻¹³ Pereira's¹⁴ study of rural GPs in NSW, on

Table 1. *Examples of recent rural palliative care initiatives*

Program/Initiative	Key Objectives
Rural Palliative Care Program Department of Health and Ageing and Royal College of General Practitioners	The program is designed to significantly improve access to quality, coordinated palliative care for people living in rural and remote communities. This will be achieved through funding projects which enhance common understandings among participants/key stakeholders, strengthen links between palliative care and mainstream service delivery, and account for the broader consumer and community interests. Further details: http://www.adgp.com.au/site/index.cfm?display=683 .
Wagga Wagga Specialist Outreach Palliative Care Service ¹⁸	The development of a visiting palliative medicine specialist outreach service for Wagga Wagga, NSW.
Griffith Area Palliative Care Service ²⁰	The elements of the model include weekly case conferences, the on-call nursing roster, patient-held records and shared protocols and procedures. Pilot evaluation showed the model achieved its aim of improving palliative care services and still continues with some modifications. The generalisability of the model is now being tested in eight rural and remote communities across Australia.
Primary Health Providers Palliative Care Education ²¹	Development and evaluation of palliative care education and workshops for primary healthcare providers in rural and remote Queensland.
SEAM – improving the quality of palliative care in regional Toowoomba, Australia: lessons learned Support, Education, Assessment, and Monitoring ²²	Support, Education, Assessment and Monitoring (SEAM) model of service delivery aimed to provide palliative services to patients and their families who live in the regional city of Toowoomba and its rural catchment area. It also aims to facilitate education, support and networking among health-care professionals, particularly general practitioners and nurses employed in general practice (practice nurses).
Education, training and support for general practitioners in palliative care ²³	Research mapped current palliative care education opportunities and identified gaps, additional resources. Department of Health and Ageing response and recommendations.
“Pop-UP” Palliative Care: Implementing palliative care in small rural and remote communities.	Developed and tested a community-wide framework for facilitating small communities to develop a palliative care team utilising existing community and health services.

average caring for eight palliative care patients, found that the majority of GPs surveyed preferred to manage the palliative care component of their patients terminal illness and to maintain this contact if admission to a local hospital was required. This is a unique aspect of the rural GP's role, which incorporates admission rights as well as community-based care.

While research highlights that GPs value the role they play in palliative care,¹² the relatively low numbers of palliative care patients they care for can lead to limited opportunities to develop specific expertise. Other challenges identified include difficulties in providing after hours access, time restraints, staff shortages, limited access to specialist or allied health services and concerns about skill level.¹⁵

McKenzie and colleagues¹⁶ study of rural community nurses highlights that community nurses are pivotal to the organisation and provision of palliative cancer care at home. The regular comprehensive assessments and complex clinical judgements made about changing health status enable nurses to liaise with medical practitioners and allied health professionals on behalf of patients to ensure that ongoing care needs are met. Nurses provide emotional support and a broad spectrum of education to patients and their families, which promote independence and reduce some of the stresses associated with their condition. While research has focused on rural community nurses, there is limited knowledge of the palliative care expertise, needs or perspectives of nurses who work in the small district hospitals, where patients may elect to spend their final days. This is an area that requires attention in future research and education programs.

Access to other members of the allied health team varies depending on geographical location and population. Access to physiotherapy and occupational therapy services varies considerably and when these services are available they can be limited to inpatient access only. Given the breadth of knowledge required of GPs overall, the local pharmacist can be a critical member of the "local" palliative care team, providing an additional resource to assist in symptom management. Perhaps the more challenging area, and one that remains unmet in many communities, is access to ongoing bereavement or specialist psychological services, which remain limited in rural communities.

Access to specialist palliative care

Access to specialist palliative care services can be required by some patients. As outlined in Table 1, a number of programs have been developed to provide rural healthcare providers with access to specialist palliative care expertise. In addition to the small number of regional specialist palliative care multidisciplinary services, many areas have access to specialist palliative care nurses. These nurses commonly have extensive experience, skills and knowledge of palliative care, providing consultation and support to the primary healthcare team, covering often large geographical areas. In WA, additional support is provided through a statewide phone contact to specialist palliative care available 24 hours, seven days a week. In NSW "fly-in"¹⁷

specialist palliative care services and the establishment of outreach clinics is another model.¹⁸ In SA video link-up between remote and rural communities and specialist palliative care in Adelaide is being trialled.¹⁹ Many rural centres support local staff to spend time in larger metropolitan and regional palliative care centres, to build knowledge and expertise.

Palliative care education

It could be said that palliative care practice of itself does not change significantly across geographical regions or population density. For most rural GPs and nurses palliative care patients will comprise only a small proportion of their caseload. This can make maintaining a depth of knowledge on recent trends in pharmaceutical management, new pain medications and approaches to using these medications challenging. Equally important is that most health professionals report that their undergraduate preparation in palliative care is lacking, leading to a perception of not being skilled in critical areas of managing the palliative care patient. Approaches to providing access to information in a format that is feasible for the GP is always a challenge and one that continues to require further attention. To date most nursing education has focused on those wishing to specialise in palliative care, neglecting community and district hospital nurses. Other members of the health team in rural Australia have yet to benefit from focused initiatives in palliative care.

Conclusion

While there remains a challenge in providing palliative care to rural and remote communities in Australia, there is evidence of a strong commitment from both rural health professionals and government to ensuring access to palliative care through innovative models and approaches to care delivery, education and support. That these models for providing palliative care vary across rural Australia is a strength, reflecting the development of programs that are tailored to meet local needs. Ongoing education and access to support for the primary healthcare team is critical to achieving palliative care outcomes.

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