

Enhancing palliative care delivery in a regional community in Australia

Jane L Phillips, Patricia M Davidson, Debra Jackson, Linda Kristjanson, Margaret L Bennett and John Daly

Abstract

Although access to palliative care is a fundamental right for people in Australia and is endorsed by government policy, there is often limited access to specialist palliative care services in regional, rural and remote areas. This article appraises the evidence pertaining to palliative care service delivery to inform a sustainable model of palliative care that meets the needs of a regional population on the mid-north coast of New South Wales.

Expert consultation and an eclectic literature review were undertaken to develop a model of palliative care service delivery appropriate to the needs of the target population and resources of the local community. On the basis of this review, a local palliative care system that is based on a population-based approach to service planning and delivery, with formalised integrated network agreements and role delineation between specialist and generalist providers, has the greatest potential to meet the palliative care needs of this regional coastal community.

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ACCESS TO PALLIATIVE CARE is a fundamental right for people in Australia and is endorsed by government policy.^{1,2} Access, a key component of all palliative care service delivery models, implies fairness not determined by geographical location.^{1–5} Despite this ideal, the increasing demand for palliative care in regional, rural and remote areas, combined with the limited number of palliative care specialists, presents considerable challenges for health service planners.^{6,7}

This discussion document reviews the evidence pertaining to model-of-care development, the policy environment and existing rural palliative care models in operation in rural Australia. This review was conducted to inform the development

What is known about the topic?

The provision of palliative care in rural and remote areas presents significant service delivery challenges, but it is not known how best to address these challenges.

What does this paper add?

This paper explores issues related to palliative care service delivery in a rapidly expanding regional coastal community. The paper outlines a population-based planning strategy to enhance capacity.

What are the implications for practitioners?

The authors propose the development of a palliative care service that builds upon the existing specialist service with greater involvement of generalist providers and ensures service development and delivery is explicitly linked to consumer needs. ♦

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of a sustainable model of palliative care delivery for the mid-north coast of New South Wales.

Mid-north coast New South Wales

The mid-north coast consists of the Coffs Harbour, Bellingen and Nambucca local government areas (LGA) which now reside within the central network of the recently created North Coast Area Health Service. Although the reorganisation of the area health service boundaries in NSW occurred subsequent to the completion of this need assessment, this does not alter the significance of these findings.⁸

This area has a population of 97 774 people, with the largest concentrated population residing in the Coffs Harbour LGA and the remaining population in smaller coastal townships, which are popular holiday destinations, or in inland farming communities.⁹ Over the past 20 years the area has had the highest population growth in NSW with an annual rate of 2.3%, primarily due to the internal migration of people over 65 years of age.¹⁰⁻¹¹ Many of these people have left behind their family, support and kinship networks with the expectation that services to which they are accustomed will be readily available in their new regional community.¹² A significant number of residents are of lower socio-economic status and are welfare recipients.^{9,13-14} There is a poor transport infrastructure in the area and limited access to community-based aged care-related services.^{13,15} A workforce shortage of general practitioners, specialists and nurses has been noted.^{9,15} Significantly, the area has a large Indigenous population, representing about 3.2% of the local population, compared with 1.9% for NSW. An additional feature of this area is also the presence of a well established Punjabi community.¹⁶

The Coffs Harbour palliative care service commenced operation in 1984¹³ and is essentially a seven day per week community-based specialist palliative care nursing service that provides direct care with minimal community nursing input. The service has a designated part-time counsellor; trained volunteers; a visiting palliative care physician service; access to hospital-based allied health

staff; a large loan equipment pool; and a bereavement support program. It has strong links with locally based oncology, renal, neurology and cardiology services and clinical experts. There is a satellite palliative care service that operates independently from Macksville Health Campus and services the Nambucca LGA.

Key challenges to palliative care service delivery on the mid-north coast

An extensive review of local epidemiological data and reports^{10,15,17} has identified the following factors as challenging local palliative care delivery.

Population ageing

It is anticipated that the popularity of the mid-north coast as a preferred retirement destination for baby boomers will continue, with 35% of the area's population growth expected to be in the over 65 age group by 2031,¹⁰ with anticipation that this area will have the highest proportion of over-65-year-olds in NSW. Of significance, mid-way through this period the number of deaths is expected to exceed the number of births.¹⁰

As increased age is associated with the onset of chronic and potentially life-limiting illnesses, for many retirees their new lifestyle is accompanied by disability. As many people have minimal or no local family support and lack the funds to purchase additional private health care services¹⁵ they are dependent upon community-based services which are already under significant pressure.

Increased demand for services

This unprecedented migration of people over 65 years has significant implications for aged and palliative care services. Although the number of specialist palliative care workers has increased from 1.5 full-time equivalents in 1984 to the current level of 6.5 full-time equivalents, the service now covers a significantly larger geographic area of three LGAs. During the same period, the number of patients referred to the community-based service has increased from 50 referrals per year in 1984 to 240 referrals in 2003,

with about 40% of these palliative care patients now electing to be cared for at home. It is estimated that on any given day, over 110 palliative care patients are registered with the local palliative care services. Given this continued growth, the specialist palliative care team is unable to meet this level of need within the current model of care.

It is now widely accepted that palliative care has a role to play at various stages of a person's disease, and this is reflected in most contemporary definitions.^{1,2,5} Symptom control has been identified as the primary reason for admission to palliative care services in Australia, followed by terminal care.¹⁸ Although adults with cancer make up 85%–90% of the palliative care patient profile in Australia, people with non-malignant progressive disorders also require access to palliative care.^{1,2,19} Advances in therapeutic approaches mean that the palliative phase of both malignant and non-malignant diseases is often longer, and determining the terminal phase for some life-limiting diseases is often difficult to predict due to the absence of reliable prognostic indicators.²⁰ As a consequence of these prolonged illness trajectories community-based services are frequently required to provide care for extended periods of time.^{21,22}

Absence of palliative care beds

As there are no designated beds on the mid-north coast, palliative care patients requiring inpatient care are admitted to one of five local hospitals. A recent planning framework has estimated that 6.7 designated palliative care beds are required for this population.⁵

Increased demand from residential aged care facilities

The high service demands on the palliative care service mean that there have been very limited opportunities to provide input, education and consultancy to the 12 local residential aged care facilities, which are collectively providing care to 397 high- and 470 low-level care residents. Locally, the majority of high-level care beds are occupied by the chronically unwell and frail

aged and in many respects function as hospices.²³ Yet, until recently, the palliative care needs of these facilities have largely been invisible,^{18,24,25} with only a little over half (54.55%) of palliative care providers in Australia having engaged in educational initiatives with this sector.¹⁸ This is despite the reality that aged care providers care for a significant number of people at the end of life, with local data revealing that 80% of all resident deaths were managed on site.²⁶

Workforce-related issues

Despite the NSW mid-north coast being an idyllic rural location, it has become increasingly difficult to attract skilled medical and nursing workforce to the area. The local Division of General Practice conservatively estimates that the area is 12 GPs short of the recommended number, and workload issues make it difficult for many GPs to respond in a timely manner to patients in need.²⁷ There is limited coordination of GP input and participation in the management of patients receiving palliative care, regardless of care setting. Time constraints and the lack of financial reward are the reasons often quoted by local GPs for not conducting home visits, including regular visits to residential aged care facilities.²³

Facilitators to service delivery

In spite of the challenges listed above, several local factors exist to drive the improvement of palliative care service delivery.

Health facilities and services

There are four public hospitals with at least one facility in each LGA and an 80 bed private hospital located in Coffs Harbour. The area's major referral hospital is also located in Coffs Harbour and provides a broad range of supporting specialties consistent with a Level 5 Base Hospital in NSW. A purpose built Cancer Care Centre with a radiotherapy unit and one linear accelerator has recently been commissioned. There has been a significant expansion in the

number of aged care beds with the numbers for the area now within established planning ratios to meet anticipated local need.^{15,28}

Information systems and data collection

Throughout Australia there is disparity in palliative care data collection, with services using a variety of definitions and collecting different data items. As a consequence there is an inadequate description of service provision and consumer needs.¹⁸ The Australian National Sub-Acute and Non-Acute Casemix Classification Study identified a five-phase classification system for palliative care that is independent of the setting and is sensitive to changes in the goal of care.^{2,3,29} This data collection system has recently been implemented locally, which will make it easier to accurately determine and map local palliative care service need.

Community participation

The local palliative care service benefits from significant local community support, which has ensured the acquisition of a large loan equipment pool through donated funds. The palliative care volunteers consist of interested local community members, and there is a voluntary organisation that assists patients requiring out-of-area medical treatment and provides accommodation and support for families at Coffs Harbour Hospital. A branch of the National Association of Loss and Grief has recently been established and there has been support of an aged care academic position by a local credit union.

Expansion of locally available education services

A tertiary education facility has been established at Coffs Harbour with the first intake of local bachelor of nursing students commencing in 2004. The College of Technical and Further Education (TAFE) conducts enrolled nursing and care assistants courses, including a designated palliative care course. A medical student program with an onsite campus located at the Base Hospital has recently been established. It is anticipated that these locally based initiatives will improve

workforce shortages in the area and adequately equip health care providers to work within regional communities.³⁰

Rural palliative care program

The Mid North Coast Division of General Practice is one of eight rural divisions in Australia that has been funded as part of the National Rural Palliative Care Program from 2004 to 2006. This program aims to strengthen local partnerships to improve the coordination and delivery of local palliative care services.³¹ The local project has adopted a collaborative approach to engage local health care organisations and providers in the delivery of palliative care across the care continuum.

Methods

CINAHL, PubMed and MEDLINE electronic databases were searched using keywords of "models*", "rural*", "palliative care models" and "service delivery models" to identify relevant literature published in the English language to inform this review. Reference lists of retrieved articles were searched for additional literature. Relevant journals held locally were hand searched for pertinent articles, and the Internet was searched using the Google search engine for related organisations or electronic documents using the keywords listed previously. Relevant palliative care policy was identified from a search of Commonwealth, state and Area Health Service and Palliative Care Australia websites. The eclectic and heterogeneous material for this review precluded the use of a systematic review methodology.

Findings

Positive policy environment

A number of significant policy frameworks shape the delivery of palliative care services within Australia. The National Palliative Care Strategy provides a guide for the development and implementation of palliative care policies, strategies and services to improve the quality,

range and coverage of palliative care.¹ A total of \$201.2 million has been allocated to palliative care throughout the 5 years of the Australian Health Care Agreement (2003–2008), with one of the priorities being to increase the range and reach of palliative care services.¹ This policy is responsive to perceived deficits and inequity of access. As part of this commitment the Australian Government has endorsed policy guidelines aimed at enhancing the delivery of a palliative approach to care for older people in residential aged care facilities.²⁴

The NSW Palliative Care Framework identifies key elements to promote access, continuity of care and standard levels of care, regardless of the service location.² The majority of funding for palliative care is derived from the state government in accordance with the resource distribution formula, and it is the responsibility of each area health service to determine how palliative care is provided locally. In 2001, all area health services were requested to prepare an Area Palliative Care Services Plan in accordance with accepted palliative care frameworks and standards,^{2,18} but little is known about whether these plans have been actioned.

Since 2003, Palliative Care Australia has released three significant policy documents which collectively provide guidance for the development of palliative care services at a national, state, regional and local level. A *guide to palliative care service development: a population based approach* provides a framework to ensure the equitable access to palliative care for all Australians which is based on the efficient, effective and ethical use of resources.³² *Palliative care service provision in Australia — a planning guide*⁵ provides a formula for determining the human resources needed for the provision of specialist palliative care services in Australia. The *Standards for providing quality palliative care for all Australians* is an integral tool for the planning and delivery of a coordinated network approach to palliative care provided by both primary and specialist service providers.⁴ Collectively these platform policy documents provide a clear framework and guidance for the

development of palliative care services throughout Australia.

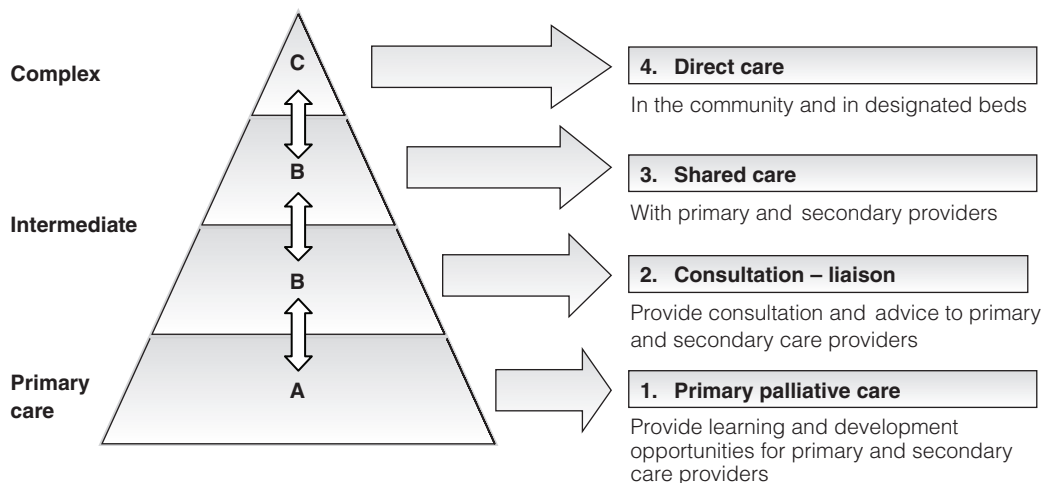
Health care organisation

In Australia, palliative care services have emerged largely as a result of funding initiatives since the 1980s with services operating in outpatient, inpatient and community-based settings, with a combination of public and private providers utilising both specialist and generalist models of care.^{1-3,13,29,33} Some of these services appear to have grown historically, and not always in response to local population needs.³² To date, minimal systematic investigation has been undertaken on palliative care delivery models.²

A recent review of palliative care services plans in NSW identified diversity among delivery models, characteristics, target groups, relationships with other services, available resources and organisational structures.¹⁸ This study was unable to identify “models of excellence” in prescribed settings and circumstances because of a lack of a uniform approach to the definition and collection of both quantitative and qualitative data by palliative care services.¹⁸ Similar difficulties were encountered by researchers in a systematic review of the literature examining organisation of palliative care for rural populations. These authors identified 26 studies suitable for inclusion in the review, but the diversity and lack of research methods in the reports made it difficult to analyse the models.³⁴

The majority of service delivery models in Australia are specialist services delivering palliative care to a small subset of the population.³² Given that not all people living with a life-limiting illness need, or desire, the same level and access to specialist palliative care services, access to these scarce specialist services should be based on the level of need.³² A recent review of palliative care service delivery in Tasmania determined that formalised clinical partnerships and role delineation between specialist and generalist services was required for effective and sustainable palliative care delivery.³⁵ This model expands upon a population-based approach by

I Specialist palliative care service delivery based on a population-based approach with four delineated levels of care



Adapted from A guide to palliative care service development: a population based approach³² (page 13) and Palliative care in Tasmania. current situation and future directions³⁵ (page 40).

integrating four delineated levels of specialist palliative care input, with clearly defined roles and responsibilities for all providers and detailed criteria for each level of service provision³⁵(Box 1).

Patient and family

Within the palliative care target population there are potentially three broad sub-groups of palliative care patients whose acuity and complexity will define the level of specialist palliative care input required (Box 1).³² The vast majority (Group A) of needs will be adequately met by primary care providers,³² including input from family, community nurses, GP and medical specialist services such as oncology, neurology and cardiology. Patients who experience occasional or sporadic exacerbations of physical, psychological or social problems (Group B) will require expert consultation from a specialist palliative care service, with their ongoing care provided by primary care.³² Within this group there is a subgroup of patients with more intense care needs that will be best served by a shared-care arrangement between a primary provider and

specialist palliative care service. The smallest sub-group of palliative care patients (Group C) will have complex care needs that haven't responded to established care protocols and require ongoing direct involvement from a specialist palliative care service.³² This service will be required to work in partnership with the primary care providers to develop and implement an appropriate care plan.³² It is expected that patient needs will change over time, requiring them to move between the different levels of care.³²

Summary

A systematic needs assessment should guide the development of local palliative care services in accordance with accepted policy and standards.^{1,2,5} Although various modes of service delivery have been identified^{13,18,29,32} there is limited literature about the process of planning, implementing and evaluating palliative care service delivery, particularly in rural Australia.^{29,34} Several studies have endeavoured to define a service delivery model for rural palliative care but encountered difficulties. The evidence suggests that a population-based

approach to palliative care service development is the most appropriate framework for the delivery of effective and efficient palliative care.³²

Palliative care for mid-north coast NSW

It is recommended that the preferred model of palliative care for mid-north coast NSW be founded on a population-based approach with defined levels of care and role delineation. Wagner's Chronic Care Model³⁶ (Box 2) has been adapted to identify strategic initiatives to assist with the reform process and ultimately enhance the delivery of palliative care.

Positive policy environment

There is a positive policy environment in Australia for a population-based approach to palliative care service delivery, articulated through key policy documents, leadership and funding initia-

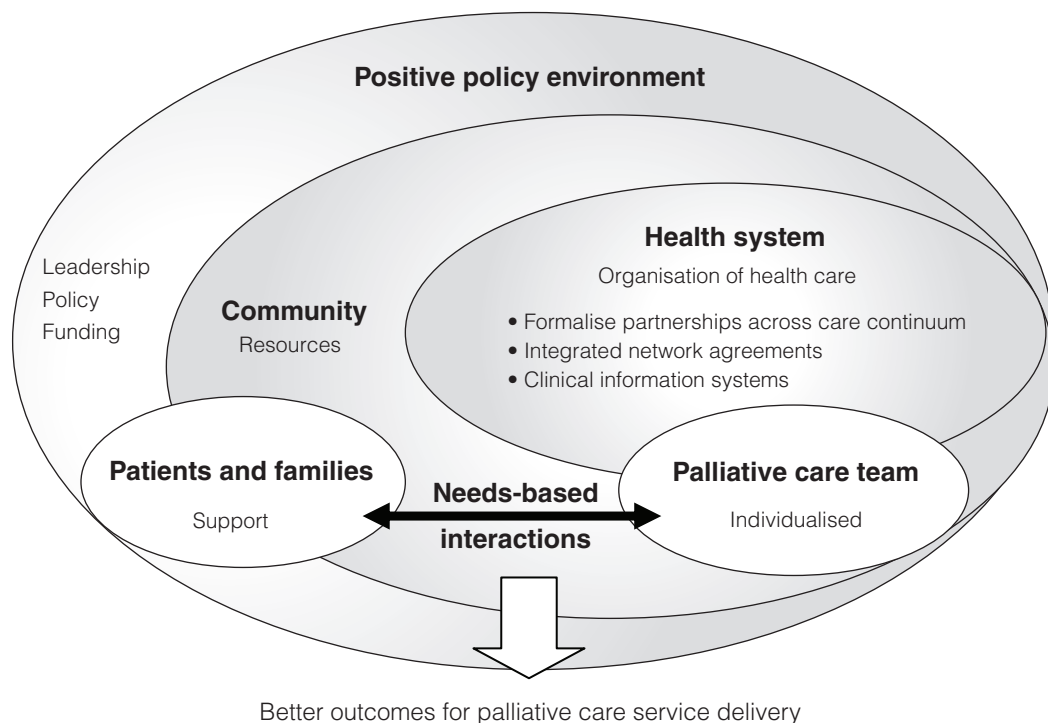
tives, as previously described.^{1,2,4,5,32} The Australian Government has also developed several funding and policy initiatives in the aged care sector that aim to enhance care provided to older people, including the delivery of a palliative approach to care.^{24,38}

There has also been policy change to develop Medical Benefit Schedule items to remunerate GPs for the central role they play in the delivery of primary health care.³⁹ These funding items provide an opportunity to more effectively engage GPs and reward them for their contribution to palliative care planning. Collectively, these policy, funding and leadership initiatives are acting as significant drivers for change.

Health systems

An integrated network palliative care system with delineated levels of care would provide the foundation for care that was developed and delivered

2 Chronic care model as applied to palliative care



Adapted from Wagner.³⁶ See also Davidson et al.³⁷

in accordance with local need and capacity.^{32,35} In this model, the specialist palliative care team structure would be retained, but these workers would deliver care according to the patient's level of need and perform the roles outlined in Box 1. The expertise of the specialist palliative care service will be used more effectively to: develop and implement learning and development opportunities for generalist providers; provide a consultancy and liaison service; contribute to the shared care of patients with more intense needs; and provide direct care to patients who have the most complex palliative care needs in the community and acute care setting.^{32,35}

Community health staff, GPs, residential aged care providers, private nursing services, acute care providers in both the public and private setting, and specialist medical and nursing staff will need to be actively engaged as partners in the delivery of palliative care in the network. This requires all health care providers' roles and responsibilities to be clearly defined, with policies and procedures which clearly outline the access and referral criteria.³⁵ Formalised role delineation partnership agreements between specialist and generalist providers will promote coordination of limited resources.³² Integration of resources will help to overcome the diseconomies of scale which might otherwise make discrete services unsustainable and improve local palliative care service delivery.^{35,40}

The formalisation of partnerships across the network provides a platform to explore creative alternatives for better continuity and coordination of local palliative delivery, including initiatives such as: co-funding of service delivery; utilising common palliative care clinical indicators and assessment and management tools; standardised data collection, developing a common language; and the use of end-of-life care pathways by generalist health care providers in all care settings.

Yet, creating the proposed integrated network palliative care system is not without significant challenges. It requires a clear commitment by all involved to actively work towards reorientating a range of services to ensure that the degree of providers' involvement in palliative care delivery is

determined by the patient's intensity of need (Box 1). In this model, generalist providers, particularly community nurses, are required to play a greater role in the delivery of primary palliative care. As community nurses currently have limited involvement in the provision of palliative care in this local area, this group of providers will require support and guidance through the proposed change. Given the potential impact the reorientation of care delivery will have on community nurses' workloads, additional resources need to be allocated.

Capacity building of local services is a key element of establishing an integrated network palliative care system. There will be a need for skill enhancement and diversification, extended roles and new scopes of practice for many health care professionals, particularly those working in acute care services, community nursing and residential aged care,^{3,24} potentially resulting in the creation of palliative care as a sub-specialty within these areas.⁴¹ The development of a palliative care "link nurse" role within local acute care services and residential aged care facilities, supported and mentored by the specialist palliative care team, is a strategy to ensure access to a resources nurse.^{42,43}

Communication strategies for timely sharing of accurate clinical information among relevant health care providers at different locations is critical.³² The use of patient-held records would enable relevant health care information to be shared between the patient and providers. There is scope to explore communication strategies regarding care planning, including the use of technology such as videoconferencing, personal digital assistants, palliative care-specific data software⁴⁴ and web-based clinical information systems.

Palliative care team

In the proposed model, an individualised palliative care team, which in some cases may be "virtual", will be created to meet the needs of each patient and their family. This team can operate in the acute care, community and residential aged care settings and seek the input of the specialist palliative care team as required. Generalist providers, input into multidisciplinary palliative care planning forums will assist in building relation-

ships across local health care systems, reinforce the importance of a team approach and enable knowledge sharing that is immediately relevant.⁴⁵ While enhanced primary care (EPC) items reimburse general practitioners for their contribution to the care planning process.³⁹

Community resources

The target population for palliative care service delivery will be people with a life-limiting illness and caregivers residing in the mid-north coast. Access to the specialist palliative care team will be based on their intensity of need.³² Given the level of community support that currently exists for the local palliative care service it is important that the proposed model be disseminated to the community and processes put in place to enable resources to be shared throughout the local palliative care system.

Conclusions and implications for clinical service delivery

The adoption of a population approach to planning palliative care service delivery on the mid-north coast of NSW is required to ensure more effective utilisation of scarce resources. An integrated palliative care network with delineated levels of care would provide the foundation for a local palliative care system to develop and deliver palliative care based on local need and capacity. Establishment of palliative care partnerships, formalising network agreements, role delineation between providers and referral and entry criteria are required, along with appropriate resources allocation. A systematic evaluation is needed and may assist in developing a model of care that is able to be used in other regions.

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Competing interests

The authors declare that they have no competing interests.

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