

SUBMISSION TO

THE SENATE COMMUNITY AFFAIRS COMMITTEES Inquiry into Palliative Care in Australia

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Abstract

This submission to the Senate Community Affairs Committee Inquiry into Palliative Care in Australia seeks to address parts a (i), b, d and e (i) and (ii) of the terms of reference namely,

(a) The factors influencing access to and choice of appropriate palliative care that meets the needs of the population, including:

(i) People living in rural and regional areas,

(b) The funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent;

(d) The effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities;

(e) The composition of the palliative care workforce, including:

(i) Its ability to meet the needs of the ageing population, and

(ii) The adequacy of workforce education and training arrangements;

The following are recommendations relating to these terms of reference:

- Investigate the utility of establishing small hospices in rural and regional area to meet the increasingly complex care needs of people requiring palliative care.
- Review the current and historical mechanisms for funding palliative care services in rural and regional areas.
- Ensure the provision of future funding incorporates the need for a multidisciplinary approach to palliative care.
- Facilitate or expand access to Medical Specialist Outreach Program (MSOP) funding for Palliative Care Physicians in rural and regional areas.
- Investigate the beneficial effect of extending Medicare reimbursement to General Practitioners for palliative care related services beyond the items currently available.
- Review and update previous and current methods of providing commonwealth funds for specialised palliative care in rural and regional areas including establishing a binary funding mechanism.
- Incorporate the proportion of end of life care spent at home (as opposed to in hospital or in care) as a cardinal measure of successful palliative care as opposed to the percentage of people who die at home.
- Review the availability of neuropathic pain medications available under the Pharmaceutical Benefits Scheme for people receiving palliative care.

- Continue funding schemes that promote the use of the palliative approach such as the Program of Experience in the Palliative Approach (PEPA).

Enhance the provision of post graduate scholarships for health professionals undertaking studies in specialist palliative care.

Introduction

The Bega Valley Shire has a population of approximately 30 060 and is located in south eastern New South Wales (NSW). The area is 6 052 square kilometers and is comprised of coast, bush and farm land which extends from Wallaga Lake (Bermagui) in the north, to the Victorian border in the south (Bega Valley Shire Council, retrieved from <http://www.begavalley.nsw.gov.au/About/About.htm>).

As an arm of the Southern Local Health District (LHD) it provides health services to the residents and visitors of the Bega Valley area and is comprised of two general district hospitals located at Bega and Pambula and three Community Health Centres situated at Bega, Pambula and Eden. A variety of nursing and allied health professionals are employed by the community health service. These professionals provide care to both hospital inpatients and community outpatients via centre based clinics and home visiting. The majority of staff are employed on a part time basis.

A Registered Nurse is employed in a specialist nursing role on a part time basis as the Palliative Care Registered Nurse (PCRN) working collaboratively with community nurses, other members of the multidisciplinary team, local General Practitioners and hospital staff. The PCRN has access to a district wide clinical nurse consultant and specialist palliative physicians located intrastate and interstate (Canberra). Whilst the majority of patients referred to the PCRN are people living with advanced, metastatic and terminal cancer, support and advice is also provided to patients and families who live with other life limiting conditions.

Forecasts predict that between 2006 and 2021 that there will be a greater increase in the number and proportion of people over 65 years of age in the Southern LHD (which includes the Bega Valley area) when compared to other areas in NSW (Cancer Institute NSW, 2011: 13). Furthermore, Southern LHD is predicted to experience the highest increase in cancer incidence and cancer related deaths in NSW largely due to the greater likelihood of developing cancer with increasing age (Cancer Institute NSW, 2011: 4 and 21). There is an expectation that these trends will result in an increase in patients who require both general and specialist palliative care services.

(a) The factors that influence access to and choice of appropriate palliative care that meets the needs of the population, including:

(i) people living in rural and regional areas,

The Bega Valley represents a typical New South Wales rural/regional coastal area that attracts a substantial number of retirees. The area exemplifies the emerging health care trends of an aging population with an escalating need for high quality and effective Palliative Care. Local experience suggests that reliance on a general palliative approach to care for those with an incurable medical condition can be inadequate without ready and reliable access to specialist palliative care assistance and local guidance on the ground.

Previous applications for Medical Specialist Outreach Program (MSOP) funding for a Palliative Care physician to provide a monthly service to the Bega Valley have been unsuccessful.

Enhancement of this funding pool and encouragement to apply for this funding should lead to the establishment of such a service in the future. Concomitant to this is the dearth of palliative care physicians in a position to provide this service given current high demand in their substantive positions. A possible proxy to their physical presence would be their availability to provide support to service providers on the ground via telemedicine link.

The capacity of general medical practitioners to meet the emerging medical needs of the palliative population is often limited due to the workload they face in private practice. This problem is particularly acute when people choose to die at home. If patients have swiftly evolving or deteriorating end of life issues it can also cause significant problems in hospital or residential facilities. When death certification or assessment of life extinct is unavailable in the home, families often contact the local ambulance service which is then obliged to involve the police. Whilst families are usually pre warned of this requirement, it nonetheless causes additional stress under already difficult circumstances. This issue is currently under review in New South Wales.

(b) The funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent.

Primary level palliative care funding for services using a ‘palliative approach’, is essentially provided through a mixture of general funding mechanisms. These include general practice rebates, public hospital and community health budgets, residential care subsidies and community services funding.

Some funding has historically been provided for enhanced primary palliative care services via the commonwealth palliative care program. This previously quarantined funding is inadequate and is unable to meet the present and future palliative care demand. Currently, this funding is used locally to fund the part time Palliative Care Registered Nurse position and provide a weekend generalist community nursing service for people requiring palliative care. Any future enhancement funding would best be directed towards service support aimed at meeting the often complex psychosocial needs of people requiring palliative care. A suitably qualified professional such as a Social Worker, Counsellor or Psychologist could be employed to fulfill this role.

The way in which future funding is determined is best addressed with a mixture of block and an appropriately weighted resource distribution formula. This would guide the distribution of appropriate current and future specialist palliative care services. The flexible application of this type of funding mechanism would allow for the creation and maintenance of minimum palliative care service levels that best meet locally assessed need.

(d) The effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities.

The question as to whether centre based palliative care needs are best met by the current combination of hospital and residential facilities or the establishment of a hospice is of topical interest in many geographical areas and the Bega Valley is no exception to this. Occasionally people who require the services of a hospice travel to the Australian Capital Territory either by

direct admission or via The Canberra Hospital having received disease modifying treatment such as radiotherapy. However, experience has shown that the vast majority of people prefer to remain close to home in the Bega Valley area despite suffering from distressing symptoms that could be better addressed in a hospice environment.

Residential facilities provide a palliative care service to a large number of people who are frail or live with a chronic incurable disease such as chronic heart failure. The quality of this service is unknown but the experience of the local Palliative Care Registered Nurse indicates that the pain assessment and management knowledge base of some staff in local facilities can best be described as rudimentary. This coincides with a scarcity of educational opportunities available at a local level for staff across all sectors wishing to increase the quality of the palliative care they provide. For the foreseeable future the variety of pedagogical experiences necessary to elevate and sustain a rise in palliative care standards will require these experiences to be supplied 'at the coal face' by staff with appropriate skills and educational preparation. In summary, quality palliative care educational preparation for rural generalists cannot be provided by any one stratagem and cannot be adequately achieved by exposure to specialist teams at other sites.

An oft stated goal in palliative care is to offer people the opportunity to die at home or in the home of a family member. The measure of success of any palliative program is frequently assessed by the percentage of people who die at home.

In our opinion this is an unnecessarily limited measure of achievement for rural palliative care. For example, it does not readily incorporate the numbers of people who remain in residential facilities until they die. More importantly, for generalist rural multidisciplinary teams that are unable to provide 24-hour or on-call care, it does not fairly reflect the legitimate outcome of number of days in hospital or care before death (as small as possible being the target). In an era of increasingly complex end of life scenarios and a scarcity of 24 hour in-home care, it can be argued that where a person dies is less important than how long they remain at home (in it's myriad senses) prior to death. In general, this goal is difficult to meet in rural and regional areas for a variety of reasons.

The provision of quality palliative care in the rural context can be directly related to the level of knowledge, experience and availability of the patient's general practitioner. This submission has already addressed factors impacting on palliative care education. With regard to the availability of general practitioners, a retrospective end of life fee structure for general practitioners could be implemented. These fees could reflect the considerable gap that may exist between the time spent leading or assisting with the complex end of life medical needs of a patient and their family and, what is able to be or is eventually claimed currently through Medicare. At present, general practitioners often provide other professionals with a form of remote supervision whereby their reports result in an alteration or adjustment of the medical treatments required at end of life. However, there is currently no direct method for this input to be claimed or adequately recompensed.

Finally, consideration needs to be given to extending the range of pain management medications that are commonly used in palliative care and making these available under the Pharmaceutical Benefits Scheme. This includes, in particular, drugs indicated for the treatment of neuropathic pain such as gabapentin.

(e) The composition of the palliative care workforce, including:

(i) its ability to meet the needs of the ageing population

In the Bega Valley there is an increasing demand for palliative care services with patient's often having to wait a number of weeks to see the Palliative Care Registered Nurse. The bulk of activity is centered on people living in the community and those admitted to hospital. A substantial proportion of these people are aged 65 and over. Little is known about the level of unmet need in the local residential aged care facilities but anecdotal evidence suggests it is significant. There are few workers in the local area who have had or are pursuing specific training in Palliative Care.

Current and predicted increases in demand for palliative care services warrant a corresponding increase in resources in order to meet this demand. This ought to include the development of other specialist palliative care positions such as a Palliative Care Social Worker.

The importance of the interdisciplinary team in palliative care is well acknowledged nationally and internationally (Palliative Care Australia, 2003, p.28; Steinhäuser, Arnold, Olsen, Lindquist, Hays, Wood, Burton, and Tulskey, 2011). For example Social Workers provide psychosocial care, practical support and counselling to patients, their families and other carers and work alongside other health care professionals and support services. The need for this type of support is amplified in rural and regional Australia where patients have no choice but to travel long distances for treatment and investigation. This results in financial hardship associated with travel and accommodation costs. Although programs such as the Isolated Patients Travel And Accommodation Scheme (IPTAAS) can assist with these costs, these subsidies are often inadequate. Regional and rural patients may require additional support and counselling due to these stressors and the isolation associated with undergoing treatment away from usual social supports. Such themes were highlighted in a recent study which examined the needs of rural cancer patients in Australia (Butow, Phillips, White, Underhill, Grimison, Yip and Goldstein, 2011).

(ii) the adequacy of workforce education and training arrangements.

An increase in local specialist Palliative Care funding would facilitate the development of further local training and education opportunities for generalist staff using a palliative approach. The Palliative Care Registered Nurse's workload places education lower on the position's list of priorities. However, experience has shown that when offered, workshops and other activities are well patronized by enthusiastic staff including nurses, allied health professionals and local doctors.

Training in a palliative care approach is offered regularly in metropolitan areas however, the distance from the Bega Valley and costs associated with travel, accommodation and course registration hinder attendance by rural and regional staff. Also, most Southern LHN staff members are employed on a part time basis making it more difficult to prioritize education and training over busy client caseloads and their home and family commitments. These deterrents apply to a wide variety of education and support opportunities that are often taken for granted by metropolitan colleagues, such as participation in peak group activities and meetings and clinical supervision.

Government assistance in the form of rural scholarships can go a long way in overcoming some of these challenges and a continuation of the current schemes is essential. However, access to such

support is not guaranteed as recently demonstrated when a local colleague's application to attend training was unsuccessful despite their enrollment in a post graduate palliative care course through Flinders University. On a more positive note, The Program of Experience in the Palliative Approach (PEPA) has provided several local staff with exposure to multidisciplinary palliative teams and the continuation of this project will be vital to the propagation of quality palliative care into the future.

Conclusion

In order to address Australia's ageing population and current and future increasing trends for palliative care services in rural and regional Australia, including the Bega Valley area, a number of areas require review, expansion and development. For example, current government initiatives such as Medicare and the Pharmaceutical Benefit Scheme (PBS) should be reviewed and expanded to further acknowledge the needs of those living with a life limiting illness who seek specialist palliative care services. Also, the way in which future funding is determined should be reviewed to ensure that it meet the needs of rural and regional local populations. This includes exploring the viability of establishing smaller hospices in rural and regional areas. Finally, funding available for workforce education, training and the establishment of new positions must be facilitated and enhanced, and reflect a multidisciplinary approach to palliative care.

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