The Royal Australasian
College of Physicians

Senate Inquiry into Palliative Care in Australia

Submission by The Royal Australasian College of Physicians

February 2012

Executive Summary

The Royal Australasian College of Physicians (RACP) welcomes the opportunity to make a submission to the Senate Community Affairs References Committee Inquiry into Palliative Care in Australia. The RACP considers that the Inquiry is highly topical given the growing demand for palliative care as a result of the continuing burden of cancer, the ageing of the population and the rise in comorbid chronic disease.

The RACP understands that other organisations, such as the Australian and New Zealand Society of Palliative Medicine (ANZSPM) and Palliative Care Australia are preparing submissions to the Inquiry that represent a comprehensive response to the Senate Committee's Terms of Reference. The RACP submission is therefore focused on the specific Terms of Reference:

(b) the funding arrangements for palliative care provision;

(d) the effectiveness of a range of palliative care arrangements;

(e) the composition of the palliative care workforce; and

(g) advance care planning.

The RACP accepts the World Health Organization's definition of palliative care as "*an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*" [1]

The RACP understands that the provision of palliative care in Australia is highly variable, reflecting the diversity of patient need. Cancer remains the leading cause of disease burden in Australia,[2] and patients with advanced cancer continue to account for the vast majority of referrals to specialist palliative care, and palliative care hospital separations. However, the ageing of the population and the rise in chronic disease is impacting on the profile of patients who require palliative care services. Patients who receive or would benefit from palliative care are increasingly experiencing chronic, progressive illness, including dementia, with varied symptom presentations, prognosis and disease trajectories.

As a result, the palliative care services that are necessary to address patient need may vary over time and with the patient themselves. Specialist palliative care may be required as medical need increases, such as symptom severity, or where there is added complexity arising from the presence of multiple comorbidities. At other times, a palliative approach administered by the patient's carer, nurse or general practitioner may be more appropriate. The care provided at the time of diagnosis may also differ from the care provided at the very end, or terminal, stage of the illness. The location for the delivery of palliative care may range from an acute hospital, sub-acute hospital, hospice, outpatient clinic or in the community, such as in the patient's home or in a residential aged care facility (RACF), depending on patient need, the stage and presentation of their illness or the capacity within specific facilities.

Palliative care services across Australia need to reflect this heterogeneity and be able to cater to the diverse needs of patients, their carers and families over both time and space. In particular, specialist care, including specialist palliative and specialist medical, must be available to patients in their preferred setting and must be accessible to vulnerable groups including people living in rural and remote areas, Aboriginal and Torres Strait Islander peoples and older people living in RACFs. Continuity of care and an integrated multidisciplinary team approach is critical to providing high quality palliative care over the duration of the patient's illness that maximises quality of life. The RACP recognises the fundamental role that funding arrangements, workforce capacity, including education and training, and advance care planning plays in ensuring that patients can access the care they need, when they need it and in the place they need it.

Recommendations

The Australian Government should ensure that:

1. The coverage and mix of palliative care services across Australia meets the diverse needs of the population.
2. Palliative care services are properly established and funded based on comprehensive, national data and evidence as to local population needs.
3. Palliative care services are transparently funded and that the funding arrangements facilitate the delivery of care in the setting that is most appropriate for the patient, which may include in their own home and in residential aged care facilities.
4. Specialist palliative care is available and accessible to patients with complex care needs in the location that best suits their needs and preferences.
5. The palliative care workforce is well trained and educated, with capacity to meet the current and future needs of patients with a life limiting illness.
6. Advance care planning is an important tool but should only be one aspect of a comprehensive palliative care strategy.

(b) Funding arrangements for palliative care provision

Funding arrangements for palliative care vary according to what service is being provided (public or private) and where it is being provided (in the hospital, in the clinic or in the community). There is considerable variability across the States and Territories as to how inpatient and community based services are funded and how funding is allocated.[3]

As a result, palliative care services have often been funded on an ad hoc basis with the availability of appropriate palliative care services depending on where the patient is located. The current funding arrangements for specialist palliative care services vary significantly between services, even within one city, risking inequality of care across services.

One of the main reasons for this has been the lack of robust data. Currently there is no comprehensive data collection on community-based palliative care services in Australia.[4] In addition, different levels of services such as outpatient services, day hospice and community palliative care services are grouped without separation, weighting or costings. The lack of differentiation in data collection does not give effective weighting to services. For example, consultation services activity data has only being collected in Victoria over the past 12 months but the meaning of the data is still unclear and issues unable to be reported.

Funding for palliative care services must be equitable and transparent to result in sufficient coverage and mix of palliative care services that can meet the current and future needs of the population. For this to be the case, funding must be based on data that identifies, classifies and costs palliative care patients.[5]

In addition, funding arrangements for palliative care must be suitably flexible so as to encourage innovative service delivery, particularly to respond to vulnerable populations with specific care needs such as older people with dementia living in RACFs. Funding arrangements must encourage the delivery of palliative care services in the location that best reflects patient need and patient choice.

National Health Reform and Activity Based Funding

The National Health Reform agreement will change funding arrangements for palliative care. Increased funding from the Federal Government to the States and Territories has already resulted in increased sub-acute palliative care beds.

An additional aspect to National Health Reform, Activity Based Funding (ABF), will significantly impact on the funding of palliative care. The RACP supports new models of funding in the health sector to encourage enhanced transparency, efficiency of funding, autonomy and patient-centred service delivery and anticipates a cautious approach to the implementation of ABF to the provision of palliative care servces.

Newly developed health care funding and purchasing arrangements need to be able to shift care from acute inpatient-based services to subacute and community palliative care services. ABF needs to be firmly based on validated palliative care outcome measures that are nationally benchmarked, for example, through the Australian Institute of Health and Welfare's National Palliative Care Performance Indicators.[6]

The application of ABF may be complex in specialist palliative care services given the diversity of services models that already exist. Services may only cover inpatient consultations, community care, hospice care, or any combination of the above, and may exist attached to acute or sub-acute hospitals, or as stand-alone services.

The RACP supports the Independent Hospital Pricing Authority strategy that interim consultancy-liaison services and community outreach specialist services will need to be block grant funded until validated evidence based outcome measures of activity can be clearly defined. This will allow for increased high quality out-of-hospital care to occur.

(d) The effectiveness of a range of palliative care arrangements

The RACP recognises the increasing demand for palliative care across Australia as a result of the ageing population, the rise in chronic disease and the ongoing burden of cancer. Palliative care hospital separations have increased by 56 per cent over a ten year period to 2008-9, and the proportion of hospital deaths with palliative care involvement has increased from 21 to 34 per cent.[7] There has been a particular rise in demand for palliative care for non-malignant conditions, including those with complex comorbidity, cognitive impairment, such as dementia, and organ failure.

The provision of palliative care for people with life-limiting illness may involve generalist, specialist and consultative services delivered across settings including acute, subacute, primary and ambulatory care, depending on patient need and the stage of the patient's illness. Specialist medical services are not just limited to a palliative medicine specialist,[8] but may also involve geriatricians, oncologists, cardiologists, respiratory physicians and general physicians.

The RACP is especially concerned that patients who require specialist medical care and specialist palliative care can access these services in the setting that is most appropriate to their needs and preferences. The RACP notes that almost two-thirds of patients with a life-limiting illness do not receive specialist palliative care.[9] Although not all patients with life-limiting illness require specialist palliative care, the RACP considers that there are still a significant number of patients who would benefit from specialist care but are unable to access it. These patients include vulnerable groups such as people living in rural and remote areas, Aboriginal and Torres Strait Islander peoples and older people living in RACFs.

Specialist care in the community

The RACP notes that many people at the end of life, particularly those with non-malignant conditions, receive little or no care in hospitals, and their primary site of care is in the community or in RACFs. Their care might be delivered by doctors, nurses, families and carers, with or without the assistance of specialist palliative care services.

Given the limited number of hospital beds and the wishes of many patients to receive end-of-life care outside of the hospital, specialist medical and palliative care should be available in primary and ambulatory settings. Ensuring that specialist medical care is available and accessible in primary and ambulatory settings will allow for changes in patient needs, especially increased acuity, to be identified and responded to early to keep patients out of hospital.

Physicians have a role to play in coordinating care across the specialist medical care needs of the patient. As such, specialist physicians must be well-integrated members of the community multidisciplinary team, and shared care model of specialist and primary care is preferable. Medicare Locals and GP Super Clinics may be one way to facilitate this. Specialist input into National Health Reforms as they are developed and implemented is imperative.

Community outreach services for palliative care need to be based on 24 hour coverage and shared care arrangements to allow for adequately supported end of life care at home. Cost drivers to promote quality and appropriate referral for subacute care, especially in a defined end of life care population, will also need to be carefully considered and included as part of the cost efficient purchasing processes adopted by managers in the jurisdictions.

Palliative care for older people

The palliative care model has mostly developed in response to cancer, which has a relatively clear acute trajectory. [10] Older people, however, often experience a slower, more haphazard decline often as a result of frailty combined with complex, comorbid disease including dementia, which is now recognised as a life-limiting illness.

Older people with dementia make up over 50 per cent of residents of aged care facilities.[11] For most of these patients, a palliative approach delivered by a well-trained and educated generalist team will be sufficient to meet their needs. For others, particularly those with a comorbidity that adds further complexity to their health condition, specialist palliative care will be required. Unfortunately, RACFs often experience difficulty accessing specialist palliative care services resulting in avoidable admission to Emergency Departments and public hospitals because the RACFs are unable to adequately respond to the patient’s increased acuity. In 2008-09, almost half of all palliative care separations in Australian hospitals were for patients aged 75 years and over.[12]

It is well-recognised that acute, public hospitals are often poor care locations for frail, older people, and particularly for those with dementia. As such, there is need to enhance the delivery of specialist palliative care services into RACFs.

There are a number of exceptional local initiatives operating to link specialist palliative care services into RACFs. Funding for these initiatives should be facilitated and promoted to enhance consistency of access across Australia. In particular, the Aged Care Funding Instrument should be revised to reflect the addition funding required to provide comprehensive palliative care to residents. Funding to provide palliative care, including specialist palliative care, in RACFs should be encouraged to ensure that vulnerable older people, particularly those with dementia and cognitive impairment, are able to receive care in place without being admitted to hospital.

(e) Palliative care workforce

The palliative care workforce is a mixture between specialist physicians, general physicians, general practitioners, nurses and other carers. There is an important role for the specialist physician to coordinate this activity. For example, the Mildura Specialist Palliative Care Clinic demonstrates a model whereby the palliative medicine specialist leads a palliative care outpatient clinic and provides teleconference support for a specialist palliative care nurse-led clinic, as well as undertaking education and liaising with GPs.[13]

The Australian New Zealand Society of Palliative Medicine (ANZSPM) states that the minimum number of palliative medicine specialists required for a reasonable provision of service is one full time equivalent per 100,000 population. This is based on the existing referral patterns and dominated by the treatment of cancer patients.[14] The RACP estimates that the current supply of palliative medicine specialists is approximately half of this recommended ratio.

As the population ages and more patients present with increasingly complex combinations of conditions, this ratio will need to rise. Palliative Care Australia suggests that a ratio of 1.5 palliative medicine specialists per 100,000 population may be more appropriate. This also accounts for the looming retirement of a significant proportion of the workforce given the age profile of palliative medicine specialists.[15]

There is thus demonstrated need to retain existing palliative medicine specialists and to attract more trainees to the specialty.

Education and training

The education and training of palliative care specialists is paramount, as is ensuring that other members of the multidisciplinary team, including GPs, nurses and other specialist physicians such as geriatricians, are appropriately equipped to respond to the palliative care needs of the Australian population now and into the future.

Currently, advanced specialist training for palliative medicine specialists requires trainees to undertake their core training at an accredited site under the supervision of two accredited specialist physicians. This requirement largely limits the sites at which potential trainees can undertake their training primarily to large urban hospitals. This affects not only on the number of trainees entering the specialty, but also the distribution of those trainees, particularly for regional and rural areas as trainees may be more likely to seek jobs in those main centres.

The RACP recognises important issues such as the capacity of supervisors to train advanced trainees in rural areas, as well as increasing options for training in rural areas. The RACP is engaged with the health care workforce reforms by Federal, State and Territory governments which aim to improve service delivery to rural areas. Additionally, the distribution of advanced specialist training sites is becoming increasingly diversified with programs such as the Federal Government's Special Training Program, which helps to accredit sites beyond traditional urban teaching hospitals.

There are also increasing opportunities for innovative education and training programs through advancing telehealth and eHealth initiatives. There is potential for remote supervision to allow trainees to undertake their advanced specialist programs outside of the large urban centres, and expand services to rural and remote communities.

However, whilst attracting and training palliative medicine specialists is important, the requirements to complete training must not be compromised. A careful balance between workforce, training requirements, supervision, and location must be reached to ensure the highest quality of care at the end of life.

Dual-training and cross-specialisation

As the organisation responsible for training and educating specialist physicians, the RACP is especially interested in opportunities for cross-specialisation. That is, opportunities for medical specialists who are involved in providing care to patients with a life-limiting illness to upskill in palliative medicine. Likewise there may be opportunities for palliative medicine specialists to upskill in geriatric medicine in recognition of the specific needs of older people with a life-limiting illness, who may also have significant cognitive impairment and/or a diagnosis of dementia.

The RACP is currently working on a proposed model of dual-trained physicians in response to rising rates of chronic, comorbid disease. The basis of the model is general physician training with further training in a specialty related to chronic disease, such as cancer diabetes or asthma. The holistic nature of general medicine gives the physician a broad range of skills to manage multisystem disease. The further training provides expertise in a narrower specialty area such as oncology, endocrinology or respiratory medicine.

The model intends to be based on local needs with the further specialised expertise of dual-trained physicians being directed to communities with high rates of certain chronic disease.

At this stage the model is directed towards regional and rural areas where narrow forms of specialisation are not practical in less populated areas. It is not realistic or cost-effective to expect every speciality to be located in every regional and rural community.

This model may be a useful template for developing new models to expand the scope of practitioners in the provision of specialist palliative care, particularly in regional and rural areas where there is limited health workforce capacity.

(f) Advance care planning

Advance care planning allows people to set out their preferences regarding end-of-life care. Best practice suggests that patients, in consultation with families and their treating health professionals, record how they wish to be treated at the end of their life. This includes their wishes regarding medical intervention as well as the location of their care and their spiritual and family's needs.

Advance care planning applied with the right advice in the right circumstances, can increase patients' 'quality of death'. Early planning and following through on those plans can provide for a peaceful death as well as help in the grieving process for family and loved ones. However, the nature of advance care planning is such that it requires sensitivity, careful consideration of treatment options, and the likelihood of successful treatment, and thus specialised training. As such, advance care planning needs greatly enhanced palliative care consultancy teams within all major hospitals and increased provision of specialist palliative care in the community (at home and in RACFs).

Advance care planning can also play an important role in the planning and delivery of palliative care services. In particular, advance care plans may direct the further development of community palliative care services, specifically those capable of managing patients at the very end or terminal stage of the illness, as research shows that the majority of people have a preference to receive care and die at home if they could choose.[16] Data from the Victorian Department of Health shows that 90 percent of those already diagnosed with a terminal illness would prefer to die at home.[17] This is in contrast with 25 per cent of patients who do actually die at home.[18]

RACP recognises that sometimes people may change their preferences or the situation renders death at home impossible, but similarly many of these cases are preventable. Early planning for end-of-life treatment (last 12 months of life) with the patient's general practitioner, specialist palliative medicine physician or specially trained nurse can assist in providing appropriate care in accordance with patient preferences at the end of life. The Respecting Patient Choices program provides one model of advance care planning from an Australian perspective.[19]

Advance care planning, and the choice to receive palliative care at home, often reflects a desire to avoid hospitalisation, emergency department admission and aggressive, unwanted treatments at the end-of-life. The result of such decision-making is that it has the potential to significantly reduce the costs and burden associated with providing end of life care in the acute hospital setting. A recent study highlighted that "there is extensive use of inpatient services and EDs in the last year of life by people whose deaths are clinically expected. The heavy reliance on the acute-care system does not necessarily reflect the most appropriate use of resources for patients at the end of life."[20]

Although improvements in advance care planning may reduce hospitalisation-related costs and hospitalisations for those at the end of life, it will not and should not replace the need for patients to receive high quality palliative care from the multidisciplinary team. Advance care planning is likely to shift demand for palliative care out of hospital-based services and onto community based practitioners and services. As such, funding and workforce arrangements for palliative care must be able to support this transition.

Advance care planning is increasingly gaining traction as a means to provide patient-centred care and, indirectly, to reduce costs and pressure on the hospital sector but it should not be seen as a complete solution to the complexities of providing care at the end of life. Human beings are unpredictable and liable to change their preferences. Medical and technological advances may render some advance care plans obsolete. Advance care planning may not be possible for a large number of patients whose capacity is comprised as a result of cognitive impairment, such as dementia or psychiatric illness, the advanced stages of the disease process or the treatment that they are receiving. The accessibility and involvement of clinicians with expertise in capacity and cognitive impairment, such as geriatricians and psychiatrists, will be valuable for the multidisciplinary palliative care team.

Palliative care service provision in Australia must reflect the substantial diversity in patient need and in patient choices which will require flexible and innovative funding arrangements and a highly trained multidisciplinary workforce that can provide seamless care across care settings.

About the RACP

The Royal Australasian College of Physicians (the RACP) trains educates and advocates on behalf of more than 13,500 physicians – often referred to as medical specialists – and 5,000 trainees, across Australia and New Zealand. The RACP represents more than 25 medical specialties including paediatrics & child health, cardiology, respiratory medicine, neurology, oncology and public health medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients.

Acknowledgements

The RACP wishes to acknowledge the input of the Fellows of the Australasian Chapter of Palliative Medicine, the Australian and New Zealand Society of Geriatric Medicine and the staff in the Policy & Advocacy Unit.

References

---

[1] World Health Organisation. Accessed from http://www.who.int/cancer/palliative/definition/en/ on 9 February 2012.

[2] AIHW 2010. Australia's health 2010. Australia's health no. 12. Cat. no. AUS 122. Canberra: AIHW.

[3] Gordon, R., Eagar, K., & Currow, D. (2009). Current funding and financing issues in the Australian hospice and palliative care sector. *Journal of Pain and Symptom Management 38*(1): 68-74.

[4] AIHW. Palliative Care. Retrieved from www.aihw.gov.au/palliativecare on 2 February 2012.

---

[5] Gordon, R., Eagar, K., & Currow, D. (2009). Current funding and financing issues in the Australian hospice and palliative care sector. *Journal of Pain and Symptom Management 38*(1): 68-74.

[6] Eagar, K., Watters, P., Currow, D.C., Aoun, S.M. & Yates, P. (2010) The Australian Palliative Care Outcomes Collaboration (PCOC) – Measuring the quality and outcomes of palliative care on a routine basis. *Australian Health Review 34*(2): 186–192.

[7] AIHW 2011. Trends in palliative care in Australian Hospitals. Cat. No. HWI 112. Canberra: AIHW.

[8] For the purposes of this submission, palliative medicine specialists refer to medical practitioners who are Fellows of the Royal Australasian College of Physicians (FRACP) and/or Fellows of the Australasian Chapter of Palliative Medicine (FAChPM).

[9] Mitchell, G., Johnson, C., Thomas, K. & Murray, S. (2010). Palliative care beyond that for cancer in Australia. *Medical Journal of Australia 193*(2): 124-126.

[10] Mitchell, G., Johnson, C., Thomas, K. & Murray, S. (2010). Palliative care beyond that for cancer in Australia. *Medical Journal of Australia 193*(2): 124-126.

[11] United Nations Economic and Social Commission for Asia and the Pacific, Regional Survey on Ageing 2011, Australia: 36.

[12] AIHW 2011. Trends in palliative care in Australian Hospitals. Cat. No. HWI 112. Canberra: AIHW.

[13] Victorian Government Department of Health. (2011). Strengthening palliative care: Policy and strategic directions 2011–2015.

[14] Australian and New Zealand Society of Palliative Medicine. (2009). Position Statement: Benchmark Number of Specialists in Palliative Medicine. Available at: http://www.anzspm.org.au/c/anzspm?a=sendfile&ft=p&fid=1320262367&sid=.

[15] Palliative Care Australia. (2003). Palliative Care Service Provision in Australia: A Planning Guide. Canberra: PCA.

[16] Higginson, I.J., Sen-Gupta, G.J.A. (2000). Place of Care in Advanced Cancer: A Qualitative Systemic Literature Review of Patient Preferences. *Journal of Palliative Medicine 3*(3): 297.

[17] Victorian Government Department of Health. (2010). Palliative Care in Victoria: Orientation Presentation".

[18] Department of Health (2010). "Palliative Care in Victoria: Orientation Presentation".

[19] http://www.respectingpatientchoices.org.au/

[20] Rosenwax, L. K., McNamara, B.A., et al. (2011). Hospital and emergency department use in the last year of life: a baseline for future modifications to end-of-life care. *Medical Journal of Australia, 194*(11): 571.