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## End-of-Life care in Australia: Issues and trends

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## Abstract

Over recent years in Australia, the integration of palliative care into health care systems has become more important. The ageing population is one of many reasons for this movement; more significant however, is the increasing realisation that all health professionals require some skill in caring for dying people. To that end then, a number of initiatives have been developed to provide broad-based education and support in a number of areas, but especially for primary health care workers. Using a primary health care framework, this paper explores a range of these developments and makes comment on future challenges of continuing to provide the most appropriate care of the dying.

## Key words

end-of-life-care, primary health care, palliative care

## 1. Introduction

In Australia for a range of reasons, the work to integrate palliative care into health care systems has gathered momentum over recent years. One of the main reasons for this shift is that dying and palliative care is being increasingly recognised and supported as "everybody's business", through emerging primary health care models. This paper describes palliative care developments in relation to the particular context of the Australian health care system and then discusses a range of primary health care approaches to palliative care as they have been applied across the country.

## 2. The Australian health care environment

The population of Australia is 22.5 million, with most living in large cities around the eastern seaboard. The population is expected to grow to 36 million by 2050 (Australian Bureau of Statistics 2012). This growth will create the need for more health services, new investment in health infrastructure and an expanded health workforce.

Australia spends about 9.4% of Gross

Domestic Product on health and the Australian government funds about 44% of total health cost, with the remainder coming from state and local governments, as well as private health insurers. Costs have increased sharply in recent years and are expected to continue growing (Australian Bureau of Statistics 2012). This split in government funding makes for difficult management and coordination of health services in areas like medicines, primary health care, hospitals, community care and aged care.

Like many other developed countries, the ageing population will substantially increase both health care needs and health expenditure. The forecast of the proportion of the population aged over 65 will increase from 14 per cent in 2010 to 23 per cent by 2050 (Australian Bureau of Statistics 2012). Chronic disease as a component of ageing is a large and increasing burden on the health system.

Six hundred thousand Australians are employed in health service occupations, which represent 5.8% of Australia's total workforce (Health Workforce Australia 2007). A workforce

shortage is already placing limitations on the delivery of health care—particularly in regional and rural Australia and this is predicted to not improve for many years. As well as training more health professionals, there will need to be a more effective in skill development and retention of the existing health workforce, which is rapidly ageing. The average age of nurses is 44 years, while more than a third of general practitioners are aged 55 and over. More than a quarter of the whole medical workforce is aged 55 and over (Health Workforce Australia 2007).

In addition, Australia's health care system struggles with a number of internal issues. 'Medicare' is the universal health coverage accessed by the whole population and paid for through taxes. About 45% of Australia's population has private health insurance, but this does not exclude them from the public services. Because healthcare is a mix of public & private systems, the services need to work together. But it also makes access difficult, with varying levels of care and expertise.

Similar to many countries, most health care is offered in population-dense areas. There are problems with access within urban, rural and remote populations. E-Health has provided some assistance with distances and is a developing area. However, very remote areas continue to rely on the Royal Flying Doctor Service, provided by airplane.

Twenty-five percent of Australia's population was born overseas coming from more than 200 different cultural groups (Australian Bureau of Statistics 2012). Immigration has been part of Australia since white settlement in 1788, but this has been especially so, since the end of World War 2. Immigration groups have shifted over time, from European dominance, to countries in the Asian region like China, India, and the Philippines. All these groups have differing attitudes to health and illness requiring consideration. In particular cultural sensitivity is needed to respect the rituals and traditions about

dying and death.

Indigenous people make up about 1/2 million people. They come from many different groups with different languages (about 200) and traditions (Australian Bureau of Statistics 2012). With a shorter life expectancy and a more complex chronic illness profile than western populations, they are traditionally suspicious of western health care. However, there has been significant work to sensitise health services to accommodate the range of needs, in particular in palliative care.

All these issues make for complexity in the delivery of healthcare in Australia and no less for palliative care services.

### 3. Palliative care in Australia

Australian deaths are 143,000 per annum from all causes, which are calculated to be 1 death every 4 minutes (Australian Bureau of Statistics 2012). Of these, it is thought that approximately 100,000 are expected deaths from cancer, heart disease and other neurological or chronic illnesses.

Palliative care has developed as a specialist service over the last 30 years or so, with approximately 145 specialist palliative care services spread across the country. Despite this, developments have perhaps not been in the most coordinated way, which will be discussed further in this article. A major achievement is that services receive significant government funding and thus palliative care is mainly provided free of charge to patients and families. The government also subsidises access to palliative care medicines, ensuring they are cost effective (Stjernswärd et al 2007). Palliative Medicine has been recognised as its own speciality, providing equality with other medical specialisations.

There have been nationally endorsed standards since the early 1990s, providing a consistent framework for all services. The peak body, Palliative Care Australia (PCA), has a number of nationally endorsed guidelines and position statements, in areas like models of care, carers, advance care planning, primary health care, aged

care and euthanasia. There is government funding for educational programs, which will be discussed further below. And there is increasing recognition of the role of carers and volunteers and how they support dying people and their families and carers.

Because palliative care enjoys government funding in Australia, there has been work undertaken to integrate palliative care into mainstream health services. The services now include acute hospital consultant teams; inpatient hospice/palliative care units; home-based care; and many home care services provide consultant team care in nursing homes. There are numbers of independent nurse practitioner roles developing, whereby nurses are able to prescribe and order tests in their own right.

#### 4. Primary health care and palliative care

The World Health Organisation has developed public health guidelines for enabling the integration of palliative care into health care systems (Stjernswärd et al 2007). Since the 1990s, building on these developments, Australia has gradually moved to such a model, especially incorporating primary health care settings, in aspects like building capacity and educating the workforce, establishing quality systems and informing the community (Palliative Care Australia 2012a).

In line with these shifts, over the last 10 years or so there has been recognition that not all dying people require specialist palliative care. Indeed services would not be able to provide care for all dying people because of the ageing population increasing the demand for palliative care. Thus has developed a catch-phrase: 'dying is everybody's business', to signify that dying needs to have a range of many people involved. Concurrent with these developments has been an Australian government commitment to reform and more effectively coordinate all primary health care services, which previously had been the responsibility of State governments.

While there are many examples of palliative care developments in primary health care in a number of countries, Australia leads the way in the significant resources that have been allocated to this area (Duckett and Willcox 2011). All work sits under the National Palliative Care Strategy, a revised version of which was released in 2010 (Australian Government, Department of Health and Ageing 2010). Besides funding the service provision for each State, some funds are kept for national projects, the advantage of which is an increasing acceptance of the national approach to the big issues.

The principles of specialist palliative care have needed to be translated to primary health care environments and this has been undertaken in many settings-the community, aged care and general practice in particular. These changes are aimed at supporting health professionals with general interests in palliative care (Australian Government, Department of Health and Ageing 2006), who incorporate care of dying people into their general workload.

In relation to educating the workforce there are a number of projects aimed at staff who works in primary health care settings. The developments in education have seen funding from the Australian Government for the development of a generic curriculum and resources for all undergraduate health science courses-medicine, nursing and allied health. Called 'PCC4U' ('Palliative Care Curriculum for Undergraduates'), the uptake has been excellent in some courses (76% of nursing courses), with palliative care content evident in 219 programs across the country (PCC4U 2012). There have been significant shifts in all curricula, especially in the creative integration of these resources into current subjects instead of introducing new subjects into already crowded curricula (PCC4U 2012).

To build capacity in the primary health care workforce, the 'Program of Experience in the Palliative Approach' (PEPA) was developed. This program aims to improve the quality, availability

& access to palliative care for dying people & their families, by developing the skills of health professionals. PEPA uses supervised clinical placements in specialist palliative care services and integrated learning workshops. The key to success of this program has been the provision of funding to backfill the position of the health provider (for example a GP), to free them to attend a supervised placement or other activity. The program has been taken up by GPs, social workers, nurses, indigenous health workers and aged care staff (Program of Experience in the Palliative Approach 2006).

Primary healthcare approaches in aged care settings have been an important piece of work. Even though a nursing home may be an older person's final residence, there has been little recognition of how palliative care could assist people who die in these settings (O'Connor 2009). In 2004, the Australian Government Department of Health and Ageing funded the project to develop the 'Guidelines for a Palliative Approach in Residential Aged Care' (Australian Government, Department of Health and Ageing 2006). A consequence of this work has been the requirement of including palliative care in the Aged Care Standards, which are used for accreditation of services. If organisations do not meet these standards, they will be penalised. More recently a companion document-'Guidelines for a Palliative Approach in Aged Care in the Community' has been developed (Australian Government, Department of Health and Ageing 2011).

In relation to quality, Palliative Care Australia has had national standards since the early 1990s, which are now in the 4th edition of the 'Standards for Providing Quality Palliative Care for all Australians' (Palliative Care Australia 2005a). More recently the 'National Standards Assessment Program' (NSAP) has been funded by the Australian government to enable demonstration of evidence of the Standards (Palliative Care Australia 2012b). NSAP assists all specialist

palliative care services to participate voluntarily in the stages of quality improvement and there will eventually be links to accreditation processes. Further work is required however, to integrate the primary care emphasis into the Standards, which will be incorporated into the 5th edition.

The Australian government commissioned an 'Inquiry into Palliative Care in Australia' in 2011, the report of which was finalised in 2012 (Australian Senate, Community Affairs References Committee 2012). The many recommendations are wide-ranging and include: addressing funding support for people in remote & rural areas; processes of support for people from different cultures (including indigenous peoples); enabling equitable access to care for children and their families; advance care planning and that funding models reflect the complexity of care.

In relation to informing the community about palliative care, community messages follow the public health model of empowering individuals through the provision of information, in advance of a health event. Messages are very difficult to impart to the community because of the perception of medicalised death associated with the 'death-denying' society and the lack of or 'invisible' community involvement, for example with carers.

Community awareness is also focused around National Palliative Care Week; although there are many other media opportunities individual services make use of. Each year, one agreed national message is facilitated by PCA, who then develop appropriate resources like posters and brochures. Besides advertisements and interviews on mainstream media of TV, radio and newspapers, in recent years, tweets, Facebook and podcasts have all been used.

But there is a long way to go to getting to true partnership with the community, where the community has a real voice in what they wish to see in end of life care. It is difficult to involve terminally ill people themselves, but carers and

the bereaved present many opportunities to be involved in community representation of palliative care.

'The National EoL (end of life) Alliance' was established among Australian Government parliamentarians in 2009. Co-Chaired by a member of each major party, they host a function at Parliament House twice a year. The meetings are open to all parliamentarians, which provide an opportunity to inform parliamentarians about aspects of palliative care, as well as a place where they can raise issues and concerns.

All national work is underpinned by a policy and advocacy framework for PCA, determined through ongoing and wide-ranging consultation with PCA's member organisations, working groups and subcommittees. These forums bring together the knowledge and expertise in palliative and end-of-life care from across Australia and the entire health sector. The main framework is underpinned by 3 key documents:

Standards for providing quality palliative care for all Australians (Palliative Care Australia 2005a)

Palliative care service provision in Australia: A planning guide (Palliative Care Australia 2003)

A guide to palliative care service development: A population based approach (Palliative Care Australia 2005b)

In addition to these reference documents, PCA has also published the 'Palliative and End-of-Life Care Glossary of Terms' (Palliative Care Australia 2008).

## 5. Discussion and Conclusion

This paper has described the many ways that palliative care services in Australia have worked to integrate palliative care into mainstream health services. The emerging primary health care models have potential to change practice, particularly for staff not specialised in palliative care. While these developments have been significant, there are many opportunities to

address the service gaps. The workforce issues will continue to be a challenge because of skills shortages and as workers age; so continued educational support is essential, particularly in supporting primary health care workers. Finding effective communication systems will continue to challenge the community as long as death continues to be invisible. Continuous national work is required on implementation of advocacy, policies, and quality programs, building on the recommendations of the National Inquiry in particular. There is a requirement to further develop and strengthen the evidence of quality improvements and to have 'real' performance measures attached to such activities. Thus research needs to be embedded into service systems, which must be linked to practice change to provide such evidence. There is much work to do in developing systems of appropriate care, to incorporate cultural and other differences and to enable death in the "best" place for each person.

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