Development of Palliative & Hospice Care in Australia

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What are the benefits of Palliative Care?
International Quality of Death Index
Definitions
Barriers to Palliative Care provision
What is the history of Palliative Care in Australia?
How has it reached its ranking in the Quality of Death Index?
### 2015 Quality of Death Index—Overall scores

<table>
<thead>
<tr>
<th>Rank</th>
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Quality of death index – rank & overall scores

Malaysia 38th-score 46.5
Thailand 44th-score 40.2
Indonesia 53rd-score 33.6
Vietnam 58th-score 31.9
China 71st-score 23.3
Myanmar 76th-score 17.1
Philippines 78th-score 15.3
International Quality of Death Index

The Quality of Death Index, commissioned by the Lien Foundation, a Singaporean philanthropic organisation, measures the quality of palliative care (as defined by the WHO) available to adults in 80 countries using 20 quantitative and qualitative indicators across five categories:

- human resources (workforce) 20%
- the affordability of care 20%
- the palliative and healthcare environment (framework for the provision of palliative care and healthcare): 20%
  - the quality of care (existence of monitoring guidelines, availability of opioids, meaningful involvement of patients and model of partnership): 30%
- the level of community engagement 10%
Barriers

While few would argue against the need for more funding for end-of-life care, money is not the only barrier to the accessibility and quality of that care.

Many factors hamper progress in this field:

- cultural taboos
- lack of understanding of end-of-life care
- geographic dispersal of populations in some countries
- the futile use of life-preserving medical technologies in places such as the US, and the spread of this model of care
Definitions - palliative care & hospice

**Palliative Care**: care of incurable illness BUT

- Including active medical therapies & treatments aimed at the disease

**Misconception that Palliative care equates with end of life care**
- Late referrals
- Poor symptom control

**Hospice**: end of life care ; American-based terminology

Both palliative care and hospice care provide comfort.

Palliative care can begin at diagnosis, and at the same time as treatment.
Changing Goals

Diagnosis

SURVIVAL > Function > Comfort

COMFORT > Function > Survival

Death
Fig 2 Appropriate care near the end of life. Adapted from Lynn and Adamson, 2003.7 With permission from RAND Corporation, Santa Monica, California, USA

Whole person care

Integrates the psychological & spiritual aspects of patient care

Western medicine focuses on the physical—illness is a problem to be solved

Recognition that patients with terminal illness struggle with their mortality, meaning

Recognition that psychological & spiritual care is as important as physical care

Impact of psychological issues on control of physical symptoms e.g. pain

Symptom control is only the beginning
Palliative care: background

Modern Palliative care originally developed as a response to unmet needs of dying patients within the **acute hospital setting**:  

**Dame Cicely Saunders, U.K. 1918-2005**  
St Christopher’s ,London 1967  

**Balfour Mount, Canada**  
Royal Victoria Hospital Montreal 1973  

Formerly, **care of the dying** given in “hospice” settings:  
- Places of high expertise-late 19th century  
- Christian religious tradition  
- **Outside mainstream health care institutions**
“You matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die.”

Dame Cicely Saunders
Australia

Inspiration from work of Cicely Saunders & Balfour Mount
- Many senior clinicians travelled to St Christopher’s in London in early 1980s

Development of Services led by visionary leaders
- Visit to Sydney’s Royal Prince Alfred Hospital by Balfour Mount 1982
- First service led by a Specialist Consultant Physician 1985

Working within existing Christian Hospices “for the dying”:
- Calvary Hospitals, Sacred Heart Hospice, Homes of Peace
Palliative Care in Australia
Short history of Palliative Medicine

1985-Palliative Care Department at RPAH Sydney, led by Professor Norelle Lickiss

1987-**World’s first academic chair** in palliative care-Flinders University Adelaide

1988-Specialist Advisory Committee in Palliative Medicine in RACP

1988-Commonwealth government funding for PC service development in all States

1989-Sydney Institute of Palliative Medicine
  ◦ Specialist training pathway

1990-First conference of Australian Association for Hospice & Palliative Care;1991

1998-Palliative Care Australia

1990s-Expansion of palliative medicine into all major teaching hospitals in Sydney
1991-RACP subspecialty training in Palliative Medicine, as General Medicine specialists
1993-Australian & NZ Society of Palliative Medicine (ANZSPM)
1999-Chapter of Palliative Medicine in RACP
2000-Foundation Fellows
2003/4-Specialist Curriculum with AMC
The exact model of care provision differs across Australia, with each state and territory having specified an approach to providing palliative care-related services (Senate Community Affairs References Committee 2012).

In recent years, there has been a focus on expanding the practice of specialist palliative care teams to support primary palliative care providers, often through consultative or consortium arrangements (AIHW 2010).
Essentials for excellent Palliative Care service delivery

The Index report suggests countries with a high quality of death share several characteristics:

• A strong and effectively implemented national palliative care policy framework;
• High levels of public spending on healthcare services;
• Extensive palliative care training resources for general and specialised medical workers;
• Generous subsidies to reduce the financial burden of palliative care on patients;
• Wide availability of opioid analgesics;
• Strong public awareness of palliative care
National Initiatives

National Strategy
National Standards
National Indicator set
National Strategy
National palliative care strategy—supporting Australians to live well at the end of life
Updated 2017

Strategic focus – increasing awareness and understanding of palliative care

Goal 1 – To ensure people understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care

Goal 2 – To increase knowledge and engagement among health, aged care and social service providers in the provision of person-centred palliative care

Strategic focus – improving Australians’ experience of palliative care

Goal 3 – To ensure that individuals, their families and carers receive the palliative care services they need, when and where required
Strategic focus – building leadership to provide direction and governance to drive action

Goal 4 – To build collaborative leadership at all levels for a more consistent experience across care settings

Goal 5 – To strengthen national governance of this Strategy to ensure the highest standards of palliative care

Strategic focus – increasing capacity to deliver quality palliative care

Goal 6 – To develop the skilled workforce, investment and infrastructure required to deliver quality palliative care in any setting are available across Australia
Ongoing

Mainstreaming of patient care

“Death awareness”-Public Health campaigns

Integration within healthcare services

Talking about dying won't kill you, Palliative Care Australia says
In Australian hospitals in 2015-16
- 50% of patients who died as an admitted patient received palliative care
- 73,900 hospitalisations were palliative care-related
- 52.2% of palliative care-related hospitalisations were for people aged 75 and over.
- The average patient age of all palliative care hospitalisations was **72.8** with little difference between the sexes.
- This was considerably older than the average age of 54.8 years for hospitalisations for all reasons.
- Only about 1 in 10 (10.9%) of the total number of palliative care-related hospitalisations was for patients aged under 55.

There was a **28.2% increase** in palliative care-related hospitalisations between 2011–12 and 2015–16, compared to a **14.6% increase in hospitalisations for all reasons** over the same period.
Workforce

226 specialist palliative medicine physicians
   ◦ 1 in 140 employed medical specialists were palliative medicine physicians

3,457 palliative care nurses were employed nationally in 2016

0.9 medical and 12.2 nursing full-time equivalent (FTE) per 100,000 population respectively
   ◦ around 1 in 90 employed nurses were palliative care nurses.
Education & training-essentials

Substantial training in specialist Palliative Care & Palliative Medicine

Standards for training-Australia, U.K.

World’s first Chair of Academic Palliative Medicine in Australia, 1987

Standardised training pathways via Chapter of Palliative Medicine of Royal Australasian College of Physicians
Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers
National Standards
Figure 1: The National Palliative Care Standards

- Assessment of needs (Standard 1)
- Developing the care plan (Standard 2)
- Caring for carers (Standard 3)
- Providing care (Standard 4)
- Transitions within and between services (Standard 5)
- Grief support (Standard 6)

- Service culture (Standard 7)
- Quality improvement (Standard 8)
- Staff qualifications and training (Standard 9)
Performance data - National Palliative Care Outcomes Collaborative (PCOC)

Assessment of:
- pain & other symptoms
- psychological & spiritual issues
- family/carer issues

Validated tools for completion by staff & patient

Designed to be part of routine clinical care

Benchmarking: measuring outcomes prompts us to improve things!
Outcome Measures-tools

Validated assessment tools exist for all symptoms

Measuring symptoms can lead to improved outcomes
- better symptom control

- “If you don’t ask, you won’t know"
  - and symptoms go uncontrolled”!
- Medical staff are the least-good at assessing
Evidence-based care & practice

Increasing attention being paid to **how people die**
- Joanne Lynn, Diane Meier

Attention to outcomes relating to *carers/families*, as well as patients
- “Palliative care is an approach that improves the quality of life of patients & their families“
The Palliative Care Clinical Studies Collaborative (PaCCSC) is a national research network that aims to:

- Generate high quality research evidence to support the use of medicines and other interventions at the end of life to better manage or alleviate symptoms in patients
- Build capacity within the health workforce in the conduct of high quality clinical research in patients nearing the end of life and the translation of research results into clinical practice.
National Indicator Set
National Indicator set

*Performance indicator 1—strategic plans:* the proportion of administrative health regions that have a written plan for palliative care that incorporates palliative care elements

*Performance indicator 2—standards:* the proportion of palliative care agencies that routinely undertake or undergo formal assessment against the current Palliative Care Australia standards

*Performance indicator 3—feedback:* the proportion of palliative care agencies that actively collect feedback from clients and staff (within the workforce) relating to services and service delivery

*Performance indicator 4—partnerships:* the proportion of palliative care agencies that have formal working partnerships with other service providers or organisations
Conclusions

Demand for Palliative Care services is set to rise in middle & lower-income countries due to:

Larger populations

Populations ageing faster

Increasing incidence of non-communicable diseases

National-level decision making can be informed by strategies in countries with established high quality Palliative and end of life Care—not just high-income countries