

University of Melbourne, the first nurse invited speaker was Linda White from the MD Anderson in Texas. White worked as a prevention and early detection specialist at the Anderson and among other roles, performed colposcopies. Her plenary talk at the meeting, sandwiched between talks on oncogenes, sparked heated debate on whether nurses here could aspire to such roles. One gynaecology specialist was adamant that Australian nurses would never be able to perform at this level.

Where then is cancer nursing on the international stage in the year 2013? From a professional perspective, nurses from Australia have played a significant role in shaping the development of the International Society of Nurses in Cancer Care (ISNCC). The previous board of ISNCC had four nurses from Australia out of 14 board members, including the President and Treasurer. From a development perspective, the work of EdCaN and the framework it produced is being used by many nurses around the world as they shape their own developments. In research, our cancer nursing intervention research is among the best in the world and is published in high impact journals, in both nursing and medicine. The early inspiration for improving practice and undertaking research for many nurses was attendance at a COSA meeting. While our development often paralleled what was happening for cancer nursing in other countries, it was always given local context by the important inter-professional dialogue that COSA enabled.

The future for cancer nursing

Today, cancer nursing is facing new pressures to adapt and reform in response the growing demand for cancer services, the recognition of cancer as a chronic disease, the need for accelerated transfer of knowledge into practice, and growing fiscal challenges. Like other health professionals, cancer nurses must respond by developing and adopting new approaches to care. For example, adopting the principles of risk stratification will help to ensure the right care gets to the right person at the right time. Care coordination is also a critical component of cancer care in Australia as an increasing number of patients receive care across different facilities, including across public/private and metro/rural settings. A shift to supported self-management approaches is also required to accommodate the chronic nature of cancer and its effects, and the reality that most people with cancer experience these treatment effects in their homes.

A recent report by Health Workforce Australia highlighted that new advanced nursing roles established in the US and UK have demonstrated potential to increase efficiency and accessibility of cancer care.¹⁰ While there are numerous barriers to acceptance and challenges in implementation of such roles,¹⁰ the redesign of traditional roles and a greater blurring of practice boundaries will present new opportunities to achieve better patient outcomes.

Ongoing work is required to ensure people affected by cancer receive the best possible care from nurses, no matter what their social, demographic or clinical circumstance. Indeed, a recent report by the Institute of Medicine (IOM) on the future of nursing confirmed that by virtue of its numbers and adaptive capacity, the nursing profession has the potential to effect wide-reaching changes in the health care system.¹ The IOM report calls for nurses to be enabled to practice to the full extent of their education and training and for clearer pathways with seamless academic progression and associated credentialing to ensure quality care. Importantly, the IOM report calls for nurses to be full partners with physicians and other health professionals in redesigning health care. COSA and the opportunities such a society presents for multidisciplinary care, mean that cancer nurses in Australia are well placed to respond to this call to action.

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EVOLUTION OF PALLIATIVE CARE IN AUSTRALIA 1973-2013

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Abstract

In parallel with the rapid development of oncology in Australia, palliative and supportive care has evolved rapidly. The sponsorship for such development was largely generated by oncology services in response to unmet needs that were encountered daily. Development of state, territory and national strategies has mirrored the professional development in service delivery, education (of existing practitioners and tomorrow's clinicians) and research. More recently, national programs are delivering better outcomes for palliative care patients and their families, world-leading clinical research, improved access to essential medications in the community and the ability to access quality evidence to inform practice and policy. These initiatives provide a valuable foundation for continuing to improve access to high quality clinical care wherever people live.

In Australia, the history of the transition from geographically and clinically limited hospice services to palliative care services over the past 40 years has paralleled closely the development of sub-specialist oncology services. Indeed, much of the impetus has come directly from leaders in oncology who recognised and acted to address patients' unmet needs in a better and more responsive way.^{1,2}

By the early 1970s, three major providers accounted for most hospice services in Australia: the Little Company of Mary; Sisters of Charity; and the Deaconess Society. The model of care was built around care for the dying and indeed, as recently as 1982, a neon sign outside one institution read 'Hospice for the Poor and Dying'. This was care in a tradition that had arisen in the middle ages to ensure that people at the margins (and the dying still face such marginalisation) were provided with care and shelter, often for extended periods of time. At the same time, nursing home bed numbers were expanding and, similar to hospices, tended also to have relatively long lengths of stay. Neither group of institutions had discharge policies, with care provided until death supervened.

The leadership shown internationally by people such as Vittorio Ventafridda (Italy), Cecily Saunders (England) and Balfour Mount (Canada) led to an undeniable shift in care for people with advanced illness. Providing quality health care for the dying that addressed physical, emotional, existential, social and sexual needs became a focus of active needs-based care, rather than simply closeting people away once death became inevitable. Australia, as one can argue often happens in health care, took the best of the international models and philosophies and adapted them to the local health and social systems. No single model could adapt perfectly to the manifest differences in health system design, funding nor geography. This allowed an eclecticism that has served well.

Development of palliative care

A watershed for the early evolution of palliative care in this country was the commissioning of a report by the Anti-Cancer Council of Victoria on care of the dying in 1983.³ This was a report whose recommendations have echoed through the subsequent three decades – there was a perceived need to have services provided at a geographical level with a team led from, and integrated, with existing health services, given that this was where the population who were facing the end of their life could be identified currently. The report also indicated that building further freestanding hospices would not serve

the target population well. The latter was a particularly salient recommendation, given that two of the country's largest freestanding hospices would close within 20 years of this report in order to move to a model that provided much closer integration with existing health services. At least three others have seen fundamental changes, with a decreasing number of beds augmented by hospital liaison and community-based teams. Such evolution has not been without controversy, but it does speak strongly to the vision held by Ross Webster and his committee in 1983 as he looked to the future needs of the population.³

By the mid-1980s several states had palliative care position statements, strategic plans or direction statements.⁴ Given the time lines, and the paucity of services globally, this showed an extraordinary level of jurisdictional leadership. Every state had its champions, and the diverse backgrounds of these medical and nursing leaders have positioned palliative care well: oncology; primary care; anaesthetics and pain medicine; general medicine; geriatrics and psychiatry.

The late 1980s saw four important steps that have shaped the ensuing quarter of a century:

- Creation of the world's first academic chair in palliative care at Flinders University in 1987 (reflecting similar appointments over the next decade at a number of institutions).
- Formation of the Specialist Advisory Committee in Palliative Medicine by the Royal Australasian College of Physicians in 1988, which was the world's first sub-specialist training program in palliative medicine.
- For the first time, the inclusion of identified funds for states and territories to use to develop palliative care services in the 1988 quinquennial Medicare agreement.
- A meeting convened by the Medical Oncology Group of Australia in 1989 to help map the future direction of palliative care from the viewpoint of oncology services.⁵

The Chair at Flinders University has evolved into a unit that delivers the largest distance education program in palliative care in the southern hemisphere and one of the biggest in the world, with 400 current post-graduate students, together with a niche program designed to provide affordable post-graduate education to clinicians in resource-poor countries spanning the Middle East to South East Asia. The department is now host to one of several productive research teams across the country, each of which has an international track record of leadership in their areas of expertise.

The Royal Australasian College of Physicians program allowed a direct path to subspecialisation that was gradually taken up. This was augmented in 2000 with the formation of a Chapter of Palliative Medicine within the college to facilitate lateral entry from other learned colleges. This has allowed a group of clinicians from a wide range of clinical backgrounds to undertake palliative medicine sub-specialty training and bring their diversity of skills to care for people at the end of life, reflecting the diversity of early clinical champions of palliative care in Australia and around the world. More recently a clinical diploma has been added to the program.⁶

Medical oncology

The 1989 meeting convened by Medical Oncology Group of Australia cemented the close relationship between oncology and palliative care, with most palliative care services still providing the majority of their clinical services to people with cancer and their families. This meeting occurred at a time when the philosophical underpinnings of palliative/hospice care were still being hotly debated. The model in the UK was struggling to move beyond cancer, especially with the advent of AIDS, but also with the changing face of dying: chronic, complex, slowly progressive diseases leading inexorably to death.⁵ Australia's policies from that time forward have not limited care by perceived prognosis (unlike the US), nor by diagnosis (unlike many charitably funded, freestanding services in the UK).

A national strategy

The 1998 national census (State of the Nation) undertaken by the newly renamed Palliative Care Australia, was an important step in measuring the progress made in ensuring that people, wherever they lived, had access to palliative care.⁷ Participants were asked to record their activity over the same 24 hour period and the data collated. This was the first national view of what services were delivering, the patients being seen and the models of service delivery that had evolved over the previous two decades. Much of this local evolution was because of widely varying mechanisms for funding and widely varying commitment at the jurisdictional and local level for the provision of palliative care. The legacy of this is still felt in varying levels of service access, with some tertiary services still only providing nominal support for the vision laid out by Ross Webster in 1983.³

The census demonstrated, as expected, that cancer accounted for approximately 90% of all referrals to services, although again there was wide variation depending on a number of local factors as to the population served. Care was delivered in the community, in hospitals (consultative, direct care or both) or a number of free standing and co-located inpatient palliative care units.

The first national strategy was endorsed by all states and territories and the Commonwealth in 2000, and updated again with jurisdictional support in 2010. This document provided a real basis on which to build, for the first time, truly national initiatives with Commonwealth funds directed nationally, not just for jurisdictional projects. Fundamental

principles included equity of access to high quality services underpinned by the best evidence available. There was a specific focus on improving community-based care, to which the Commonwealth has continued to provide resources. As part of this work, a review of research capability in palliative care was commissioned by the Commonwealth, which demonstrated few units with strong competitive track record or the requisite pipeline of researchers coming through.

National programs that arose included improving:

- research capability
- education of the existing and the future workforce
- affordable community availability of key medications for symptom control
- quality of care delivered
- access to the evidence to inform practice and policy.

These programs have put Australia at the forefront of palliative care in the world. This program was conceived and delivered by Rita Evans in the Department of Health and Ageing through the National Palliative Care Program. Without her vision these programs could not have come to fruition.

A variety of models of service delivery evolved. There was however, a key shift with the development of the National Palliative Care Strategy (2000), to which each state, territory and the Commonwealth became a signatory. This set the stage for investment by the Commonwealth directly in initiatives at a national level. This investment has been far-reaching, with each of the subsequent Medicare agreements providing funding in parallel with national initiatives. Much of this initial funding seeded new services, improving geographical coverage.

Research capability

In research, the Commonwealth invested in a specific program which included bursaries for research higher degrees at a masters and doctoral level, together with a number of seed grants that allowed researchers to establish a category 1 track record with a view to improving their access to competitive grants nationally. This program, in conjunction with the National Health and Medical Research Council, was a two way process, as it also encouraged the council to consider reviewers who had research expertise in palliative care. The Commonwealth's investment has been successful and, within a decade, palliative care has been gaining category 1 grants and completing these studies.⁸

Health workforce education

In education, the Palliative Care Curriculum program (www.PCC4U.org) has developed and worked to disseminate the key undergraduate competencies for all health professionals irrespective of their discipline. The competencies include: individual attributes (empathy, compassion, caring and a non-judgmental approach); clinical skills (assessment, pathophysiology of dying, pharmacology); communication skills (active listening, reflection); and palliative care

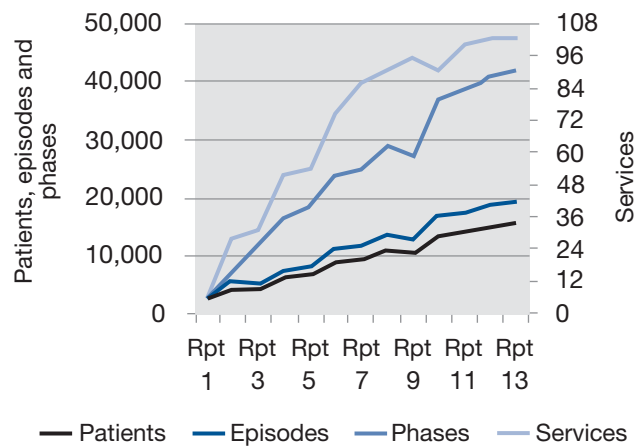
principles (philosophy, multi-disciplinary care). The program has worked with universities to assimilate these handful of essential concepts into curricula.⁹ Uptake has been more likely if a curriculum is being rewritten and so the process of uptake will take time. Simultaneously, there have been funded opportunities for existing practitioners to learn or update their skills in palliative care; the Program of Experience in the Palliative Approach (PEPA) has seen a wide range of practitioners take the opportunity for attachments to services often within their referral network.

Care and medications

The Palliative Care Clinical Studies Collaborative was a Commonwealth initiative whose genesis lay in the challenges of creating the first patient-defined section of the Pharmaceutical Benefits Scheme (PBS) in Australia. Until 2004, all sections of the PBS had been defined only by the clinician who was entitled to write that prescription. Shifting specific sections to a patient-based focus has since been emulated in both paediatrics and Aboriginal and Torres Strait Islander health. The palliative care section of the PBS started with medications where indications were already registered with the Therapeutic Goods Administration and where there was sufficient evidence to support cost effectiveness for a Pharmaceutical Benefits Advisory Committee application. February 2004 saw this section established and it has grown consistently every year since. However, there were still a number of medications considered 'essential' by clinicians for symptom control in the community,¹⁰ for which there was not sufficient evidence for either registration or subsequent subsidy applications. As a result of this, the Palliative Care Clinical Studies Collaborative was established and is conducting nine phase III clinical trials to improve the evidence base. To date, more than 1000 participants have been randomised in these rigorously designed, adequately powered studies to improve the quality of care that is offered. The first of these studies has been reported.¹¹

Improving the quality of care has been a focus of the Palliative Care Outcomes Collaborative.¹² The collaborative is built around: point-of-care data collection; aggregated analysis of data nationally, at a jurisdictional level and by model of service delivery; and benchmarking across the country in order to highlight key areas where outcomes can be improved by better models of service delivery. Key success factors for the program include a focused dataset with direct clinical utility, timely feedback of results and trained quality improvement facilitators to work with services in order to improve each service's own outcomes. To date, more than 15,000 patients are reported in each six monthly report, with clear evidence that the outcomes are improving over the 13 six-monthly periods so far reported (figure 1). More recently, this has been complemented with a National Standards Assessment Program. The program relies on self-report of process measures that are thought likely to influence the quality of care offered. Both of these programs are designed to improve care.

Figure 1: Number of patients, episodes of care, phases (left y axis) and services (right y axis) reported nationally through the Palliative Care Outcomes Collaborative in six monthly time periods 2006-2012.



Access to evidence

Improving the access to evidence is crucial in palliative care. Given its universal nature, the palliative care literature is spread literally across hundreds of journals.¹³ This is a huge challenge for practitioners and researchers in the field. CareSearch was created by the Commonwealth to improve that access and uses a unique system of real time interrogation of PubMed in order to ensure currency, together with unique access to the grey literature (conference abstracts that have not been converted into peer-reviewed publication, government reports, theses and journals before being listed on Index Medicus). It has structured searches for more than 50 topics that are validated for sensitivity, specificity and accuracy. This has improved access both for clinicians and researchers to literature wherever it occurs in the body of knowledge in real time (and is a model now being adapted to Aboriginal health and primary care).

Ultimately, is palliative care living up to the hopes and aspirations of those who championed the needs of people at the end of life? What would Australia's early palliative care champions, Fred Gunz or Wally Moon say today? Almost every teaching hospital now has a palliative care team, but many still do not have outpatient clinics (especially co-located with the services that are most likely to refer to them), nor the ability to admit patients directly under their care. Some still fail to provide real access to support around the clock for the emergency department.¹⁴ In the community, the models of service delivery vary widely, and clearly some people do not yet have equitable access.¹⁵ But there is now a national approach to many things that until recently have been piecemeal, and quality evidence that the care that is being provided is systematically improving, a claim that can be made by very few specialties at a national level. Access to palliative care has improved where there has been a focused investment in services, but the challenge of poor access persists where health services have failed to make the investment required to strengthen local palliative care. Given the documented level

of acute care service delivery that has palliative intent,¹⁶ this is a sadly short-sighted decision at the local level of several large hospitals and health services in Australia in 2013.

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RADIO THERAPY - A LEAP FORWARD IN CANCER CARE

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Abstract

Radiotherapy is a cornerstone of modern integrated cancer care. It combines the real human face of caring for people with cancer with extraordinary science and technology. Its history is rich and our modern specialty of radiation oncology is built on the shoulders of giants, both in technology and biology. It is a highly cost-effective treatment that stands proudly on a large and robust evidence base. Quality radiation treatment can add significantly to the chance of curing many people with cancer and remains an invaluable palliative treatment for others. About half of all cancer patients benefit from having radiotherapy, mostly through improved survival. The specialty and what it can bring to patients continues to evolve apace and the high quality of treatment delivery is critical to its success.

Radiation treatment has evolved over the past 12 decades into a highly sophisticated, cost-effective cornerstone treatment for people with cancer. It adds significantly to the chance of cure for many people with cancer and can be very effective in helping relieve symptoms for those in whom cure is not possible. Since 1956, when linear accelerators (linacs) came into mainstream clinical use in Australia, radiotherapy technology has advanced greatly. This, accompanied by major advances in our understanding of the biology of cancer and radiobiology, and exploitation of the benefits of combined modality

treatment with surgery and systemic therapies, has led to significant improvements in treatment outcomes. Although we have described the developments separately, often we see advances in technology, biology and integration occurring simultaneously and scattered across the globe.

The primary goal of radiation treatment delivery for cancer is, always has been and always will be to maximally treat cancer tissue and maximally spare normal tissue. This underlying philosophy has guided almost all of the developments in radiation oncology from the outset. The