

# 40 YEARS OF CANCER NURSING IN AUSTRALIA: THE EMERGENCE OF A SPECIALTY

**Patsy Yates<sup>1</sup> and Sanchia Aranda.<sup>2,3</sup>**

1. Institute of Health and Biomedical Innovation, Queensland University of Technology, Brisbane, Queensland.

2. Cancer Institute New South Wales, Eveleigh, New South Wales.

3. School of Health Sciences, University of Melbourne, Melbourne, Victoria

Email: p.yates@qut.edu.au

## Abstract

Over the past 40 years, the nature and scope of cancer nursing practice has been shaped to a large extent by scientific and medical advances, as well as by social, economic and political factors. Nurses' role in cancer care has evolved from being predominantly functional and dependent in its approach to being a specialty with clearly defined standards of practice underpinned by a growing evidence base and an agreed set of professional performance capabilities. The unique contribution that nurses make to minimising the effects of cancer on a person's life and improving the patient experience is now well established and Australian cancer nurses are recognised as leaders in the field internationally. Nurses have achieved improved outcomes for people affected by cancer as part of a multidisciplinary team. By being active participants in the Clinical Oncological Society of Australia for at least 30 of the organisation's 40 year history, Australian cancer nurses have been provided unique opportunities for professional development and inter-professional collaboration. To meet future challenges in delivering quality cancer care, cancer nurses will need to be full partners with consumers and with other health professionals in redesigning health care systems that are more responsive to changes in social, demographic, scientific and technological contexts.

Like other health professions, the past 40 years has seen the scope of cancer nursing practice being shaped largely by medical, scientific and technological advances. Indeed, the emergence of a predominantly ambulatory care model of practice, increasingly sophisticated methods for delivering personalised cancer therapies, and the growing demand for highly specialised disease-specific knowledge, has meant the nursing profession has had to demonstrate extraordinary capacity to adapt to change.<sup>1</sup> Importantly, the practice of cancer nursing has also been shaped by social, economic and political factors that present significant opportunities, as well as challenges, in today's health care environment.

## Milestones in the development of cancer nursing

Hilkemeyer argues it would have been unthinkable in the early 1950s for a nurse to administer cytotoxic agents to cancer patients.<sup>2</sup> While nurses had long played a role in supporting cancer patients, it was not until the 1970s that the specialty of cancer nursing as we know it today emerged. The late Robert Tiffany, founder and inaugural President of the International Society of Nurses in Cancer Care, described the 1970s as a time of "extension and expansion of the role and function of the nurse in cancer care", alongside the development of educational programs designed to prepare nurses to meet the demands presented by changing cancer treatments.<sup>3</sup> Tiffany's 1987 landmark paper, *The Development of Cancer Nursing as a Specialty*, described for the first time a role for the specialist cancer nurse as an expert in a specific aspect of oncology nursing. Tiffany argued that the specialist cancer nurse required

advanced education preparation to adequately perform their role. At this time in Australia, the only specialist training in cancer nursing was at the Peter MacCallum Cancer Centre, where a largely radiotherapy focused program had been running since the 1950s. The 1970s saw many nurses from Australia and New Zealand travel to the Royal Marsden Hospital in London to undertake specialist courses.

However, the 1970s was a period of time where nursing care was largely functional in its approach and nursing practices were primitive in comparison to today's standards. Cytotoxic drugs were often reconstituted and administered by nurses, a practice unacceptable by today's standards, and the management of chemotherapy side-effects was a trial and error process.<sup>4</sup> For example, Henke-Yarbro noted that "...if one antiemetic did not work, another was tried and that combination of antiemetic regimens were unheard of." She also noted that patient education materials were "uncommon or nonexistent." Specialist nursing courses in the 1970s were largely focused on understanding cancer and its treatment, with nursing responses largely based on clinical protocols (eg. nasogastric feeding), with no substantial evidence base.

As the nursing profession evolved from this functional, task-based approach, to one which was more holistic and patient centred, the core features of contemporary cancer nursing started to emerge. The 1980s in particular, was an historic time for nurses in Australia, as the Commonwealth Government announced its intention to fully transfer preparation of registered nurses to university settings, a process which was not fully complete until 1994.

The transfer, while occurring later than it did in some other countries, distinguished Australia as one of the few countries in the world to have a bachelors degree as the single point of entry to practice as a registered nurse. Arguably, this period of time was where Tiffany's vision for specialist cancer nursing came to be realised, as the paradigm shifted from nurses offering care and comfort to one where nurses based their practice on scientific knowledge.<sup>5</sup>

By the 1990s, the need for reform in cancer care in Australia was also gaining momentum. Nurses, who now benefitted from much better educational preparation, were increasingly acknowledged for the role they would have in ensuring a quality cancer care system. For example, the 1995 House of Representatives Inquiry into the management and treatment of breast cancer in Australia was replete with examples of the inadequacies of the existing systems of care,<sup>6</sup> and the lack of compassion and sensitivity that was sometimes experienced by women diagnosed with breast cancer. While the multidisciplinary team at that time was narrowly defined in the inquiry report by medical specialties (ie. surgeons working closely with their colleagues in radiation and medical oncology), the key role that nurses were to play in improving the patient experience in the years which followed was also signalled. As the committee report noted: *"It is unfortunate that in Australia, the need for the integrated participation of the specially trained nurse or some other professionally trained counsellor in the management and treatment of breast cancer, has received only marginal recognition... The under utilisation of the nurse/counsellor on an integrated pre and post operative basis is the result of the current fragmentation in which rather than referral to a team which includes a specialist nurse or counsellor, referral is made to a broad range of specialists in different physical locations not working as a team"* (p. 21-22).

Importantly, nurses' capacity to contribute to improved patient care was further strengthened during the 1990s by new postgraduate education opportunities in the specialty. In Australia, the first postgraduate diploma in cancer nursing commenced at LaTrobe University in 1990, while the first masters level program, with a specialty in cancer nursing, commenced at Queensland University of Technology in 1995. The year 1991 also saw publication of the first *Australian Standards for Oncology Nursing* by the Clinical Oncological Society of Australia (COSA) Nurses Group. The second edition of these standards was published in 1996, with a preamble specifically highlighting that nursing practice continued to extend beyond medically related care, requiring the inclusion of new standards in areas including communication, fatigue and hope.<sup>7</sup>

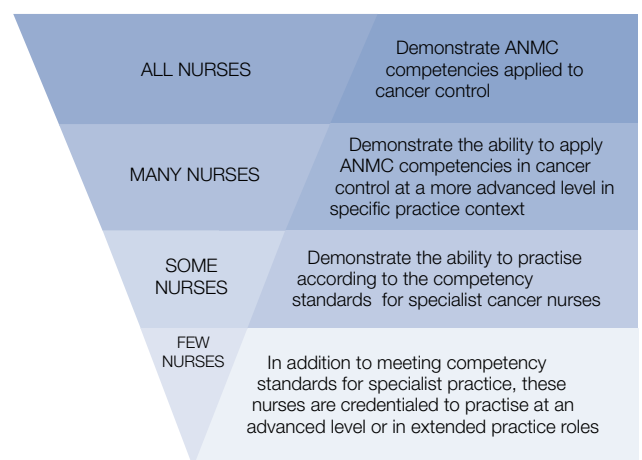
In the 2000s, the demand for more patient centred approaches to care continued to be a major theme in key reports and policy documents such as *Optimising Cancer Care* and *National Service Improvement Framework for*

*Cancer*. These documents emphasised the complex needs of people across the cancer experience and highlighted the importance of supportive care interventions and the need for better coordination of cancer care.

Cancer nursing practice has evolved to play a key role in these areas, with two major developments during this decade worthy of mention. Firstly, under the Australian Government's Strengthening Cancer Care initiative, funding was provided for the development of education programs for nurses. The resulting program, the National Cancer Nursing Education Project (EdCaN), led to the development of a framework and a set of capabilities outlining the role expectations of nurses working in cancer control, and an associated set of teaching and learning resources to help nurses acquire these capabilities. A key feature of the framework is that the priorities, needs and experiences of people affected by cancer are central to the development of cancer control programs and to the involvement of nurses in such programs. The model presented in figure<sup>1</sup> describes nurses' varying contributions at all phases of the cancer continuum, outlining the competency standards required of nurses working in different roles, in different settings and at different points along this continuum.<sup>8</sup> With the continued support of Cancer Australia, the EdCaN framework continues to define the minimum standards expected for cancer nurses today, with the framework and learning resources used extensively in the design, implementation and evaluation of continuing professional development and postgraduate programs across the country and internationally.

**Figure 1: EdCaN Professional Development Model for Nursing in Cancer Control.**

## PEOPLE AFFECTED BY CANCER REQUIRE A RANGE OF NURSING SERVICES



The second major development in cancer nursing during this period has been the strengthening of the evidence base for cancer nursing practice, with nursing research having a greater focus on outcomes from nursing intervention and the processes of care that contribute to better outcomes for patients. For example, one systematic review considered resource-use data and nursing-outcome data collated from 76 case studies of patients referred to 12 specialist cancer and palliative nursing teams (home-based and hospital-based) in the UK. The review concluded that patients who reported better nursing outcomes had a higher proportion of specialist nursing interventions than those reporting poor nursing outcomes (45% v25%). Moreover, the review noted that the overall pattern of health-care use was different for those patients who reported positive nursing outcomes.<sup>9</sup>

### Australian cancer nursing and COSA

The history of cancer nursing in Australia reflects close ties between the profession and COSA. In Australia, a national professional group for cancer nurses did not form until the late 1970s. This first group formed under the banner of COSA, initially as a sub-group of the Medical Oncology Group, beginning a long history of collaboration and partnership between a professionally organised group of cancer nurses and other health professionals working in the field of cancer care. By the mid-1980s, the COSA Nurses Group was formed and gained a seat on COSA Council and the first nurse sat on the Executive Committee in 1991.

The Cancer Nurses Society of Australia (CNSA) evolved from the former COSA Nurses Group and officially commenced operations on 1 January 2000, following several years of debate about the merits of forming a more independent group. The desire for an independent group was very much spurred by members' experiences of the Oncology Nursing Society in the US, where the development of cancer nursing was well advanced. Much of the debate in Australia centred on ensuring that close ties between the new professional group and COSA were enshrined. The following extract from the discussion paper Establishing the Cancer Nurses Society of Australia, distributed to COSA Nurses Group members during 1996, highlights the high value placed on the relationship with COSA at this time: "In 1995, two discussion papers addressing the advantages and disadvantages of forming a national group were circulated amongst cancer nurses in Australia. Written comments from a number of state groups and individual cancer nurses were collated and presented at the COSA Nurses' Group AGM in 1995. Following discussion of these reports at the 1995 AGM, 75 nurses unanimously agreed to develop a national nursing organisation separate to COSA, while maintaining membership within COSA and a place on the COSA Council... This decision was reached as there appears to be general agreement amongst cancer nurses that there are many advantages for nurses to maintaining such a close affiliation with COSA. This means that membership of CNSA will automatically mean membership of COSA. There also appears to be widespread support for further strengthening our collaborative links with COSA, however, the nature of the relationship between the CNSA

and COSA will need to be re-negotiated to accommodate the development of this separate independent group for nurses".

Table 1 lists the nurses who have participated as Chair/President for the COSA Nurses Group.

**Table 1: Nurses who have participated as Chair/President of the COSA Nurses Group.**

Years	Name
unknown	Elsbeth Wark
1984-1985	Ruth Odelle
1986 – 1989	Libby White
1990 - 1994	Sanchia Aranda
1995 – 1998	Laurie Grealish
1999 – 2002	Patsy Yates* (CNSA Established 2000)
2003 – 2006	Kate Cameron
2007 – 2009	Gabrielle Prest
2010 – 2012	Meinir Krishnasamy
2013 -	Sandy McKiernan

In 2011, CNSA's constitution was amended such that it is now no longer a requirement for nurses to hold both membership of CNSA and COSA. This change reflects an increasing sophistication of CNSA's governance models and a growing diversity in the professional activities of CNSA. This shift aims to encourage nurses who may be new to cancer nursing or whose links with cancer are part of a broader role (e.g. respiratory specialists). However, CNSA's commitment to a strong relationship with COSA has not changed, with Associate Professor Meinir Krishnasamy the first nurse to be elected as President of COSA commencing from 2014. Indeed, COSA's commitment to its multidisciplinary model, and the privileged position that nurses have played in the society, is unique internationally. It has enabled cancer nursing in this country to thrive and is recognised by many as being fundamental to a unified and coordinated approach to improving cancer care in Australia.

### Australian cancer nurses - international players

In the 1970s, cancer nurses from Australia were travelling internationally and being exposed to developments in the specialisation. From courses at the Royal Marsden in London to attendance at the Oncology Nursing Society (US) annual meetings, these nurses returned with stories of what was happening elsewhere. Our role in such conferences was largely passive, listening but not presenting, often feeling as if Australia was very behind. The substantial contribution of nurse consultants and clinical nurses specialists in the UK and US sparked the imagination of nurses in Australia and helped ignite a passion that did not receive universal support. At a COSA meeting in the early 1980s at the

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.<sup>10</sup> While there are numerous barriers to acceptance and challenges in implementation of such roles,<sup>10</sup> 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.<sup>1</sup> 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.

## References

1. Institute of Medicine. *The Future of Nursing: Leading Change, Advancing Health*. Washington DC, National Academies Press; 2010.
2. Hilkemeyer R. A historical perspective in cancer nursing. *Oncol Nurs Forum*. 2005;12(1):6-15.
3. Tiffany R. The development of cancer nursing as a speciality. *Int Nurs Rev*. 1987;34(2):35-9.
4. Henke Yarbro C. President's Address: Visions: Our hope for the future. *Cancer Nurs*. 1999;22(1): 1-4.
5. Grealish L. (Ed) *Outcomes Standards for Australian Cancer Nursing*. Sydney, Clinical Oncological Society of Australia; 1996.
6. Commonwealth of Australia. *Report on the management and treatment of breast cancer in Australia*. House of Representatives Standing Committee on Community Affairs; 1995.
7. Health Workforce Australia. *Cancer workforce Literature review*. 2011
8. Haylock PJ. Cancer nursing: the modern era. *Oncol Nurs Forum*. 2011; 38(Suppl): E7-E14.
9. Aranda S, Yates P. *A national professional development framework for cancer nursing*. 2nd edn. Canberra: The National Cancer Nursing Education Project (EdCaN), Cancer Australia; 2009, p.9.
10. Douglas, HR, Hallida, D, Normand, C, Corner, J, Bath, P, Beech, N, Clark D, Hughes P, Marples R, Seymour, J, Skillbeck, J, Webb, T. 2003. Economic evaluation of specialist cancer and palliative nursing: Macmillan evaluation study findings. *Int J Palliat Nurs*. 2003; 9(10): 429-38.

## EVOLUTION OF PALLIATIVE CARE IN AUSTRALIA 1973-2013

**David C Currow<sup>1,2</sup> and Jane Phillips.<sup>3,4</sup>**

1. Cancer Institute New South Wales, Eveleigh, New South Wales.
  2. Palliative and Supportive Services, Flinders University, Bedford Park, South Australia.
  3. School of Nursing, University of Notre Dame, Sydney Campus, Darlinghurst, New South Wales.
  4. The Cunningham Centre for Palliative Care, Sacred Heart Hospice, Darlinghurst, New South Wales.
- Email: davidcurrow@cancerInstitute.org.au