

## TOM REEVE ORATION AWARD ACHIEVING PERSON CENTRED CANCER CARE: REFLECTING ON PROGRESS

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Receiving the Tom Reeve Oration Award is a great honour for those of us working in cancer care. I have worked in this field for nearly 30 years and have been actively involved with the Clinical Oncological Society of Australia (COSA) for much of this time. During this time, I have had the privilege of working with Tom Reeve on a number of guidelines projects, as well as with many of the previous recipients of this award. Knowing what Tom and the previous recipients of this award have achieved for cancer care makes this award very special indeed. I am pleased to have this opportunity to pay tribute to Tom and to thank him for his support and mentorship over the years.

In this paper, I will reflect on 'lessons I have learnt' about factors that are important to improving care of people affected by cancer. These lessons include:

- understanding the experiences of people affected by cancer is necessary to improve cancer care
- ongoing learning, research and evidence are critical elements of efforts to advance the field
- professional organisations can positively influence cancer care, and
- multidisciplinary collaborations provide rich opportunities for improving cancer outcomes.

### **Understanding the experience of people affected by cancer**

I completed my training as a registered nurse at Princess Alexandra Hospital in Brisbane in the early 1980s. While approaches to nursing education continue to generate debate within and outside the profession today, the apprenticeship system of training I completed was then, and remains today, incompatible with the requirements of a complex health system.<sup>1</sup> I finished my training, feeling quite dissatisfied with my career choice as a nurse and feeling very disempowered. As a new graduate nurse, I worked in respiratory medicine with people with lung cancer who were experiencing very difficult symptoms which we did not manage effectively. I recall in my second week as the only registered nurse on night duty, being asked to call a family to inform them of their loved one's death. I had very little understanding of the patient's clinical condition, let alone their personal and family circumstances. I do not recall having had any preparation for how to deal with these situations.

I went on to work in a gynae-oncology unit at the Mater Hospital. This was a time when extensive surgery and platinum based therapies were common for treatment for

gynaecological cancers. It was also pre-5HT3 antagonist and other modern antiemetic and supportive therapies. In the mid-1980s, I worked in infectious diseases, where I came across several patients with head and neck cancers who had undergone radical surgery. I also cared for some of the first patients diagnosed with AIDS. It struck me that these were among our most marginalised patients and that we desperately needed a system which was more compassionate just in how it provided its health care.

The sorts of disease and treatment related effects that were problems in my early days as a nurse continue to present challenges for us today. For example, a recent systematic review identified that cancer pain prevalence today continues to be high: 64% (CI 58% to 69%) in patients with metastatic, advanced or terminal disease, 59% (CI 44% to 73%) in patients on anti-cancer treatment and 33% (CI 21% to 46%) in patients who had been cured of cancer. Importantly, the review noted that available data suggest pain prevalence rates have not changed substantially from those reported in earlier reviews.<sup>2</sup>

Despite these challenges, what is different today is that supportive care is now mainstream, considered an essential component of cancer services.<sup>3</sup> We have at our disposal many more effective supportive interventions to prevent and actively control treatment related effects,<sup>4</sup> and we place much greater emphasis on educating and empowering patient themselves to self-manage these effects.<sup>5</sup> Today, because we have a much greater understanding of patient and family experiences, we have evidence-based guidelines to direct our responses in such situations<sup>6</sup> and high quality training programs, considered core curriculum, for improving health professionals' skills in supportive care.<sup>7,8</sup>

### **Ongoing learning, research and evidence**

Those early days as a registered nurse were important in helping me to appreciate that good nursing care is concerned with understanding and responding to some of the physical, emotional and practical challenges people can face when diagnosed with cancer, such as emotional distress, fear, nausea or mucositis.<sup>9</sup> But it was also obvious that there was much to learn to be more effective in responding to such challenges.

In the early 1980s, there were limited opportunities for professional development in nursing, with only a few hospital training courses in cancer nursing. I commenced a degree in psychology to fill some of the gaps in my knowledge, completing majors in political science, and a number of courses in sociology along the way. This

study helped me to understand that while working at the individual level can do a lot, we also need to work at the systems level. It also instilled an appreciation that research could help to address some of the deficits I saw in cancer care. This type of learning had been an important gap in my earlier nursing training.

I took my first job as a nurse educator at Holy Spirit Hospital in Brisbane, as I said at the interview for that position, “to change the system”. After a few years as a hospital educator, I decided that an academic career in nursing would provide me with more opportunities to research ways to improve care of people affected by cancer and to teach others to appreciate the important contribution of nurses in cancer care. For the last 15 years, the focus of my work has been building such education and research programs in cancer nursing. This work started with a joint appointment as senior lecturer between Royal Brisbane Hospital and Queensland University of Technology, where I was tasked to work with senior cancer nurses in Brisbane to upgrade the previous six month hospital certificate course in oncology nursing to a university level postgraduate course. The result was the establishment of the second graduate diploma level course in oncology nursing in Australia (the other being offered in Melbourne at Latrobe University at that time) and the first masters level course in cancer nursing in the country. This transition to university level education for nurses in cancer care represented a major milestone, as for the first time, we had a pathway for nurses to study in their own discipline that recognised the depth, rigour and scholarship needed to underpin our discipline.

With the launch of the Australian Government supported EdCaN resources this year,<sup>7</sup> we have reached yet another milestone. We now have a clearly articulated, evidence-based framework for the professional development of nurses that defines the knowledge, skills and abilities needed to provide safe and quality care for all people affected by cancer. It was quite an extraordinary opportunity to work with Professor Sanchia Aranda from Peter MacCallum Cancer Centre and cancer nurses across the country, to develop this unique framework. The framework is now generating interest among other specialty groups in nursing nationally and among cancer nurses in other countries.

I have also been fortunate to have worked with some outstanding researchers over the past 15 years building a program of supportive care research. Dr Geoff Beadle, a medical oncologist in Brisbane, gave me my first break at a time when psycho-oncology and supportive care research did not have a high profile. Geoff was interested in understanding why people with cancer chose to use complimentary and alternative medicines and provided the opportunity to work with him for my masters research.<sup>10</sup> In those early days, my PhD supervisor, Professor Jake Najman, a renowned health sociologist, patiently worked with our nursing team to teach us the rigour required to be a good researcher. Through Jake’s mentorship and support, we received our first National Health and Medical Research Council (NHMRC) grant in 1999, one of the few nursing led teams successful in securing NHMRC grant funding. This grant enabled us to undertake our first randomised control trial of a patient education intervention to improve adherence to opioids for cancer pain.<sup>11</sup>

Sanchia Aranda and I have built a solid collaborative research program over the past 10 years. We have now completed randomised control trials of supportive care interventions for pain,<sup>11</sup> fatigue,<sup>12</sup> breathlessness,<sup>13</sup> support needs for women with advanced cancer,<sup>14</sup> and pre-chemotherapy education.<sup>15</sup> And we have recently received NHMRC funding for a new trial of aetiology based guidelines for managing nausea in advanced disease. The future for research in supportive care is very promising, with the many leaders in psycho-oncology and supportive care research that have been nurtured in Australia. Developments such as the establishment of a psycho-oncology research collaborative ([www.pocog.org.au](http://www.pocog.org.au)), lead by Professor Phyllis Butow and her team, demonstrate just how much progress has been made in this field.

### Professional organisation can positively influence cancer care

When I was a young nurse educator, I worked with a number of nurse leaders who had lobbied and negotiated hard to bring about the transfer of nurse education to the higher education sector. These were women of enormous integrity who had such strong belief in the contribution that nursing makes to ensuring the dignity and wellbeing of people that one couldn’t help but be inspired. These nurse leaders, Margaret Vider, Serita Saba and Joan Penridge, would cajole me into attending to various professional meetings of the Royal College of Nursing and other groups, showing me by example how a united professional group can make a difference to patients.

I started to attend the Clinical Oncological Society of Australia (COSA) Annual Scientific Meetings in the early 1990s, when the then COSA nurses’ group was noisy and enthusiastic, but probably not very well organised. I was an active participant in the many discussions we had at the time about establishing a separate organisation for cancer nurses. Under the leadership of Laurie Grealish and with the very wise counsel and support from Lawrie Wright (former Executive Officer for COSA) and Alan Coates (former Chief Executive Officer of Cancer Council Australia), we established the Cancer Nurses Society of Australia (CNSA), while still maintaining a strong commitment to ensuring that nurses were part of COSA as the peak multidisciplinary body. Thanks to Laurie Grealish’s leadership, CNSA’s work had a very clear mission which reflected a commitment to improving the quality of life and outcomes for people affected by cancer through nursing care. I was honoured to be elected as the inaugural National Chairperson for CNSA in 1999 and oversaw a busy period, which included achievements such as the hosting of a regular annual winter congress, establishing the *Australian Journal of Cancer Nursing*, development of standards and guidelines for chemotherapy nursing practice and standards for nursing education, the publication of position statements on issues such as the cancer nursing workforce and the organisation of a grants and awards program for cancer nurses. There are many cancer nursing colleagues and friends who need to be acknowledged for their work at this time. In particular, CNSA Executive Committee members including Maryanne Hargraves, Gabrielle Prest,

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Tish Lancaster, Margaret Proctor, Cath Johnson and Kate Cameron are individuals who worked tirelessly as volunteers for the society. This experience of working with an effective, productive, professionally organised group, has taught me that unity and commitment to common values and goals is a very powerful force.

## Multidisciplinary collaborations provide rich opportunities for improving cancer outcomes

The importance of multidisciplinary teams to cancer care has come to the forefront in recent years. COSA is unique in providing opportunities to promote collaborative cross-disciplinary work. There are from time to time tensions between disciplinary groups, but the strength of multidisciplinary collaborations is evident through COSA's achievements. I can remember my earliest days on COSA Council, feeling very nervous about what contribution I could make as the nursing representative. However, I also remember a number of key people on COSA Council who tried to ensure that the nursing voice, along with other 'non-medical' groups on Council, was heard. The outcomes from these conversations were often different as a result of the multiple perspectives that were considered. I acknowledge recent COSA presidents David Currow, David Goldstein, Liz Kenny, John Zalberg and Steve Ackland for their commitment to the multidisciplinary nature of COSA.

While early COSA Annual Scientific Meetings were organised around topics of interest to separate disciplinary groups, today's Annual Scientific Meetings provide a very different forum for advancing cancer care. Today, we have a program where the topics which we address are centred around health issues and concerns of patients, and what we bring as different disciplines and as a team to addressing these concerns, rather than being focused solely on disciplinary interests. Our separate professional meetings will continue to be critical for developing our disciplinary base, however the opportunity we have to work collaboratively through our responses as a team of cancer professionals is unique and likely to provide even further opportunities to advance the field. I would like to pay tribute to Margaret McJannet, Executive Officer of COSA, and Ian Olver, Chief Executive Officer of the Cancer Council Australia, for their outstanding leadership in this regard.

## Conclusion

Working with people affected by cancer has presented some challenges at times, but it has been enormously rewarding. I have had a very privileged career, being mentored by,

and working with, many talented cancer professionals and researchers. The lessons I have described in this paper are very consistent with what COSA stands for as a peak body for cancer professionals in Australia. The future for cancer care in this country is promising, as we continue to build on the type of forum that COSA provides to achieve more person centred approaches to care and improve the journey for people affected by cancer.

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