Title page

‘We are only what we always were’: 50 years of oncology nursing.

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Introduction

In this 50th anniversary year of the Journal of Advanced Nursing I am pleased to reflect on how far cancer treatment and care have advanced since 1976, and how oncology nursing has changed in that time.

The title is a line borrowed from the Crucible by Arthur Miller. The phrase can be interpreted differently, but for me it serves as a reminder that as cancer science continues to advance, so the clinical expertise and intelligent kindness that oncology nurses employ remain central requirements for excellent care. This is the starting point for these reflections.

My own career mirrors most of this period (more than 40 of those years anyway), so I am grateful for the opportunity to make this contribution. It will be impossible to mention everything that is relevant, but signposting some key points is the approach taken in this paper.

The 1970s and 80s

The Journal of Advanced Nursing has published peer-reviewed studies in nursing since 1976. I will mention a small number here. The first paper on an oncology topic in the Journal of Advanced Nursing was published by Robert Tiffany in January 1979 with the title Mobilizing Nursing Skills (Tiffany, 1979). Tiffany was a central figure in the early development of oncology nursing in the UK and Europe. At the time he was Director of Patient Services at the Royal Marsden Hospital in London. He argued that as oncology nurses we should be following a nursing model, rather than the medical model. This, he claimed, would help to avoid ritualised ways of working within a ‘hierarchical profession.’ This thinking progressed to development of the Clinical Nurse Specialist role at the Royal Marsden Hospital; this was groundbreaking and became the precursor to consultant nurses. Over the next decade Tiffany would also help to establish the European Oncology Nursing Society and the International Society of Nurses in Cancer Care. He also launched the Royal Manual of Clinical Nursing Procedures (still in use today) for which I was invited to

co-author the first chapter of the fourth edition on ‘Assessment, communication and consent.’

In 1984 oncology nursing became my career choice after I qualified from the Integrated nursing and social sciences degree programme at Edinburgh University and took up one of my first RN posts in a busy medical oncology unit at the Edinburgh Cancer Centre. Four years later I would return to the same unit as a Charge Nurse. In the intervening years I completed the oncology nursing certificate at the Royal Marsden and encountered the leadership of Robert Tiffany first hand. I also had worked at St Columba’s Hospice in Edinburgh which consolidated my interest in end-of-life care.

Towards kinder cancer treatments

During my time as Charge Nurse our unit was involved in clinical research to trial new anti-emetic agents to be used with Cisplatin, a highly emetic agent used to treat ovarian and other cancers. The results were remarkable and is an example of kinder cancer treatments being championed at the time, alongside new treatment regimes, including high dose chemotherapy and radiotherapy with bone marrow rescue. Agents that stimulated white cell production also became available to shorten the recovery period which may have been spent in protective isolation due to neutropenia. The concept of supportive cancer care was being strengthened with new psychosocial support interventions and the balance between care and cure was debated openly. A key concern was improving communication about cancer with patients and families. One paper by Dr Susie Wilkinson in the Journal of Advanced Nursing was impactful and led to similar research exploring the social taboo and secrecy that existed around cancer, and the impact of this silence in clinical settings (Wilkinson 1991).

In the early 1990’s I returned to the Royal Marsden Hospital and Institute of Cancer Research in the newly established Centre for Cancer & Palliative Care studies. As a Lecturer I was involved in teaching on the first undergraduate and then MSc programmes in cancer care and worked with many wonderful students and colleagues, some of whom I remain in touch with today. The 1990’s became a

decade of rapid development of more precise cancer treatments. Molecular biology research led to the discovery of oncogenes and tumour suppressor genes such as BRCA1 & 2. The genetic base of cancer expanded with the launch of the Human Genome Project in 1990. Cancer screening was also supported, especially in breast cancer, and targeted therapies, including Herceptin for HER2-positive breast cancer, was approved in 1998. My first cancer-related publication in this journal was published in the same year (Kelly, 1998).

Care across the cancer experience

Alongside cancer science advances the growth of Oncology nursing research was a feature of the decade, with concerns about quality of life being translated into research studies that focused attention back on to the individual patient. A wide range of nurse-led research explored the control of distressing symptoms such as pain, dyspnoea, fatigue, radiotherapy skin care and abdominal ascites. Concerns also emerged about age-specific support needs, and I led the first evaluation of a unit for Adolescent and Young Adult cancer patients (Kelly et al, 2004).

An enduring interest was the care of people who would not survive cancer, especially in acute settings where end of life care could be a problematic issue. There often existed the possibility of prolonging treatment, even when death was likely. One study in the Journal of Advanced Nursing by David Field ‘We didn’t want him to die on his own’ (Field 1987) had caught my attention and I used it to inform my teaching and, later, research with groups where death was a more sensitive outcome. I addressed the topic of quality of end-of-life care for my master’s degree dissertation at Surrey University in 1992. This interest led to further research on death and dying in haemato-oncology and paediatric oncology settings (Kelly et al, 2000, Kelly et al 2025).

A new millennium

The new millennium saw me undertaking a doctorate in medical sociology – a subject I had always enjoyed since my undergraduate days at Edinburgh. The focus of this research was prostate cancer, and I adopted an ethnographic methodology to

follow a group of men through their treatment (Kelly, 2011). The findings reinforced the personal impact on the everyday lives of men using the conceptual model of embodiment. Prostate cancer was another topic I would return to regularly over the next twenty years.

The decade of the new millennium also saw advances in cancer genetics with the human genome project being completed in 2003. Biomarker science, high resolution imagery and genetic testing for cancer risk became more established. The HPV Vaccine was introduced in the second half of the decade, and it is now known that young women vaccinated in 2008 have experienced no, or significantly reduced, cases of cervical cancer. The campaign to expand vaccination has occupied my time since 2019 working with the HPV Action Network of the European Cancer Organisation (Bennett et al, 2022).

Breakthroughs and success

Technologies for cancer control continued apace in the 2010s with a range of major breakthroughs in immunotherapies including immune checkpoint inhibitors that led to remission of cancer even in advanced poor prognosis diagnoses such as melanoma, lung and renal cancer. Liquid biopsies – using blood tests to detect cancer activity- became available and robotic and minimally invasive surgery were also developing apace and revolutionising cancer surgery. With the passage of time cancer risk became more widely understood with smoking rates dropping in some countries alongside the introduction of smoking bans in public spaces.

Oncology nursing at the same time was concerned with supporting people with cancer by developing interventions to manage problematic symptoms or side-effects (many of which arose from the treatments rather than cancer itself). The RECAN project was launched (Recognising the role of Cancer Nursing) in 2015 by the European Oncology Nursing Society (EONS) and collaborations exploring leadership and innovation were forged with the US Oncology Nursing Society. The evidence base required to support the role of expert, specialist cancer nursing became the focus of attention when I became EONS president in 2015. The importance of

advocacy for safe and personalised cancer treatment continues until today (Kelly et al, 2022, Sharp et al, 2019).

Now, and then

The fifth decade of the Journal of Advanced Nursing brings us to the current day and the present status of cancer control. Many cancers, previously regarded as poor prognosis, are now viewed as treatable thanks to new targeted agents that can be given alone or in combination. Some are now oral agents which is easier for patients in terms of lifestyle, but they do not remove the need for support and education on side effects. Melanoma and lung cancer are two examples of note. Other cancers are now seen as preventable if vaccination against cancer-inducing viruses (such as HPV) is made available. These include cervical, anal and oropharyngeal cancers. The latter are rising in incidence in men as they are linked to HPV exposure; a result of men not being offered the HPV vaccine in the initial roll out. Thankfully this is changing as more countries now offer gender-neutral HPV vaccination (although others still do not). Cervical cancer is likely to be eliminated as a public health concern in Sweden and Australia by the end of the current decade.

Taken together this is a remarkable success story with cancer scientists and public health services working together to develop vaccine programmes that are easily accessible and delivered by nurses as part of a system that educates parents and young people and encourages uptake. However, this current decade also has shown how some powerful countries are now promoting scepticism towards vaccines as their political class view vaccination as dangerous and reflecting the power of ‘experts’ rather than recognising them as a force for human wellbeing. This illustrates another example of how, as humans, some are indeed only what they always were.

However, any oncology nurse who has cared for patients with cervical, oropharyngeal or anal cancer know the suffering that can be involved and will have witnessed first-hand the impact of these cancers in unvaccinated individuals.

In this fifth decade will see the growing impact of new digital technologies to predict cancer even before symptoms appear. AI is now offering more precise analysis of

medical images, assessing subtle cellular changes and employing machine learning from previous cases to predict the most effective treatment options. A new era of clinical accuracy is also upon us (such as use of machine vision in robotic cancer surgery which reduces human error) but does not remove the need for expert nurses to support people through the cancer experience. More people are now coming to the cancer clinic armed with information from AI sources. Their expectations will be high, and they are likely to question clinicians and expect the best. For nurses this will present new challenges but the core requirement to educate and support individuals will remain.

Written by haematologist Siddhartha Mukherjee, The Emperor of All Maladies (Mukherjee, 2010) is a Pulitzer Prize-winning ‘biography of cancer’ that describes a situation in the past where chemotherapy could be prescribed by a ‘smiling oncologist who does not know whether his patients vomit or not’. Even if they did, they might have considered such side effects tolerable and worth the prize of cure. This takes us back full circle to my early career example where women with ovarian cancer were hooked up to their Cisplatin chemotherapy overnight and would be vomiting within 30 minutes of the infusion starting. The research into anti-emetic drugs, therefore, was a welcome step change and helped to make this cancer treatment much more tolerable. Until the new anti-emetics became available in the early 1990s it was the nurses who sat with the women as they retched and felt wretched. It was the nurses who used the PRN medication to try to settle the women for the night. Sometimes it worked, often it did not. My memories of admitting newly diagnosed women for their first chemotherapy, usually after they had experienced extensive pelvic surgery, are filled with trying to protect them from the sounds and sights of those already on the chemotherapy infusion.

Towards the future

This one clinical example serves to illustrate just how far the treatment for cancer has improved. In the five decades since this journal was first published the advances in cancer science have been remarkable. Sir Richard Doll, the man who discovered the link between smoking and lung cancer in the 1950s had a favourite saying, ‘Death in old age is inevitable, but death before old age is not.’ Saving more lives

from cancer requires all the scientific advancements we have seen over the past 5 decades, alongside kinder treatments that will hopefully become even more common. The nature of the human cancer cell and the environments in which it thrives is now much better understood. Diagnostics are increasingly less open to error thanks to AI and supportive cancer care, offered alongside more acceptable treatments, is now the norm.

Through all of this, however, is the enduring role played by oncology nurses and I have had the enormous pleasure of working with so many who have impressed me with their wisdom and intelligent kindness. There are also many colleagues from a range of other cancer disciplines, as well as many patients, that I have had the good fortune to meet and work with. As the title suggests we really are what we always were because, as cancer science continues to advance, humane cancer care will always rely on the input of one key member of the team: the oncology nurse.

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