Lost in Translation? Bridging modern oncology and human experiences

EONS Board Member Mary Wells delivered the annual Robert Tiffany lecture at The Royal Marsden on the evening of the Anniversary Event. The lecture is in memory of this pioneering cancer nurse and is delivered by someone who has achieved prominence in oncology nursing.

Mary Wells started out by reflecting on 30 years of being a nurse – most of them in cancer nursing – and on her love of the intuitive elements of nursing. These ranged from the ability to apply nursing skills and knowledge to situations where it is not always clear what the problems are, to recognising and responding to distress, discomfort and deterioration instinctively, to the often hidden aspects of peoples’ experiences – the issues, she said, that were often left unsaid between nurses and patients, between nurses and doctors, and the neglected groups, the messy and the complex.

Addressing an audience of many cancer nursing leaders, she explained the title of her lecture, ‘Lost in translation? Cancer nursing in a future that is not what it used to be’. Many experiences, physical symptoms and emotional responses can so easily get lost in translation – between a person with cancer and his or her loved ones, between nurses and other members of the multidisciplinary team and, of course, between nurses and patients. She pointed out that research often fails to be translated into practice because we don’t ask the right questions, use the right methods or report the most useful information.

THE VALUE OF NURSING

Referring to RN4CAST, a large European study of more than 33,000 nurses, Professor Wells said we should be concerned that the aspects of care that nurses reported as most likely to be left undone, were being with and talking with patients, developing care plans, educating patients and families and providing oral hygiene. At the same time, she stressed that data from the same
study also provided powerful evidence of the value of nursing. It showed that an increase in a nurse’s workload by one patient increased the likelihood of an inpatient dying within 30 days of admission by 7%, and every 10% increase in the number of nurses with a bachelor’s degree was associated with a decrease in this likelihood by 7% – clear evidence that nurse staffing and graduate education make a genuine difference to patient outcomes.

It was clear that the aspects of being a person, not just a patient, is often what research by cancer nurses is successful at uncovering. Mary Wells said, “It is so important for cancer nurses to look beyond what is presented to us. The way we ask questions in practice and in research, and the way we listen and respond, is absolutely crucial to legitimising and validating the experience of patients.”

Returning to the source and meaning of her title, borrowed from the French poet Paul Valery, she explained, “I think it captures the challenges we currently face in cancer nursing but, importantly, it also captures the reality that faces a person diagnosed with cancer – the future is no longer what they imagined for themselves, and I believe that cancer nurses, and cancer nursing research, have a hugely important contribution to make to helping those people to re-imagine and live their future.”

A SUCCESS STORY
So why is the future not what it used to be? Partly it is a success story, that increasing numbers of people survive a diagnosis of cancer. However, there are still worrying differences in survival across tumour and demographic groups – and these differences can also be seen in relation to access to clinical nurse specialists (which is better for more affluent, younger patients with certain types of cancer), in relation to quality of life, and to participation in research.

Professor Wells went on to point out that as the population ages significantly, the majority of people who are diagnosed with cancer also have a range of other co-morbid conditions. This has consequences for diagnosis, treatment and survival, and the site specialisation that we have so carefully protected over the last 15-20 years does not always serve nurses or their patients well, as nurses are so locked in their own areas of expertise that they do not always think beyond those boundaries. Research has also shown that survivors of cancer are significantly more at risk of poor physical and psychological health, chronic disease and serious adverse events, and experience significant unmet needs.

“We need to chart a new course if we are to provide care that is more patient-centred, accessible, coordinated, and evidence-based. We need to chart that course for people who are affected by cancer and who suddenly find themselves in unfamiliar territory, who are, literally, lost in translation,” Mary explained.

A POSITIVE FUTURE
In conclusion, Mary Wells said that cancer nurses have the ability, the skills and the knowledge to recognise, acknowledge, understand and respond to both the complexity of oncological treatment for the individual, and the simple and everyday ways in which all aspects of life, including a person’s sense of future, are changed by a diagnosis of cancer.

The research that cancer nurses do, she argued, can translate individual patient experiences into a language and evidence base that not only takes risks and confronts difficult questions, but can translate between the increasingly complex world of cancer treatment, technology and science and the experience of individuals who are affected by cancer in a way that is scientifically and practically meaningful.

Professor Wells finished by saying that the future could be very positive indeed for the new generation of oncology nurses. “Cancer nurses have an opportunity to seize and demonstrate what matters, to bridge the world of modern oncology and the world of human experiences,” she concluded.

Mary Wells is Professor of Cancer Nursing Research & Practice, NMAHP Research Unit, University of Stirling.